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The Relationship between Chronic Health Conditions and Health Literacy, Resiliency and Support/Self-advocacy in Youth

by

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Abstract

Over the past several decades the number of youth living with a chronic health condition has drastically increased. A chronic health condition can be defined as an illness that lasts three months or more that can be controlled but not cured (Centers for Disease Control and Prevention [CDC], 2010). Although there is existing literature on youth with chronic health conditions, there are very few studies that examine the levels of health literacy, resiliency and support/advocacy within this population. The current study is a secondary analysis that utilized data collected from the 37-item Youth Health Literacy and Resiliency Scale (HLRS-Y version) in order to determine if there was a relationship between different categories of chronic health conditions and reported levels of health literacy, resiliency and support/advocacy. Ages of participants were also examined to determine if there was an interaction effect.

The study consisted of a 143 youth between the ages of 13- 21 years old. All participants completed the Youth Health Literacy and Resiliency Scale (Bradley-Klug, Shaffer-Hudkins, Lynn, DeLoatche, & Montgomery, 2017) and were placed into one of three categories of chronic health condition: 1*) Endocrine, nutritional, and metabolic diseases, 2) Diseases of the musculoskeletal system and connective tissue, and 3) Diseases of congenital malformation, deformations, and chromosomal abnormalities.* The data were analyzed to determine if there was a difference in the reported constructs of health literacy, resiliency and support/self-advocacy among the three different categories of chronic health illnesses.

The results indicated that there was a significant relation between support/self-advocacy and age. As participants increased in age, they reported having lower levels of support/self-advocacy. This finding was significant regardless of the category of chronic health condition that the participants were placed in. There were no other significant findings for the other constructs. This study contributes to the literature because it is one of few to examine health literacy, resiliency and support/self-advocacy levels among youth with chronic health conditions. In addition, it is the first study aside from the pilot, to utilize the HLRS. The findings from this study can be utilized to drive support/self-advocacy interventions for youth with chronic health conditions.

Chapter I

Introduction

Statement of the Problem

The increasing rate of chronic health conditions in youth and young adults in the United States has been a growing issue over the past several decades. Within the United States about 15% to 18% of youth are currently living with a chronic health condition. Many of these health conditions in youth include, but are not limited to: asthma (the most common), diabetes, cerebral palsy, sickle cell anemia, cystic fibrosis, obesity, congenital heart conditions, and cancer. Although these conditions range in severity, it is important to understand the impact that having the diagnosis of a chronic illness can have on youth. This is important to note because these conditions can affect not only the physical health of youth but also their mental health, psychosocial development, and educational outcomes.

When examining the impact of living with a chronic health condition it is necessary to discuss management of the disorder. Management, especially among youth who have chronic illnesses, can vary significantly. The reason for this variation is because often children and adolescents initially are more dependent on the actions of their parents or caregivers. Therefore, it is logical to think that a parent who is more informed and has the availability of resources may model a positive management style as compared to caregivers who are less knowledgeable and have less access to resources. This is necessary to consider because youth tend to model the management examples of their caregivers. If a student has not learned the optimal way to deal with his/her condition in the home, this can have an effect on the student's management style outside of the home (e.g., school, extracurricular activities). For example, Javalkar, Johnson, Kshirsagar, Ocegueda, Detwiler, and Ferris (2016), examined the specific factors that contribute to overall self-management and self-readiness. Among the four factors that were considered to be critical in youth and young adults developing self-management, strong familial support was one of them. Using the UNC x TRANSITION Scale (Ferris et al., 2012), the authors found that those individuals who had strong familial support also demonstrated more knowledge of topics such as type of illness, medication adherence, nutrition and the importance of seeking support.

Although chronic health conditions may present different challenges for youth and young adults who have them in comparison to their healthy peers, it is critical to discuss those factors that contribute to a successful daily life. In this context, success is defined as having good mental health, positive school experiences, and the best possible physical health. Adolescents in general struggle with common issues such as developing independence, peer relationships, and school transitions (van Roekel et al., 2015). However, those individuals living with chronic health conditions have not only these common struggles, but also face challenges related to their illness. These challenges may include, but are not limited to, unknown disease course, pain management, treatment adherence, illness disclosure, and late effects of treatment (Hopper et al., 2014).

Although debatable, it is believed that factors such as resiliency, health literacy and support/self-advocacy are important to consider when discussing youth with chronic health conditions. These factors are thought to contribute to positive physical, mental, social, and academic outcomes (Kazak et al., 2002). However, currently there is a dearth of research focusing on the impact of being resilient, health literate, and having support/self-advocacy for youth living with a chronic health condition. Investigating the relationship between these three factors and categories of chronic health conditions could provide insight into the types of supports needed for various subgroups of youth with health issues. The three categories of chronic health conditions that are explored in this study include: 1) Endocrine, nutritional, and metabolic diseases (e.g., cystic fibrosis, diabetes), 2) Diseases of the musculoskeletal system and connective tissue (e.g., juvenile rheumatoid arthritis, fibromyalgia), and 3) Diseases of congenital malformation, deformations, and chromosomal abnormalities (e.g., Ehlers Danlos, Marfan's syndrome).

Conceptual Framework

Traditional assessments of chronic health conditions. When considering the implications that chronic health conditions can have on an individual, it is common to focus on the symptomatology of that particular illness. Specifically it makes sense for individuals to be concerned with the potential negative effects of the chronic illness and how this may affect a person in their day-to-day life. This study looks to explore those factors that help to contribute to a more "successful" life, rather than focus on the negative aspects associated with illness. In particular, the goal of this study is to identify positive relationships among specific categories of chronic health conditions and the factors of resiliency, health literacy and support/self advocacy.

Health Literacy. Acknowledging the importance of health literacy is necessary for families and youth who are trying to cope with, and adapt to, living with a chronic health condition. Although health literacy can be defined in many different ways, for the purpose of this study it is defined as “the capacity to make sound health decisions in the context of everyday life” (Kickbusch, 2008, p. 2). Overall, it has been found that health literacy helps individuals to adhere to specific treatment regimens and sustain a positive quality of life despite their health concerns.

Although there is limited research in the area of health literacy and youth with chronic health conditions, studies have shown that having a high level of health literacy is essential in youth because it correlates with their knowledge of basic health information (Trout, Hoffman, Epstein, Nelson, & Thompson, 2014). Understanding one’s health condition can be extremely helpful when making important health decisions, such as accessing prevention or treatment services (Trout, Hoffman, Epstein, Nelson, & Thompson, 2014).

For youth with chronic health conditions, the ability to assess and implement different interventions and preventative techniques is critical. This decision making process is imperative especially when trying to understand the importance of treatment adherence during the transitional phase from childhood to adulthood. Although studies have shown health literacy to be helpful in these instances (e.g., treatment adherence, transitional phases; Navarra, Neu, Toussi, Nelson, & Larson, 2014) the literature is limited in providing insight as to whether health literacy varies across different categories of chronic health conditions.

Resiliency. Resiliency is a desirable trait that can be useful for individuals with or without a chronic health condition. Resiliency is that “it” factor that helps individuals to persevere and succeed during difficult situations and sudden change (Flett & Hewitt, 2014). Ideally, for youth who are dealing with a chronic health condition, the resiliency trait would aid these individuals in remaining positive throughout difficult situations. There are several models of resiliency that can be referenced including, Wanderlander and Varni’s Disability-Stress-Coping model (Thompson et al., 1993), Thompson and Gustafson’s Transactional Stress and Coping Model (Thompson, et al. 1989) and Kazak’s Social Ecological model (Kazak, 2001). Although these models all have very specific approaches to resiliency that differentiate them from one another, they all acknowledge the important role that the environment has on cultivating resiliency. In particular, the role of parents is a key factor that is discussed across the three models. Although the models present the ways in which resiliency can be cultivated, it is important to look at the outcome effects that resiliency can have on chronic health conditions. Perrin, Ayoub, and Willett (1993) reported that youth with chronic health conditions who demonstrated higher levels of resiliency also exhibited better emotionality and were more well-adjusted in their home and school life, in comparison to those who were identified as less resilient. This is important to note because resiliency has been linked to better mental health, which is just as critical as physical health. Although there has been some research conducted on resiliency and youth with chronic health conditions, little has been published since the creation of the models listed above. The current study examines how resiliency may vary among individuals with various chronic health conditions.

Support/Self- Advocacy. Parallel to the health literacy and resiliency constructs, garnering support and self-advocating can be facilitative when dealing with a chronic health condition. This is important for youth because support systems should extend well beyond the family and into the school environment. For youth with chronic health conditions, there is a considerable amount of literature that explains the importance of a support system. More so it has been noted that the amount and type of support that youth receive throughout their development can have an effect on their ability to self-advocate (Brashers et al., 2009). Self-advocacy can be described as an individual's ability to effectively understand, communicate, and impose his or her own beliefs in order to promote individual gain (VanReusen et al., 1994). In order to develop self-advocacy, an individual must have both knowledge of self and knowledge of rights (Test, Fowler, Wood, Brewer, & Eddy, 2005). More specifically, for those with chronic health conditions, these individuals must have knowledge about their own disorder and their own personal needs in any given situation. For the transitional phase from childhood to adulthood, self-advocacy is vital (Brashers, Hass, & Neidig, 2009). In order to build these skills it is reported that as children become older and advance into their teenage years it is necessary for parents to relinquish this responsibility in order for the child to develop more independence (Brashers, Hass, & Neidig, 2009). Therefore, once children leave for college or moves out on their own, they will have a thorough understanding of their disorder and how to cope with it independently.

Purpose and Research Questions

The current study explored the existence of relationships between three different categories of youth chronic illness and the factors of resiliency, health literacy and self-advocacy/support. The Youth Health Literacy and Resiliency Scale (HLRS-Y) (Bradley-Klug, Shaffer-Hudkins, Lynn, DeLoatche, & Montgomery, 2017) measure was used to investigate these relationships. The YHRS is a new measure of health literacy and resiliency in youth and young adults with chronic health conditions. The purpose of the scale is to help practitioners identify areas in need of intervention in order to promote positive outcomes for these individuals.

This study served as the first secondary analysis that was conducted using data from the scale development. In addition to examining the relationship between chronic health conditions and the three factors, age of the participants was also examined in order to determine an interaction effect. The following research questions explored the relationships across these three health illness categories: 1*) Endocrine, nutritional, and metabolic diseases, 2) Diseases of the musculoskeletal system and connective tissue, and 3) Diseases of congenital malformation, deformations, and chromosomal abnormalities.*

Rationale

By examining the differences among chronic health conditions, this will overall help to promote interventions for these youth. Research has indicated that factors such as resiliency, health literacy and support/self-advocacy are correlated with positive outcomes that include: better mental health, higher treatment adherence, better quality of life, etc. The current study sought to determine if individuals within three specific categories of chronic health conditions showed differences in these factors. This is important to explore because as noted, many youth (15%-18%) are currently living with a chronic health condition. Exploring this topic will help to determine if there are specific health conditions that may need more prevention and intervention supports. For school psychologists, the goal is to ensure that the needs of youth are met. By improving levels such as health literacy and support/self-advocacy this could help to improve not only academic outcomes but also physical and mental health outcomes.

Research questions.

1) What is the relationship between categories of chronic illness and health literacy?
    a. Does the relationship between categories of chronic illness and health literacy differ by age?
2) What is the relationship between categories of chronic illness and health resiliency?
    a. Does the relationship between categories of chronic illness and resiliency differ by age?
3) What is the relationship between categories of chronic illness and self-advocacy/support?
    a. Does the relationship between categories of chronic illness and self-advocacy/support differ by age?

Significance of the Study

Importance of the proposed study to school psychology. Over the past several decades the traditional role of the school psychologist has expanded from serving as the gatekeeper for entrance into special education to an expanded role of providing both prevention and intervention services to all students, including those with chronic health conditions (Tan, 2015). Due to the impact that chronic health conditions can have on students academically, physically and mentally, it is necessary that school psychologists are aware of these issues so that these students can be supported to achieve positive outcomes in school.

Instead of viewing these students as being a product of the medical diagnosis, school psychologists can apply a tiered approach of service delivery (e.g. Multi-tiered System of Supports; Batsche et al., 2005), to help these students be successful in the school setting regardless of their condition. As more information becomes available through research, school psychologists can eventually implement specific prevention and intervention approaches within the schools to support positive outcomes for youth and young adults living with a chronic health condition.

Contributions to the literature. This study contributes to the existing knowledge base in the areas of pediatric school psychology. There is a dearth of empirical research in the areas concerning youth with chronic health conditions and the overall impact, in particular, related to resiliency and health literacy. Although few studies that have been conducted indicate that these factors may be related to positive outcomes (Kazak, 2001; Wolf et al., 2006), there are few studies that examine specific classifications of chronic health conditions and their relationship with resiliency and health literacy.

The current study also specifically contributes to the literature by examining individuals in three classifications of chronic health conditions and the relationship to levels of health literacy, resiliency and support/self-advocacy. Findings from this study are useful because they can help to drive interventions, particularly for those groups who may have lower levels of these three factors. Overall it is acknowledged that these factors (resiliency, health literacy and support/self-advocacy) are important; however, the goal is to increase these factors among all youth with chronic health conditions in order to promote positive outcomes.

Key Terms

Chronic Health Condition. An illness that lasts three months or more that can be controlled but not cured (Centers for Disease Control and Prevention [CDC], 2010).

Health Literacy. “The capacity to make sound health decisions in the context of everyday life. Health literacy contributes to an individual’s knowledge and understanding of their health condition, and their ability to adapt to an illness, adhere to specific treatment regimens, and maintain a positive quality of life despite health concerns” (Kickbusch, 2008, p. 2).

Resiliency. Resiliency is defined as the ability to recover quickly from change, hardship or a difficult situation. Resilient people demonstrate strength, flexibility, optimism and are open to growth and adjustment (Center for Creative Leadership, 2011).

Support/Self-Advocacy. “The extent to which young people advocate on behalf of the accommodations and care they need and whether those around them are supportive of these needs” (Tutle et al., 2007, p. 1).

ICD-9-CM Codes- The International Classification of Diseases 9th Revision, (ICD 9) was used to categorize the chronic illnesses. Within this classification system, the three categories of Endocrine, nutritional and metabolic diseases; Diseases of the musculoskeletal system and connective tissue; and Diseases of Congenital malformations, deformations and chromosomal abnormalities were used to classify the chronic illnesses in this study.

Chapter II

Review of Literature

` Chronic health conditions affect the population worldwide. Typically, a chronic health condition is defined as an illness that lasts three months or more that can be controlled but not cured (Centers for Disease Control and Prevention [CDC], 2010). The rising rate in chronic health conditions within the United States has been an ongoing issue over the past decade. Increasing amounts of attentiveness towards some of the common (e.g., asthma, diabetes), yet incurable, conditions have also been noted. However, despite this increasing awareness, chronic health conditions continue to rise among the pediatric population (Van der Lee, Mokkink, Grootenhuis, Heymans & Offringa, 2007).

Chronic health conditions can develop as a result of genetic inheritance, environmental factors, or a combination of both (Kardia et al., 2003). For adults in the United States, examples of the most common chronic diseases include arthritis, cardiovascular diseases such as heart attacks and stroke, cancer such as breast and colon cancer, diabetes, epilepsy and seizures, obesity, and oral health problems. For youth some of the most common chronic health conditions consist of asthma (the most common), diabetes, obesity, cerebral palsy, sickle cell anemia, cystic fibrosis and cancer. The differences in chronic health conditions between youth and adults seem to be that many adult chronic health conditions tend to be more related to lifestyle outcomes, while many chronic health conditions in youth are more likely attributed to genetics (American Academy of Pediatrics, 1997).

According to the Centers for Disease Control and Prevention (CDC), approximately 15% to 18% of youth in the United States have a chronic health condition (CDC, 2010). Over the past fifty years, chronic health conditions and disabilities among children and youth have gradually risen, primarily from four classes of common conditions: asthma, obesity, mental health conditions, and neurodevelopmental disorders (Perrin, Anderson, & Van Cleave, 2014). Continuous growth of these chronic conditions in youth became noticeable in the 1980s and 1990s; however rates of youth obesity and asthma have appeared to level out within the past decade (Perrin et al., 2014). In addition, there also has been an increase in diagnosis for conditions such as Attention-Deficit/Hyperactivity Disorder (ADHD) and autism spectrum disorders (ASD), particularly among children from low income backgrounds (Pulcini, Zima, Kelleher, & Houtrow, 2016). However this is hypothesized to be due to the increased awareness of the conditions rather than actual growth in their prevalence (Perrin et al., 2014). More importantly, these data merely indicate an approximation for the number of children who are dealing with a chronic health condition within schools as well. Due to the increasing rate of chronic health conditions among youth, it is critical that parents, school personnel and medical professionals are prepared to assist youth with these conditions. These youth are not only coping with the symptomatology of their condition, but also are facing struggles in schools such as academic performance and peer relationships. The impact of chronic health can affect the child academically, behaviorally, psychosocially, and developmentally (Compas, Jaser, Dunn, & Rodriguez, 2012).

Chronic Health Conditions

Chronic health conditions can alter and potentially impede the daily activities of individuals (Compas, Jasper, Dunn, & Rodriguez, 2012). When examining chronic health conditions in children, it is important to understand how different areas of life are impacted. One important aspect of the child’s life that may be affected by a chronic illness is school performance. Receiving an education is a critical part of development for children. During childhood and adolescence students are expected to go to school in order to prepare for adulthood. This is important to note because although most students struggle at some point throughout their academic career, research has shown that students with chronic health conditions tend to suffer more academically in comparison to their peers (Champaloux & Young, 2014). Crump et al. (2013) chose to explore the impact of chronic illnesses on academic outcomes further by comparing the language arts and math scores of physically healthy youth and youth with chronic health conditions. The purpose of this study was to determine if chronic health conditions are associated with low school performance. Specifically, the authors wanted to determine if there were any significant differences between the two groups. The study consisted of 22,730 children and youth (grades 2-11), with 2891 (12.7%) being identified as having a chronic health condition. Within the participant sample, 50.2% were identified as Hispanic, 27.6% White, 13.8% Asian, 3.4% Black, and 5.0% were other ethnicities. Almost half of the participants (46.7%) received free and reduced price lunch. The study consisted of students from 52 schools (27 elementary, 7 middle, 7 high, and 11 alternative) in the San Jose Unified School District and lasted over the course of three years, 2007-2010. Within the study, three main components were identified among the students: health condition, school absenteeism, and academic performance. Students' health conditions were identified through a written health information survey that was completed by the parents, while school daily attendance records and school California Standardized Test (CST) scores results were used to identify school absenteeism and academic performances, respectively. Results indicated that independent of race and socio-economic status, students with chronic health conditions had lower English language arts and math scores in comparison to their peers. The study also adjusted for absenteeism and found that students with chronic conditions still fell behind their peers academically.

In addition to youth with chronic health conditions having lower academic performance, it also was found that students with chronic health conditions have lower educational attainment in comparison to individuals who do not have a chronic health condition (Champaloux & Young, 2014). Educational attainment is referred to as the highest degree of education an individual has completed as defined by the US Census Bureau Glossary (U.S. Census Bureau, 2012). This particular study was a secondary analysis using the National Longitudinal Survey of Youth- Cohort 1997. The survey included a cohort of 8,984 youth from 12-16 years of age. Initial information was collected in 1997, but was annually assessed in order to examine transition over time from school to work and then to adulthood. Measures included participant and parent interviews in which both parties were asked to identify and describe the chronic health condition of the student. Chronic health conditions were classified into four groups: (1) asthma; (2) cancer, diabetes, or epilepsy; (3) heart and cardiovascular conditions; and (4) other. These categories were formed based on previous research indicating that non-asthmatic chronic health conditions such as cancer, diabetes, or epilepsy may have a greater impact on educational attainment compared to asthma (Champaloux & Young, 2014). Cancer, diabetes, and epilepsy were combined in one separate category due to small individual sample sizes. Heart and cardiovascular conditions also were combined in a separate category, but this was due to the limited literature concerning the relationship between these conditions and educational attainment and their high frequency among the survey of youth. All other chronic conditions were grouped separately because there was an incomplete record of the conditions reported. Overall, the study concluded that factors such as the specific disorder and overall absenteeism did have an impact. Students who reported having conditions such as epilepsy, cancer, or diabetes displayed higher school absences as compared to their peers in the other groups. This resulted in higher rates of retainment and higher depressive symptoms for these students as compared to those in the other health condition groups (Champaloux & Young, 2014).

Psychosocial Component

In addition to youth with chronic health conditions often struggling academically, they also often have psychosocial difficulties (Barlow & Ellard, 2006). For youth, maturing from one stage in life to the next can be difficult even in the absence of a chronic health condition. For example, as students emerge from childhood into adolescence, there are physical, mental and emotional transitions that occur with puberty. As difficult as this time can be for physically healthy adolescents (van Roekel, et al., 2015), it appears that students with chronic health conditions are confronted with additional challenges with making this transition. In a recent study of 9,107 students (ages 9–13) 18% of students that reportedly had a chronic health condition. Of that 18%, 28% reported an impact of their illness or disability on their activities (e.g., exercising) and daily life (Denny et al., 2014). Forty percent of those with a chronic health condition also reported experiencing difficulties with socializing as compared to 10% of their healthy peers. Depressive symptoms were significantly higher for those with a chronic health condition than among students without a chronic health condition (Denny et al., 2014). These depressive symptoms were determined by the Reynolds Adolescent Depression Scale–Short Form (RADS-SF) (Reynolds, 2008), which examines four dimensions of depression: dysphoric mood, negative affect, negative self-evaluation and somatic complaints. It also is important to note that chronic physical conditions in youth are associated with a slightly elevated risk for self-harm, suicidal thinking, and attempted suicide (Barnes, Eisenberg & Resnick, 2010).

Quality of Life

Quality of life (QOL), which is a multidimensional concept encompassing several subcategories such as life satisfaction, well-being, happiness, meaning, and economic indices (Bagwell, 2014), also can be impacted by a chronic health condition. QOL is directly associated with important life factors such as happiness and well-being. However, when considering youth with a chronic health condition, quality of life appears to be at a greater risk. Research has shown that oftentimes there is a misperception between one's self-perception of their quality of life as compared to the perception of others. McDougall and Wright (2014) examined this finding further. The purpose of the study was to assess the personal, interpersonal, and environmental factors associated with perceived quality of life (QOL) for youth with chronic health conditions and to determine if the perspective of the parent and child regarding the child's QOL aligned. The study sample consisted of 439 participants ranging from 11 to 17 years of age with various types of non-progressive chronic conditions. A non-progressive condition is defined as being static and unchanging at the time. The results indicated there was a negative correlation between youth and parent perceptions of youth QOL, which included perceptions of pain/other physical symptoms and emotional symptoms. Parents tended to believe that their child was experiencing a higher quality of life than what the child reported. Youth indicated that their disorder caused them to feel physically inadequate in comparison to their peers, which also resulted in them experiencing depressive symptoms about their current circumstances. In contrast, youth and parent perception of quality of life was highly correlated in the areas of spirituality and school productivity (McDougall & Wright, 2014).

The impact that chronic health conditions have on youth can vary. As demonstrated in the literature, this variation in impact can range from quality of life to mental health stability. In addition to these factors being affected by different types of chronic health conditions, the current study seeks to examine specifically if other factors such as health literacy, resilience and support/advocacy also have a varied impact among youth with chronic illnesses.

Patient Activation

For the current study the constructs of health literacy, resiliency and support/ self-advocacy were assessed. Despite that there is a clear distinction between the meanings of each of these constructs, previous research has indicated that these factors are related to positive outcomes for youth with chronic health conditions. More specifically these factors can be connected through what is known as patient activation. Patient activation, also often referred to as patient engagement, can be defined as "understanding one's role in the care process and having the knowledge, skill, and confidence to manage one's health and health care (Hibbard, Stockard, Mahoney, & Tusler, 2004, p. 1008). This definition also refers to the patient as being independent and actively involved in the decision-making regarding their personal health (Hibbard and Greene, 2013). In some instances, patient engagement can represent a broader aspect that actually includes patient activation as a portion of its definition. In this case, patient engagement would be defined as the interventions used to increased overall patient activation, along with the behavioral outcomes that stem from those specific interventions (Hibbard & Green, 2013). Some examples can include a patient's increased/decreased efforts to obtaining preventive care or engaging in regular physical exercise.

The purpose of patient activation is to essentially motivate the individual to become a positive change agent when making daily health related decisions. Those who have higher patient activation have shown to possess positive qualities such as confidence in seeking out a doctor when experiencing health complications, confidence in sharing their health needs and better problem solving skills (Fowles, Terry, Xi, Hibbard, Bloom & Harvey, 2009; Green, Hibbard, Sacks & Overton, unpublished). These outcomes are important to mention because the factors of health literacy, resiliency and support/advocacy are also correlated with these exact same outcomes for youth with chronic health conditions. It is necessary to understand how these aspects fit together so that effective prevention and intervention strategies can be created.

Health Literacy

Healthy literacy can be defined in many different ways. The National Network of Libraries of Medicine (NNLM, 2015) and the CDC describe 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. However, in contrast, some perceive health literacy as the ability to read, comprehend, and apply medical terminology that may be displayed on a prescription or medical journal (Sukka et al., 2015). There are essentially three types of health literacy that patients can display. These specific types include functional, interactive and critical heath literacy. Functional health literacy can be described as an "individual's capacity to obtain, process, and understand basic health information and services sufficiently to make appropriate health decisions" (Institute of Medicine, 2004). Functional health literacy is also an indicator of an individual's cognitive ability to manage their chronic health condition, with these cognitive abilities being verbal fluency, working memory and reasoning (Federman, Sano, Wolf, Siu, & Halm, 2009). When considering interactive health literacy, it is important to acknowledge the communication component. Interactive health literacy acknowledges the importance of having patient interaction with medical professionals. This communication between the individual with the chronic health condition and doctor can range from the patient vocalizing their medical concerns to asking the doctor about specifications of a prescription (Parmer, Furtado, Rubin, Freimuth, Kaley, Okundaye, 2015). This type of health literacy is what helps patients to take an active role throughout the span of their chronic health condition. Finally the third type of health literacy is described as critical health literacy. This form of health literacy is somewhat more difficult to obtain because it does involve a higher level of thinking. Critical health literacy surpasses the basic definition of health literacy by including the ability the improve health from the broader perspective (Sykes, Wills, Rowlands, & Popple, 2013). More specifically, those individuals who have critical health literacy may use their knowledge to improve health through a political system or social justice movement. This type of health literacy is thought to be less necessary during daily interactions with medical professionals, but more useful when looking to foster change on a larger scale (Sykes, Wills, Rowlands, & Popple, 2013).

For this current study health literacy is defined as “the capacity to make sound health decisions in the context of everyday life” (Kickbusch, 2008, p. 2). Individuals who have higher levels of health literacy are able to advocate for their health needs rather than be passive recipients of the treatment decisions of health professionals. “Health literacy contributes to an individual’s knowledge and understanding of their health condition, and their ability to adapt to an illness, adhere to specific treatment regimens, and maintain a positive quality of life despite health concerns” (Kickbusch, 2008, p. 2). Being knowledgeable of the context of health literacy within this study is necessary because it indicates whether or not youth have the ability to cope with and understand day-to-day issues related to their chronic health condition.

In general, it is important for youth to have high levels of health literacy because a high level correlates with their knowledge of basic health information to eventually make important health decisions including accessing prevention or treatment services

(Trout, Hoffman, Epstein, Nelson, & Thompson, 2014). The ability to assess and implement different interventions and preventative techniques is critical for youth with and without chronic health conditions. The reason for this is because youth, especially those with chronic illnesses, have to learn how to adapt to living independently with their condition. Having sufficient health literacy can potentially help this transition to independence be more successful. Sufficient health literacy, in this case, means having the ability to make appropriate decision regarding personal health. Although health literacy is necessary for all youth, there are some individuals who have to be more health literate than others in order to have a higher quality of life. An example of this can be seen in Trout et al. (2014), who specifically explain how at risk youth, living in an out-of- home setting, have to essentially be more health literate when living in that environment. Out-of-home settings are classified as group homes, boarding schools or orphanages. The reason for this is because patients in these settings must have the ability to follow a doctor's orders and have knowledge about health care resources. Due to circumstances, many of these youth have not had the opportunity to learn from parents or other family members about the importance of health literacy. The purpose of the study was to investigate the depth to which at-risk youth living in out-of-home settings were able to seek and access health information to help manage healthcare needs through prevention and intervention. The study consisted of 229 at-risk youth who had a range of mental and physical health, educational, and behavioral problems. They were recruited from a private high school housed on the campus of a large, residential care provider located in the Midwest. The average participant was 17 years of age, with 62% being male. Participants were (45%) White, (29%) Black, and the remaining were Hispanic (11%), American Indian (5%), or multiracial (9%) youth. Participants appeared to be almost evenly split across high school grade levels, with freshmen and sophomores each at (22%), juniors at (28%) and seniors at (27%). To help assess health literacy, participants were given the Rapid Estimate of Adolescent Literacy in Medicine Scale (Wolf et al., 2006). This scale was used to determine the actual literacy component of youth by testing the comprehension and word recognition of health related terms. This scale helped to determine if these youth were “health literate” enough to seek the appropriate assistance when having health issues in the future. Although not all of the participants were identified as having a chronic health condition or medical problem, their previous life circumstance placed them as “at-risk” for having health issues in the future. Overall, the results indicated that only one-third of youth were considered to be health literate, meaning they had the ability to make appropriate individual health decisions. It is believed that the lack of knowledge among this population was due to the limited family supports and overall guidance that was available to these students.

With regards to youth specifically with chronic health conditions, previous research has indicated that those individuals who are health literate tend to not only have a better understanding and are more accepting of their disorder, but also are more likely to adhere to their treatment plan (Navarra et al., 2014). These positive outcomes related to health literacy are important to emphasize because they can potentially make a difference in overall life expectancy and quality of life. Navarra and colleagues (2014) examined the association of treatment adherence of Antiretroviral Therapy (ART) with health literacy. Using an expanded health literacy model, the authors examined the relationship of health literacy, functional literacy, beliefs about Antiretroviral Therapy (ART), media use, and adherence to the ART treatment. From a convenience sample the authors utilized adolescents (*n* = 50) infected with HIV recruited from a larger study. The overall outcome of adherence was measured through a 3-day process of self-reports, while the health literacy component was tested using a version of the Test of Functional Health Literacy in Adults (TOFHLA) (Hæsum, Ehlers, & Hejlesen, 2015). The results indicated that most participants had high health literacy and most participants did adhere to medication; however, they were not predictive of one another. When examining the expanded health literacy model, the overall functional and health literacy of Antiretroviral Therapy treatment did have an impact. Findings indicated that individuals having higher positive outcome expectancy scores regarding ART were more likely to report 100% adherence, and participants with below-grade-level reading were less likely to report 100% adherence (Navarra, Neu, Toussi, Nelson, & Larson, 2014). Therefore those individuals who received higher scores on the TOFLA were more likely to adhere to the treatment. This demonstrates the impact that the health literacy can have on youth with chronic health conditions. The level of knowledge regarding a child's own health and chronic illness can potentially have an influence on the daily decisions he or/she makes in relationship to their condition.

Resiliency

Resiliency is defined as the ability to recover quickly from change, hardship or a difficult situation (Center for Creative Leadership, 2011). To be resilient, individuals must possess certain factors that help them adapt and cope with their chronic illness. Resilient people demonstrate strength, flexibility, optimism and are open to growth and adjustment (Center for Creative Leadership, 2011). When dealing with a chronic health condition, resiliency is considered to be a protective factor. Research has shown that youth who have high resiliency are more likely to have lower levels of stress, higher confidence, and have more optimistic reactions to difficult situations (Flett & Hewitt, 2014). Although research shows that resiliency leads to positive outcomes for individuals, there is much debate in regards to how resiliency is fostered and what components contribute to better outcomes for youth. Within the area of pediatric psychology, specific models have been developed to examine the potential factors that can lead to the development of resiliency in youth with chronic illness.

Models for Resiliency in Youth

When exploring resiliency, there are a variety of models used to help explain how this construct is developed within youth who have chronic health conditions. First is Wanderlander and Varni's Disability-Stress-Coping model. This model suggests that child and parent psychosocial adjustment to chronic illness are affected by numerous biopsychosocial risk and resistance factors (Wallander et al., 1989). This model hypothesizes that an increase in risk factors (e.g., poverty, lack of social support) leads to worse psychosocial adjustment, whereas increases in resistance factors (e.g., family cohesion, adaptive coping styles) lead to positive psychosocial adjustment (Minnesota Univ.,1991).

Another model that is used to explore resiliency is Thompson and Gustafson's Transactional Stress and Coping Model. This model suggests that adjustment outcomes are impacted by illness-specific variables (e.g., disease type, diagnosis, and illness severity), demographic variables (e.g., socioeconomic status, gender, and age), and various intrapersonal adjustment processes. Within this model, the child’s chronic illness and its associated treatment are viewed as potential stressors to which the child and the family are striving to adapt and cope (Thompson et al., 1993). This model has been examined across a large number of chronic illness populations, including pediatric cancer, diabetes, sickle cell disease, and asthma, receiving extensive research support.

Lastly, a third model that has been discussed in the literature is Kazak’s Social Ecological Model. This model suggests that the many systems (i.e., child, family, social group, school, community, and culture) in which the child and parent reside have the potential to significantly affect child and parent adjustment to a chronic illness. Kazak’s model emphasizes the importance of a constant interplay between system levels, including the interactive nature between the child’s diagnosis and each ecological system (Kazak, 2001). Although the child remains at the center of these subsystems, the Social Ecological Model hypothesizes that adjustment to chronic health conditions may be effectively captured by understanding how specific subsystems interconnect with the child and family (Kazak, 2001).

When examining youth with chronic health conditions, there appear to be some commonalities between each model. One common aspect is the role of parents. It seems that the support and understanding that parents have regarding the chronic illness of the child tends to impact the development of resiliency. Flett and Hewitt (2014) indicated that the overall adjustment of both the child and parents to the child’s chronic illness are strong indicators of resiliency for the child. Nonetheless it is important to note that resiliency is an overall combination of factors, including health literacy that help youth with chronic illnesses cope with their condition. Together, resiliency and health literacy can combine to potentially provide youth with an overall high quality of life.

Drotar and colleagues chose to investigate the importance of resiliency in children with chronic health conditions by specifically looking at the differences between resilient children and those who develop emotional problems while having a chronic health condition. They explored how parent and family functioning contributed to the overall adjustment of the child as they are dealing with the everyday impact of their chronic illness. The authors compared several studies that researched the impact of family dynamics on youth. The authors wanted to pinpoint if differences in resiliency were attributed to the specific chronic health condition or to family influences. Within this article the authors refer to Perrin, Ayoub and Willett (1993), who explored the specific characteristics that mothers and other family members exhibit that may aid in fostering resiliency in youth. The overall sample consisted of youth from urban, suburban, and rural areas, with each group containing an equal number of males and females between the ages 7-18 years. The perspective of the parent, child and teacher were acquired through various reports and assessments. These assessments and reports were used to measure child adjustment and resiliency. Based on the data that were collected, the results indicated that overall children without a chronic health condition were more adjusted and resilient than those dealing with chronic health conditions. In addition, the results also showed that there were characteristics specific to the family unit that correlated with those youth who were rated as being more well-adjusted. For example, those who were in Groups 2 and 3 (epilepsy group) tended to come from families where the mothers had a high maternal health locus of control. The authors concluded that this factor for youth with epilepsy had a positive relationship with the overall psychological and adjustment and resiliency of youth with that specific chronic health condition (Perrin et al., 1993). In addition it was found that there was a correlation across all categories with problematic parent/family functioning and overall adjustment and resiliency. Essentially those youth who did have experiences with problematic family or parent dynamics tended to be less adjusted according to parent, teacher and child self-report. This is thought to be attributed to the fact that youth are concerned more about their home life situation rather than making sure that they are healthy. In addition, it is probable that troubled home life can impact how knowledgeable the student is about their chronic condition and how prepared they are to deal with the illness while in school.

Support/Self-Advocacy

The words advocacy and advocate are used frequently when discussing those with chronic health conditions. Advocacy can be defined as, “the act or process of advocating or supporting a cause or proposal” (Tutle et al., 2007, p. 1). The word advocate is defined as someone who “speaks out for a cause and works toward a solution” (Tutle et al., 2007, p. 1). In reference to individuals with chronic health conditions, it is important to understand the role that “advocacy” plays in daily life. This construct differs from the construct of resiliency in that patients are actively voicing their health needs and concerns in order to garner the support of those around them. However in contrast, the support that is described in the resiliency construct comes from the child’s natural environment. This support does not come from the child advocating their needs, but instead is the support that has been provided to child from their ecosystem. Commonly, advocacy for youth with chronic health conditions is displayed through either local or national groups (e.g., Cystic Fibrosis Foundation, National Down Syndrome Society and Childs Sickle Cell Foundation), or through parents/guardians and teachers of the child with a chronic health condition. Although all of these resources are considered effective, it is important to note that self-advocacy is especially critical for youth with chronic health conditions. Self-advocacy can be defined as an individual’s ability to effectively communicate, relate and even impose his or her own beliefs in order to promote personal gain (VanReusen et al., 1994). In order to develop self-advocacy, an individual must have both knowledge of self and knowledge of rights (Test, Fowler, Wood, Brewer, & Eddy, 2005). Knowledge of self essentially means the ability to understand one’s own identity in relation to their chronic illness. Knowledge of rights can be described as the ability to convey and communicate essential needs that are related with an individual’s disorder. These two constructs are crucial because in order for individuals to effectively communicate to others their needs and rights, they must have a full understanding of themselves (Test et al., 2005). In addition, it also is important to note that self-management is a contributing factor to one’s ability to self-advocate.

Self-management is a key component of self-advocacy because of the connection that it has with the transition from childhood to adult care. Javalkar, Johnson, Kshirsagar, Ocegueda, Detwiler, and Ferris (2016), examined this topic specifically by assessing factors that contribute to self-management and self- readiness. Within this study, researchers selected 511 adolescents and young adults with chronic health conditions ranging from ages 12-31 years of age. The average age of the sample was approximately 20 years. Demographically, 45% of participants were classified as white, 42% Black and 13% other. Approximately half (54%) were female. The study was framed around the Health Care Transition Research Consortium Model. This model is important because it examines those factors that help contribute to the level of preparation for adulthood for youth with chronic health conditions. The model consists of four domains: individual, health care system, family/social support, and environment. Under the domain labeled individual, factors such as age and actual diagnosis are examined, while the health care system domain examines the patient's access to health care services (e.g., insurance status, availability to appropriate health care providers). For the family/social domain, the model examines the relationships that individuals have with friends and family, whereas the environmental domain focuses on ecological and geographical factors. The UNC TRxANSITION Scale (Ferris et al., 2012) was used to assess level of readiness and self-management. This scale is a 33 item instrument that examines topics such as knowledge around medication adherence, information regarding illness, insurance knowledge, and related topics. Utilizing this scale, Javalkar and colleagues (2016) were able to report findings regarding self-management and readiness among adolescents and young adults. Results indicated that age appeared to be a predictor of knowledge on type of illness, medication, nutrition and insurance, with older individuals having more knowledge. In addition there also were significant findings regarding gender, with female participants having more knowledge on topics such as type of illness, medication adherence, nutrition, and seeking support compared to male participants. Race also seemed to be a factor with those who identified as Caucasian. Overall these participants reported having more knowledge in general regarding medication and type of illness in comparison to the remaining participants. This is important to note because many of these factors are what contribute to an individual successfully self-managing and self-advocating for their needs. Knowledge of this information can help determine which youth may need more support in cultivating these skills.

Learning how to advocate for one's individual needs and rights related to a chronic health condition can be extremely beneficial. For example, those who have self-advocacy tend to have more knowledge of their disorder. They also are more likely to receive accommodations because they request them (Ferris et al., 2012). In contrast, the inability to self-advocate can lead to problematic outcomes in the future. Brashers, Hass and Neidig (2009) examined the positive aspects of self-advocacy by utilizing data from a Patient Self Advocacy Scale (Brashers et al., 2009). The scale assessed particular factors such as knowledge surrounding one's chronic health condition, overall assertiveness, and overall adherence. The study originally was administered to two samples of participants, 174 adults from an HIV-AIDS population and 218 adults in the general population. The study was conducted primarily to provide reliability and validity data for the Patient Self Advocacy Scale (PSAS).

Based on their prior research, the authors chose to describe self-advocacy as behaviors that were used to represent one's own beliefs (Brashers et al., 2009). They believed that these skills were often times not innate to individuals, but were developed by witnessing great models of advocacy (e.g., support groups, other patients, doctors, etc.) Although the population used in this study to examine self-advocacy consisted of adults rather than youth, the authors did discuss the importance of the transition period that occurs between pediatric and adult care. It is during this transitional phase that youth sharpen their self-advocacy skills and become more involved in the management of their own disorder (Brashers et al, 2009). This study also indicated the importance of having an increased level of the knowledge regarding one's chronic illness. As mentioned earlier, it is vital that individuals are widely knowledgeable about their condition so that they can fully advocate and educate others on the details of the disorder and their rights. One particular factor discussed by the authors was that one of the first steps to obtaining increased knowledge of one's chronic illness is when the patient openly begins to desire involvement by specifically learning about the diagnosis, prognosis, treatment plans and prescribed medications (Mahler & Kulik, 1991). Having background knowledge of these particular factors is crucial because they help to form foundational knowledge regarding the condition. The authors indicated that individuals who put forth the effort to learn about both the broad and specific facts related to their health condition were more likely to seek the appropriate help when facing a life-threatening situation caused by their condition. For example, the authors found that individuals in the HIV population who were less adamant about seeking information about their disorder tended to overlook going to doctor when they were feeling sick and tended to shut down upon receiving negative news from the doctor. In contrast, individuals who were more knowledgeable regarding their disorder were more likely to be actively involved in every step of the process (Mahler & Kulik, 1991).

In addition to identifying increased need for knowledge of the chronic health condition as a necessity for building self-advocacy, the study also demonstrated how having increased assertiveness also is important. The authors referred to this as psychological autonomy, in which there is a manifestation of increased ability to challenge authoritative decisions, ask relevant questions to physicians and be an active participant in the decision making process for the course of treatment (Brashers et al., 2009). Previous research has shown that this aspect of self-advocacy is more difficult for patients to participate in due to their lack of confidence when being in a medical setting. The results from this study indicated that patients were less likely to participate in directly asking the doctor questions about their illness. This is interesting to note because, in populations where the chronic illnesses may be more stigmatized, such as HIV, it is thought that patients would want to know more about what is happening to them and what they should expect to see over time. However, it was found in this study that patients may sometimes be afraid of asking “dumb” questions, wasting the time of the physician or scared to learn more bad news (Brashers et al., 2009).

Interestingly, the last dimension that was included in the self-advocacy scale was described as patients’ tendency to purposefully not adhere to treatment for personal reasons. The idea of “mindful adherence or nonadherence” (Brashers et al., 2009, p. 102), is important to consider because in the past doctors often times believed that when a patient did not adhere to their medication it was considered to be a sign of defiance. However, more recently it has been shown that if patients are choosing not to adhere to their medication treatment for a “mindful” reason it is considered patient psychological autonomy because the patient is making an active decision regarding their condition.

Although self-advocacy can be extremely useful throughout all stages of life, it becomes more critical during the transition phase from pediatric care and adult care for youth. Hopper, Dokken, and Ahmann (2014) explain how increased technology has created a new wave of patients, meaning that individuals with serve childhood chronic health conditions are now living beyond their designated life expectancy. For example, patients with some congenital disorders who were previously not reaching adulthood are now living longer lives. As a result of the increasing population of youth reaching and transitioning to adulthood, there are not enough specialists available to meet their specific needs. Due to medical advances, youth with chronic health conditions are living longer, which means that they require specialist as adults. There also is the concern that medical professionals are not preparing youth for this transition until they have actually turned eighteen (Hopper, Dokken, & Ahmann, 2014). This is problematic because once the student has turned 18 there is a limited time for the patients to be prepared to make this big change. Failing to adequately prepare youth for this transition can potentially lead to poor treatment adherence, lack of adequate care, increased risk of secondary conditions and increased emergency room and hospital use (Hopper et al., 2014). This is lack of preparation is important to note because it can impact the overall process of developing medical independence.

The Clinical Report (2011) explained there are different components necessary to help youth become successful self-advocators. The authors essentially created an algorithm that was used to help determine if students would be prepared with self-advocacy and self-management skills to transition into adulthood successfully. There was an emphasis on making sure that not only youth are ready for this transition, but also the health care provider and the family. In order for the child to be successful with this transition, it is important to involve the entire team that has supported the child throughout the years. Students who have chronic health conditions may often have some form of dependence on these support figures that should slowly diminish over of time. Youth who are able to make this smooth transition are more likely to experience positive long-term effects such as effective self-advocacy and self-management.

When preparing youth to transition to become independent, the role of the health care provider is essential to building skills of self-advocacy (Clinical Report, 2011). Health care providers should help the child to understand how his/her insurance might change and how might the overall doctor experience may change from across settings. They should try to make the child feel comfortable enough to attend visits alone and should ensure the child that his/her opinion is always valued. Building this rapport and creating a high level of comfort is essential because this can directly affect how assertive the patient may be during visits. The overall goal is to ensure that patients are asking the right questions and are actively involved in their medical treatment plan. In addition to the role of the health care providers being essential to building self-advocacy skills, the role of guardians and family is also important to consider. Research has shown that parents tend to also have a difficult time during this transitional period as well (Clinical Report, 2011). The reason for this is because caregivers may be reluctant to release some of the responsibility to the child, as this has been their role for many years. It is important that parents are fully involved throughout this transitional phase, however in a very subtle way. “The parents’ role is to actively engage in the process and move in and out of the decision-making position as appropriate” (Clinical Report, 2011, p. 187). Parents should be available to fill in the gaps that the youth is unable to fill. During this phase youth should be fully maximizing their independence, while family and health care providers are available for consultation and limited decision-making. This can easily be compared to the scaffolding approach that is utilized in the field of school psychology. It is similar in that students who require extra academic or behavioral supports within the schools ideally will move from having these intense extra supports at the Tier 3 level to eventually be integrated at the Tier 1 level.

In addition to other youth with chronic health conditions, youth with ADHD also experience difficulties when transitioning from adolescence and into adulthood. Although there are many factors that contribute to this, the lack of self advocacy is one important aspect that interferes with this success. Stamp, Banerjee and Brown (2014) examined this further by looking at self-advocacy and overall college readiness for youth with ADHD. Within this study the authors interviewed a total of 12 participants who struggled academically with transitioning from high school to college. These participants initially were at a larger university before switching to a smaller private university that specifically worked with students with ADHD or a learning disability. Demographically, there were 8 males, with the majority of the participants falling within the 20-22 year old age range. These individuals then participated in a one-on-one interview where they shared the challenges that they had with transitioning at the previous university. Within these interviews there were many common themes that surfaced. For example, participants expressed feelings of frustration and depression, difficulty with setting limits with peers and avoidance and lack of self-advocacy. When examining the level of self-advocacy among this group of individuals it appeared that the lack of this skill impeded their success while trying to adjust to the new college environment. These self-advocacy difficulties could be seen specifically with their peer and teacher relationships. Students reported that when it came to their peers they were unable to express some of the challenges that they had with their assignments. This resulted in participants agreeing to party with their peers when instead they should have been studying or completing their homework assignments. Many of these challenges also were present when students were dealing with teachers. Participants reported that it was difficult to advocate for their needs within the classroom for many reasons. For example, many students reported that it was difficult to self-advocate because they did not possess the skills to do so. Other participants indicated that they did not want to appear incompetent or like they were making excuses. In contrast, some participants were actually not aware that they needed help with self-advocating skills until they had either already missed a deadline or failed a test. These findings were interesting because one particular participant reported that "most people that have ADHD have a continuously diminishing self-value, especially if they were bright when they were younger" (Stamp, Banerjee, & Brown, 2014, p. 14). This is important to consider because highly intelligent students with ADHD may be more likely to lack self-advocacy skills when entering college because they had never needed them in the past. In response to this dilemma, the authors have proposed that students with chronic health conditions should be given consistent support and guidance during this transition phase. In addition, students should also receive training prior to this college transition phase on what it means to self-advocate for one's needs and the importance being able to self-advocate.

There are many factors that contribute to self-advocacy. Self-advocacy encompasses different subsets of skills that aid youth in developing a healthy, independent lifestyle. Families and health care providers are essential to helping youth develop these skills, particularly during the transitional phase. In addition it is evident that there are clear factors that help to build skills in self-advocacy within youth. These factors range from being exposed to other advocates in their daily life (e.g., parents, teachers) to having psychological autonomy.

Literature Review Conclusions

In summary, the literature demonstrates the importance of having factors such as health literacy, resiliency, and support/self-advocacy. Specifically, these qualities are shown to be particularly useful for those individuals who have chronic health conditions. For youth with chronic health conditions, evidence shows that having an understanding of one's own illness is linked to positive medical habits such as treatment adherence (Navarra et al., 2014). In addition the health literacy being an adaptive trait for this population, factors such as resiliency and support/self advocacy are also viewed as facilitative. The resiliency models: Wanderlander and Varni's Disability-Stress-Coping model (Thompson et al., 1993), Thompson and Gustafson's Transactional Stress and Coping Model (Thompson, et al. 1989) and Kazak's Social Ecological model (Kazak et al., 2002), all demonstrate the importance of fostering resiliency for youth with chronic health conditions. In particular, these models explain how resiliency is developed through either experiences or through the interactions and relationships within the child's environment. Resiliency helps to promote increased mental health and psychological adjustment (Perrin et al., 1993). In regards to support/self-advocacy, there is an extensive amount of literature that explores the importance of this factor for this population. The literature shows that self-advocacy is especially crucial to have during the adolescent and young adults. The ability to self-advocate is accompanied by the ability effectively communicate, relate and even impose specific concerns regarding one's own chronic health condition (VanReusen et al., 1994). Self- advocacy is particularly helpful during the transitioning phase from pediatric care to adult care (Clinical Report, 2011). Overall, it is evident that these three factors can impact the lives of individuals with chronic health conditions. The current study will add to this literature by specifically exploring how different categories of chronic health conditions relate to levels of health literacy, resiliency and support/self advocacy.

Table 1

Previous Measures of Constructs

Scales	Description
The Health Literacy Assessment Scale for Adolescents (HAS-A)	The purpose of this tool is to measure health literacy in Adolescents (ages 12-19). It is a self-report measure that focuses on four domains of health literacy; the ability to obtain, communicate, understand, and process health information (Manganello, DeVellis, Davis, & Schottler-Thai, 2015).
Connor-Davidson Resilience Scale (CD-RISC)	The Connor-Davidson Resilience Scale (CD-RISC) was developed to help measure resilient characteristics and an individual's ability to adapt. There are total of five subscales (Gonzalez, Moore, Newton, & Galli, 2016).
Self-Advocacy Interview for Students	The Self-Advocacy Interview was developed to measure self-advocacy in students. It was specifically created to measure self-advocacy in students with learning disabilities. The tool specifically assesses the two constructs of knowledge and communication within self-advocacy. (SAI; Brunello-Prudencio, 2001). .
Self-Advocacy Measure for Youth ***(SAMY)***	The Self-Advocacy Measure for Youth (SAMY) was developed to assess the global construct of self-advocacy along with quantitatively measuring students' self-advocacy skills at the primary level. It is the first instrument with validity evidence to measure self-advocacy skills in students in the ADHD population (Adams, 2015).
The Brief Resilience Scale (BRS)	The Brief Resilience Scale was developed to assess the ability to recover from stressful situations. Specifically, this 6-item scale looks to provide information regarding individuals' ability to cope with health-related stressors (Smith, Dalen, Wiggins, Tooley, Christopher, & Bernard, 2008).

Chapter III

Method

A quantitative approach utilizing a purposive sample was implemented for the current study. This chapter will provide a discussion of the methods for this study. The first section describes the research design and detailed procedures followed to develop the Youth Health Literacy and Resiliency Scale and the data that were used for this study. The next section presents the secondary data analysis plan. The following study examined if there was an overall relationship between categories of chronic illness *(Endocrine, nutritional and metabolic diseases, Diseases of the musculoskeletal system and connective tissue and Disease of Congenital malformations, deformations and chromosomal abnormalities*) and health literacy, resiliency, and support/self-advocacy.

Research Questions

1. What is the relationship between categories of chronic illness and health literacy?
    - Does the relationship between categories of chronic illness and health literacy differ by age?
2. What is the relationship between categories of chronic illness and resiliency?
    - Does the relationship between categories of chronic illness and self-advocacy/support differ by age?
3. What is the relationship between categories of chronic illness and self-advocacy/support?

- Does the relationship between categories of chronic illness and resiliency differ by age?

Research Design

This study is a secondary analysis that utilized data collected from the Youth Health Literacy and Resiliency Scale (HLRS-Y version). This scale was developed in order to measure health literacy, resiliency and self-advocacy in youth with chronic health conditions. These data are from a larger study conducted by Dr. Bradley-Klug, the Principal Investigator, from the School Psychology Program at the University of South Florida. The current study used a portion of the data from this larger study. Quantitative methods were employed to answer the research questions regarding the relationship between different categories of chronic health conditions and resiliency, health literacy and support/self-advocacy. The design also examined the interaction effect of age and the extent to which the relationships between chronic health conditions and resiliency, health literacy and support/self-advocacy are consistent for older and younger students.

Construction of the Initial Scale

The development of the scale was completed in four phases. The guidelines outlined by DeVellis (2012) were used to define the overall purpose of the scale. After utilizing these guidelines, the scale developers decided that the measurement of health literacy, specifically in youth, would be the targeted population for this scale. Each of the four phases of scale development is described in detail in the following sections.

Phase 1

Within Phase 1 of the scale development, the researchers initially defined the scale constructs (health literacy and resiliency), conducted focus groups and generated a pool of items for the scale. For the purpose of this scale, health literacy is defined as the ability to make informed health decisions in everyday life (Kickbusch, 2008). Health resiliency was described as a tool to help youth (children and adolescents) and young adults adapt and cope with their chronic illness (Moskowitz, 2010). After implementing these definitions as a guiding framework, two focus groups were organized in order to gain a better understanding of how adolescents and young adults view their chronic illness, their beliefs in their ability to manage and cope with their health condition, and how they communicate their health needs to others (Bradley-Klug et al., 2017). The health literacy items that were constructed were classified as critical health literacy questions as described in the literature review. The first focus group consisted of young adults with Type I diabetes and the second group included three adolescents with cancer and one with a bleeding disorder. All participants had been aware of their condition for at least six months. Within each focus group several themes such as understanding and dealing with one's health condition were discussed. In addition, themes such as hopefulness and access to an available support system also were discussed. Using these themes along with information gathered during the literature review process, 101 scale items were generated for the initial scale. All of the items that were generated were original; items from outside measures were not included. In order to eliminate neutral responses, the scale was created using a Likert scale that contained four response options ranging from 1 (Strongly Disagree) to 4 (Strongly Agree). The scale was developed as an online survey because it was easier to access by respondents and because it was more appealing to the age group that would be asked to complete the scale.

Phase 2

During Phase 2, the scale was reviewed and the number of items was reduced. To review the initial 101 items, an expert team of four individuals in the fields of measurement and scale development, health literacy, resiliency, and pediatric psychology was assembled. These experts contributed by assessing the overall relevance and impact of the items, as well as their format and general readability. Expert reviewers received an incentive of $100 for providing their time and feedback on the scale. When feedback from the experts resulted in conflicting ideas or suggestions regarding an item, the researchers discussed the item in further detail prior to considering it for revision or removal. After this process of revising and removing items, the number of items in the scale was reduced to 80 at the end of Phase 2.

Phase 3

Within Phase 3, a pilot sample of youth with chronic health conditions was recruited to gather both quantitative and qualitative data regarding the scale. The 80-item HLRS-Y was first administered to an initial sample of 25 participants, ages 13-21 years, with chronic health conditions. These participants had been aware of their condition for at least six months. Participants were offered a $25 electronic gift card for completing the survey. Participants took the survey online through the Survey Monkey website (http://www.surveymonkey.com). In order to gain additional feedback regarding the format and relevance of the items, participants also were asked if each item was too complex to understand, made them feel uncomfortable, or whether the item should be considered for deletion. There was a designated section at the end of the survey for participants to answers these questions and to provide overall qualitative feedback on the survey. In addition, after completing the survey, participants were asked if there were questions that they believed would contribute to the scale that they had not already seen (Bradley Klug et al., 2017). The overall purpose of Phase 3 was to narrow down the number of items on the scale. The descriptive statistics for each item (e.g., mean, standard deviation, minimum, maximum) were analyzed to assess levels of variation. The amount of responsiveness to each item in comparison to others also was examined, along with measures relating to scale cohesiveness, primarily corrected item-total correlations and Cronbach's alpha (Bradley Klug et al., 2017). Items were considered for removal when they didn't demonstrate strong properties on these measures and if the mean of the item was 3.5 or higher (on a scale of 1-4). This indicated that there was a small variation in responses and that the item did not contribute in differentiating any information regarding the constructs. Items were also considered for deletion if the absolute value of the corrected item-total correlation was.10 or lower or the alpha coefficient increased by.05 or more when the item was deleted (Bradley Klug et al., 2017). Any items with large amounts of non-response in the form of missing data or responses of Does Not Apply were also flagged for removal from the scale. The final scale contained 37 items across the three areas of health literary (10 Items), resiliency (14 Items), and support/self-advocacy (13 Items). Samples items from the scale for each of the three constructs are provided below:

Health Literacy Subscale

- I know the common symptoms of my health condition
- I know what medication(s) I need to take to manage my health condition

Resilience Subscale

- I focus on the positive aspects of my life
- I find ways to do fun activities with friends and family while living with my health condition

Self-Advocacy/Support

- I tell others when I am not feeling well
- I accept help from family and friends in managing my health condition

Phase 4

Phase 4 included participant recruitment on a national level, scale administration, scale analyses and scale item finalization. A portion of the data gathered in Phase 4 were analyzed for this current study.

Participants

Data were obtained from a national sample of 204 participants with chronic health conditions. Participants had to be English-speaking youth and young adults between the ages of 13 and 21 years with a primary diagnosis of a chronic health condition. Participants had to live in the United States and have known about their primary health condition for at least six months prior to participation in the study. Participants with significant cognitive impairment were excluded in order to ensure all respondents comprehended the wording and intent of the scale items. Participants were recruited from community-based agencies (e.g., local hospitals, medical facilities) as well as social media outlets (e.g., Facebook). Every 10 participants who completed the survey were entered to win a $25 electronic gift card, thus each participant had a one in ten chance of receiving this incentive. The resulting sample from this national study consisted of 75.7% female respondents with the average age of the sample being 17.6 years of age (range = 13 – 21). The majority of the participants, 175 (86.6%), ethnically identified as White. When asked, participants indicated that they first learned of their condition in either middle school (22.8%) or high school (21.8%); however in contrast, many indicated, “I have known as long as I can remember” (20.8%) (Bradley Klug et al., 2017). When reviewing the large number of different chronic health conditions reported by respondents, the researchers determined that categorizing these conditions using an accepted classification system would aid in organizing and analyzing the data. The International Classification of Diseases 10th Edition (ICD-9) was chosen to group individuals based on their self-reported, primary health condition. Using this classification system, 35% of participants had a chronic health condition that fell in the category of Endocrine, nutritional, and metabolic diseases (e.g., cystic fibrosis, diabetes), 25% in Diseases of the Musculoskeletal System and Connective Tissue (e.g., juvenile rheumatoid arthritis fibromyalgia), and 13% in Congenital Anomalies (e.g., Ehlers Danlos, Marfan’s syndrome). A remaining percentage of participants fell into the categories of Diseases of the Blood and Blood-forming Organs (9%), Diseases of the Nervous System (7%), and Diseases of the Digestive System (7%). For the purpose of the current study, only data from participants in the three larger categories were used in the analyses. Of the total 204 respondents, 143 were classified into one these three categories. Nearly all 204 respondents (98%) indicated being covered by some type of insurance. Of those, most were covered by private insurance (70.2%), 16.7% by public programs, and 13.1% were unsure of their type of insurance. A large majority of the sample also indicated currently being enrolled in school (81.2%).

Procedure

After obtaining informed consent, participants completed a demographic survey and the HLRS-Y via Survey Monkey (http://www.surveymonkey.com). The demographic survey consisted of questions about the participant's age, gender, race/ethnicity, primary and secondary health condition, educational attainment, and insurance (i.e., public, private, not sure). After completion of the demographic survey, they were then directed to complete the HLRS-Y.

Scale Analysis

An Exploratory Factor Analysis (EFA) was conducted. The purpose of this analysis was to determine the underlining constructs that each of the items identified with. In order to be included under a specific construct, items had to have coefficients that were greater than or equal to 0.40. Items were removed if they did not fit this criteria for any of the factors and also if there was cross loading of ($\geq$ 0.35) with more than one construct (Bradley Klug et al., 2017). Once the analysis was conducted, it was discovered that there was another factor in addition to that of health literacy and resiliency. These items were reviewed and then labeled as the third construct of support/ self-advocacy. The final measure includes a total 37 items, with a breakdown of: health literacy (10 items; α= .88), resiliency (13 items; α= .93) and support/self-advocacy (14 items; α= .94). It also is important to note that some items loaded heavily on more than one construct. These items were grouped under the construct that had the highest value.

Plan for Data Analysis

Descriptive Analyses. To address the research questions for this current study, data from the 143 respondents categorized in the three ICD-9 categories described previously were analyzed. All descriptive data analyses were conducted using the program Statistical Package for the Social Sciences (SPSS). Descriptive analyses for the current study consisted of means, standard deviations, normality (skewness and kurtosis), and correlations for the resiliency, health literacy and support/advocacy variables.

Univariate Analysis. Prior to conducting the univariate analyses, Cronbach's alpha was computed for each of the three subscales. This examined the item to total correlations. Univariate analyses also were conducted for the independent variables of categories of chronic health conditions and age. A frequency count for the number of participants in each of the three health categories and the age category was taken. This simple analysis produced the central tendency and dispersion in order to determine initial patterns that can be found with the sample. Univariate data also were calculated for the dependent variables, which depict the central tendencies and the dispersion of the overall responses that were given by participants in the sample.

Independent variables

1. Category of Chronic Health Condition- These categories were created using the ICD-9-CM (International Classification of Diseases, 9th edition, Clinical Modification. The three categories in which participants were classified included:

a) Endocrine, nutritional, and metabolic diseases (e.g., cystic fibrosis, diabetes)
b) Diseases of the Musculoskeletal System and Connective Tissue (e.g., juvenile rheumatoid arthritis, fibromyalgia)
c) Congenital Anomalies (e.g., Ehlers Danlos, Marfan's syndrome).

2. Age – This variable was viewed as a continuous variable with participants ranging from ages 13-21.

Dependent Variables

1. Level of Health Literacy- The level in which participants are able to make sound health decisions in the context of everyday life.
2. Level of Resiliency- The level in which participants can recover quickly from change, hardship or a difficult situation, and adapt to this new situation
3. Level of Support/Self Advocacy- Level of support systems available and the ability to seek help for individual needs

Bivariate Analysis. In order to determine if there were relationships between the variables, bivariate analyses were conducted. The bivariate analyses consisted of Pearson's product-moment correlations (PPMC) which compared the three subscales (e.g., health literacy, resiliency and support/self advocacy) and age (IV). This demonstrated if there were a relationship between participant's age and the outcomes of the dependent variable. Specifically this determined if there was a relationship between the age of the participants (13-21 year) and their reported levels of health literacy, resiliency and support/self advocacy. In addition, three One-way ANOVAs also were conducted for the independent variable of categories of chronic illness. The purpose of the One-Way ANOVA was to determine whether there was any significant relationship and difference between the means of the three separate classifications of chronic illness. The ANOVA also was necessary because the chronic health condition variable is considered to be a categorical variable. The ANOVAs were conducted with the three categories of the chronic health conditions and three dependent variables of health literacy, resiliency and support/self-advocacy. When conducting the three One-way ANOVA's there was an increase in the likelihood of a type 1 error. In order to check if the assumptions of the One-way ANOVA's have been met, Levene's test was conducted to test the homogeneity of variance along with an examination of the distribution of the graph of residuals to test normality.

Multiple Regression (hierarchical). For the culminating analysis, hierarchical multiple regression was utilized. The multiple regression formulates the multivariate analysis when incorporating the interaction effect of age and category of chronic health condition on health literacy, resiliency and support/self advocacy. Two dummy variables were created in order to categorize the participants into one of the three categories of chronic illness. The purpose of the dummy variables, also referred to as indicator variables, is to help represent multiple subgroups within a variable. In addition, the dummy variables also change variables that are categorical (such as categories of chronic health condition) to interval, which is necessary to run the multiple regression. There also are assumptions that were evaluated. In order to do this the graphical distribution of the residuals was examined to assess the linearity, homoscedasticity and multicollinearity. Specifically the residuals in the scatterplots along with the tolerance level and Variance Inflation Factor (VIC) in the coefficient tables check for these assumptions. Viewing the histograms of the residuals was used to assess normality.

The overall goal of the study was to determine if there is a relationship between different categories of chronic health conditions and the factors of health literacy, resiliency and support/self/advocacy. Currently there is a significant gap in the literature pertaining to youth chronic illness and the impact of having health literacy and resiliency. This secondary study seeks to minimize this gap by exploring these factors using the HLRS-Y.

Chapter IV

Results

This chapter includes the results of the analyses conducted to answer the research questions. The overall purpose of this study was to explore the relationships between three different categories of youth chronic illnesses and the factors of resiliency, health literacy and self-advocacy/support. First, the results from the preliminary analyses and descriptive statistics are discussed, followed by the correlational analyses comparing the three subscales (e.g., health literacy, resiliency and support/self advocacy) and age. Finally, results from the analyses of variance and regression analyses are provided to address the three research questions.

Preliminary Analysis

Data entry. All of the original data that were collected using Survey Monkey were automatically downloaded into an Excel spreadsheet. Due to only a select amount of data being used from the original sample, the data utilized for the current study were taken from this original spreadsheet and transferred to a new spreadsheet. This was done to help separate the participants into the three categories. Next the data were uploaded directly from Excel into SPSS. Descriptive analyses for the current study consisted of means, standard deviations, normality (skewness and kurtosis), and correlations for the resiliency, health literacy and support/advocacy variables. Table 2 presents the detailed results of the analyses.

Table 2

Descriptive Statistics for Health Literacy, Resiliency and Support/Self-Advocacy

Subscale	# of items	Cronbach's alpha	*M*	*SD*	Skewness	Kurtosis
Health Literacy	10	.88	3.47	0.48	-2.00	6.55
Resiliency	14	.88	3.28	0.47	-0.17	-1.00
Self-Advocacy/Support	13	.87	3.05	0.51	-0.80	0.66

Note. Subscale scores were measured using a 1 to 4 response scale.

Distribution of data. The descriptive statistics for the dataset are shown in Table 2. For the category of health literacy the sample of participants scored an average of 3.47 (*SD* = 0.48). For resiliency and self-advocacy/support participants scored an average of 3.28 (*SD* = 0.47) and 3.05 (*SD*= 0.51), respectively. In order to examine the normality of each of the three dependent variables, the skewness and kurtosis were calculated. For the skewness, all of the values fell in the range between -2.0 and 2.0, which indicates that there were no extreme departures from normality. For the kurtosis, all of the variables except for health literacy were approximately normally distributed. This high positive kurtosis value for the health literacy scores suggests that the distribution is leptokurtic, meaning that the values are more clustered around the mean.

Missing Data. Of the 143 participants, 126 (88%) answered all of the questions. For the health literacy category, the response rate of participants ranged from 90% - 98% across all questions. For the resiliency category, the response rate ranged from 85% - 96% across questions, and for the support/self-advocacy category, the response rate ranged from 81% - 97% across questions. Items that were related to school (items

#43, 60, 62, and 63) received the lowest response rates from participants (see Appendix B).

Reliability of the measures. The Cronbach's alphas for each of the three factors within the Health Literacy and Resiliency Scale were calculated (see Table 2). The Cronbach's alphas for each of the three factors were considered good, with values of .88, .88, and .87 (Hatte, 1985). The values of the three numbers also may suggest that the levels of internal consistency for these factors are very similar. These Cronbach alpha values differ from the values calculated in the original sample.

Table 3

Pearson Product-Moment Correlations Between Youth Health Resiliency Subscales and Age

Subscale	Health	Resiliency	Support	Age
Health Literacy				
Resiliency	.40			
Support/ Self-Advocacy	.34	.41		
Age	.02	.04	-.28	

n = 126

Correlational data were collected on the independent variable of age and the dependent variables of health literacy, resiliency and support/self advocacy. For the age variable there was not a strong correlation with the variables of heath literacy and resiliency. However, there was a negative moderate correlation (*r* =-.28) between the variable of age and support/self-advocacy, suggesting that as participants increase in age, they report a lower score in support/self-advocacy. In addition, there was a positive moderate correlation (*r* = .40) between the dependent variables of health literacy and resiliency and also between health literacy and support/ self-advocacy (*r* = .34). This suggests that individuals who had higher responses on health literacy items also had higher responses on the resiliency and the support/self advocacy items.

Assumptions

Linearity*.* In order to assess the linearity of the independent and dependent variables, the residuals were examined. This was done by assessing the residual plots of the standardized residuals by the standardized predicted values. Based on a visual observation of plots, the assumption of linearity did not appear to be violated.

Homoscedasticity*.* To assess the homoscedasticity, the variance of errors had to be examined. A visual observation of the residual plots was conducted. Based on the observations, there were not any apparent violations of the assumption of homoscedasticity. All the errors appeared to have the same spread across all independent variables.

Normality*.* In order to assess the normality, the distributions of the residuals were examined. Examining the skewness and kurtosis values was used to assess normality of the residuals. Based on the data, there appeared to be some violations of normality due to the large kurtosis value.

Multicollinearity*.* To assess multicollinearity, the tolerance indicators were assessed. Tolerance values for the data were higher than the recommended minimum level of .10 (Tabachnick & Fidell, 2001), indicating that there were no violations in assumptions.

Multiple Regression Analysis

Multiple regression analyses were conducted in order to answer the research question: *What is the relationship between categories of chronic illness (the endocrine, nutritional and metabolic diseases, diseases of the musculoskeletal system and connective tissue and disease of congenital malformations, deformations and chromosomal abnormalities) and health literacy, resiliency, and support/self-advocacy?* Two dummy variables were created to categorize the participants into one of the three categories of chronic illness. The purpose of the dummy variables, also referred to as indicator variables, is to help represent multiple subgroups within a variable. Specifically the categories of chronic health conditions were dummy coded with three dichotomous variables with the *endocrine, nutritional and metabolic diseases* as the reference group.

Categories of chronic health conditions as predictors of health literacy

In the hierarchical regression for health literacy the variance in scores was not largely explained by the independent variables of type of category of chronic health conditions and age. When explaining the levels of health literacy, age accounted for less than 1% of the variance in these health literacy scores. When including age and condition, this also accounted for less than 1% of the variance. Finally when including age, condition and the interactions between these two variables, only 2.3 % of the variance in the scores could be explained. None of the R^2 values were significantly different than zero. This indicates that the type of chronic health condition, along with age did not contribute significantly to the variation in health literacy scores (see Table 4).

Overall the results indicate that the variables of categories of chronic health condition and age do not have a main effect on the reported level of health literacy.

Table 4
Summary of Hierarchical Regression Analysis for Variables Predicting Health Literacy

	Model 1			Model 2			Model 3		
Variable	*B*	*SE B*	**B**	*B*	*SE B*	**B**	*B*	*SE B*	**B**
Age	.003	0.02	0.02	.003	0.02	0.02	-.02	0.02	-.10
Musculoskeletal				0.05	0.10	0.05	-1.0	0.66	-.97
Congenital				0.04	0.11	0.03	-.27	0.75	-.22
Age x Musculoskeletal							0.06	0.04	1.04
Age x Congenital							.017	0.04	0.26
R^2		.000			.003			.023	
F for change in R^2		0.039			0.166			1.30	

Note. None of the R^2 values were significantly different from zero ($p > 0.05$).

Categories of chronic health conditions as predictors of resiliency

In the hierarchical regression for resiliency the variance in scores was not largely explained by the independent variables of type of category of chronic health conditions and age. When explaining the levels of resiliency, age accounted for less than 1% of the variance in these resiliency scores. When including age and condition, this also accounted for less than 3.2% of the variance. Finally, when including age, condition and the interactions between these two variables, only 5.4% of the variance in the scores was explained. None of the R^2 were significantly different from zero. This indicates that the type of chronic health condition, along with age did not contribute significantly to the variation in resiliency scores. Overall the results indicate that the variables of categories of chronic health condition and age do not have a main effect on the reported level of resiliency (see Table 5).

Table 5
Summary of Hierarchical Regression Analysis for Variables Predicting Resiliency

	Model 1			Model 2			Model 3		
Variable	*B*	*SE B*	**B**	*B*	*SE B*	**B**	*B*	*SE B*	**B**
Age	-.01	0.02	-.04	-.01	0.02	-.03	-.0.4	0.02	-.20
Musculoskeletal				0.09	0.09	0.09	-.78	0.61	-.81
Congenital				-.14	0.11	-.12	-1.19	0.74	-1.00
Age x Musculoskeletal							0.05	0.03	0.90
Age x Congenital							0.06	0.04	0.90
R^2	.001			.032			.054		
F for change in R^2	.162			2.07			1.51		

Note. None of the R^2 values were significantly different from zero ($p > .05$).

Categories of chronic health conditions as predictors of support/self-advocacy

In the hierarchical regression for support/self-advocacy the variance in scores was not largely explained by the independent variables of type of category of chronic health conditions. When explaining the levels of support/self-advocacy, age accounted for 8% of the variance in these support/self-advocacy scores. When including age and condition, this also accounted for 10% of the variance. Finally when including age, condition and the interactions between these two variables, 12.1% of the variance in the scores could be explained. The results indicated that variance in scores due to age was significant. However when examining the variance due to variable of categories of chronic health conditions and the interaction with age, there was not a significant effect (see Table 6).

Table 6

Summary of Hierarchical Regression Analysis for Variables Predicting Support

	Model 1			Model 2			Model 3		
Variable	*B*	*SE B*	**B**	*B*	*SE B*	**B**	*B*	*SE B*	**B**
Age	-.05	0.02	-.28*	-.05	0.02	-.27**	-.07	0.03	-.38**
Musculoskeletal				0.17	1.00	0.15	-.88	0.67	-.78
Congenital				0.11	0.12	0.09	0.13	0.78	0.10
Age x Musculoskeletal							0.06	0.04	0.95
Age x Congenital							-.00	0.04	-.01
R^2	0.08			.100			.121		
F for change in R^2	10.6			1.48			1.43		

* *p* < .05. ***p* < .01

Summary of Significant Findings

After completing the data analysis, there were limited significant findings. The results indicated that the dependent variables of resiliency, health literacy and support/self advocacy were not significantly related to the independent variables of categories of chronic health conditions. However there was a significant finding with the variable of age. Age was examined in order to determine if there was an interaction effect between the participants and how they responded to the three constructs. After examining the effect of age and controlling for the different categories of chronic health conditions, there was a significant finding of age and the dependent variable of support/self-advocacy. As individuals increased in age they reported having decreased levels of support/self-advocacy, while those individuals who were younger in age reported having higher levels of support/self-advocacy. There were no significant findings between age and reported levels of health literacy and resiliency. The overall results of this study appear to align with the purpose of the HLRS. The HLRS was created to serve as a broad tool to be used across medical conditions to measure levels of health literacy, resiliency and support/self-advocacy. The results indicate that the tool did not discriminate among the conditions.

CHAPTER V

Discussion

The overall purpose of this study was to examine the relationships between three different categories of youth chronic illnesses and the factors of resiliency, health literacy and self-advocacy/support. More specifically, this study sought to investigate the relationships between the independent variables of type of category of chronic health condition, age and the interaction of age and type of category of chronic health condition, and the dependent variables of health literacy, resiliency and support/self-advocacy.

This chapter provides a detailed discussion of the study results. In addition, the limitations of the study, implications of these results for practice, and recommendations for future research will be presented.

Overview of the Study

Within the United States there are approximately 15% to 18% of youth living with a chronic health condition (CDC, 2010). Although not all youth living with a chronic illness experience adversity due to their condition, it is important to note that chronic health conditions may impact not only the physical health of youth but also their mental health, psychosocial development, and educational outcomes. The current study sought to explore if there was a relationship between specific chronic health conditions and the factors of health literacy, resiliency and support/self-advocacy. In particular, youth in the current study completed the HLRS-Y, where participants were categorized based on the type of chronic health condition. Only individuals in one of the three ICD-9 categories were included: 1*) Endocrine, nutritional, and metabolic diseases, 2) Diseases of the musculoskeletal system and connective tissue, and 3) Diseases of congenital malformation, deformations, and chromosomal abnormalities.* Findings from this study have the potential to drive interventions, particularly for those groups who may have lower levels of these three factors.

Discussion of Results

Research question one. *What is the relationship between categories of chronic illness and health literacy? Does the relationship between categories of chronic illness and health literacy differ by age?*

Research question one explored whether or not there was a relationship between health literacy and different types of chronic health conditions. In addition, the current study also explored if this relationship would differ by the age of participants.

Based on the results there were no significant findings related to this research question. When taking into account the category of chronic health condition, age and the interaction between these two variables, only 2.3% of the variance in health literacy scores was accounted for by these variables. Additionally, the age of the participants also was not significant and this account for less than 1% of the variance. Although the research on health literacy and youth living with a chronic health condition is very limited, these results were unexpected. It was anticipated that the individuals in the *Endocrine, nutritional, and metabolic diseases* category would have a higher level of health literacy. The rationale for this is that some chronic health conditions tend to be more prominent than others, which may stimulate research for these illnesses. Chao, Minges, Park, Dumser, Murphy, Grey and Whitmore (2016) report that type 1 diabetes is one of the most common chronic health conditions found among youth. This is important to note because in the current study, those participants with type 1 diabetes made up the largest category of youth with chronic health conditions. Within the United States, this chronic illness is diagnosed in more than 15,000 youth per year. There is a range of literature on youth with diabetes that includes quality of life and the exact stressors that are linked to the disorder that is not present for other chronic illnesses. More specifically, in comparison to other illnesses, there is more research on the direct medical effects that type 1 diabetes can have on a patient. Research has shown how characteristics such as self-management can help to prevent short and long-term complications such as seizures, nephropathy, diabetic ketoacidosis, neuropathy, and retinopathy; while maintaining good glycemic control (Guo, Whittemore, & He, 2011; Campbell et al., 2014). This demonstrates the range of research that has been done in the area of type 1 diabetes in youth. Although there was not an original hypothesis that was identified in this study with health literacy and the different categories of chronic health conditions, there was an expectation that the individuals in the more prevalent chronic health condition categories may demonstrate a higher level of health literacy. More so with this higher level being attributed to the fact there is more research that has been conducted in this area. Logically there is more research in the areas where there is a higher need and prevalence. However, this current study indicates that just because there is more available literature in a particular area, it does not suggest that the literature is being disseminated to those who may benefit from it the most. This is important to note because it suggests that there are other factors, such as methods of dissemination that are contributing to the level of understanding that youth may have of their chronic health conditions. Although the youth diabetes literature is extensive, the information may not be as readily available to these youth and their families. In response to this, it is recommended that information continue to be available to youth and their families through outlets such as pamphlets, educational videos, and social media sites. As researchers, it is critical to explore methods to share this information to patients and families. It is important to ensure that these individuals have all the possible advantages when maneuvering through life with a chronic health condition.

Research question two. *What is the relationship between categories of chronic illness and resiliency? Does the relationship between categories of chronic illness and resiliency differ by age?*

Research question number two examined whether or not there was a relationship between different types of chronic health conditions and the level of resiliency. In addition, the current study also explored whether this relationship would differ by the age of participants.

Despite that there were no significant findings among the categories of chronic health conditions and resiliency, the results did show that there was a moderate correlation between resiliency and the other dependent variables. More specifically, the data depicted a positive relationship, which says that higher scores in resiliency on the HLRS may indicate higher scores in health literacy and support/self-advocacy.

Although there were no hypotheses associated with this research question, the results were somewhat surprising. Based on the literature that is provided for youth with chronic health conditions, the expectation was that there would be more variation in the level of responses, with those in the *Endocrine, nutritional, and metabolic diseases* category having higher levels of resiliency, than the other two categories. The rationale for this is that within the sample two of the most common chronic health conditions among youth (Type 1 Diabetes and Cystic Fibrosis) can be found in this category. Type 1 diabetes and cystic fibrosis comprised of approximately 30% of the entire sample. For type 1 diabetes there is a greater range in research that has been conducted regarding the illness in comparison to other chronic health conditions. This is important to note because it indicates that there is more knowledge and information available for youth who are living with this condition. For example, for youth living with diabetes, there is literature on how to foster protective factors in order to help youth develop resiliency. Interestingly enough, Monaghan, Clary, Stern, Hilliard, and Streisand (2015) explored some protective factors in youth with diabetes and found that those individuals who had parents with lower stress levels and lower parent depressive symptoms also reported higher levels of resiliency and quality of life. This is an important finding because it sheds light on environmental factors that can help aid chronically ill youth within their everyday life. In addition to there being more literature for chronic conditions such as diabetes and cystic fibrosis, there is another aspect to consider. When concerning youth who have had an early childhood diagnosis, they tend to demonstrate higher levels of resiliency in comparison to their peers who have received a diagnosis in later childhood. For example youth with cystic fibrosis, usually receive a diagnosis no later than the age of 2 years. This is important to note because there were individuals within the current study who had cystic fibrosis. Mitmansgruber, Smrekar, Rabanser, Beck, Eder, and Ellemunter (2016), explained how individuals with cystic fibrosis tend to display high levels of resiliency. Patients within this study took the Intolerance of Uncertainty Scale (IUS), Cystic Fibrosis Questionnaire-Revised (CFQ-R) and the Resilience Scale (RS) and the results demonstrated high levels of resiliency and low levels of cognitive avoidance among these patients. The authors concluded that these positive results could be attributed to the fact that these participants were all diagnosed with their chronic health condition during infancy. Over time these individuals had learned to cope and live a life that was not centered around their diagnosis. Overall it is clear that the results found in the current study do not align with the results that are found in the literature. It may be beneficial to further explore this relationship in future research.

Research question three. *What is the relationship between categories of chronic illness and support/self-advocacy? Does the relationship between categories of chronic illness and support/self-advocacy differ by age?*

Research question number three examined whether or not there was a relationship between categories of chronic health conditions and the level support/self-advocacy. In addition, the current study also explored whether this relationship would differ by the age of participants.

Similar to results from research questions number one and two, there were no significant findings among the categories of chronic health conditions and support/self-advocacy. These findings indicate that the variance in the levels of support/self-advocacy scores were not significantly affected by individuals being within different groups. Although the results were not significant, it was found that the levels of support/self-advocacy were significantly related to the age of the respondents. Those individuals who were younger tended to demonstrate higher levels of support/self-advocacy in comparison to their older peers. Although there were not any initial hypotheses regarding this research question, the results did not correspond with what can be found within the literature regarding support/self-advocacy among youth with chronic health conditions. An example of this in the literature can be seen in a study by Okumura, Saunders, and Rehm (2015) where they demonstrated how youth from ages 16-25 learned to become advocates for themselves. Much of this was attributed to the process where individuals are transitioning from pediatric care to adult care/adulthood and have to learn to navigate through the healthcare system without assistance from others (i.e., parents, mentors, previous health care providers). Thus, over time youth learn how to become more independent which may be linked to their increased ability to advocate for themselves and their healthcare needs. Another example of this in the literature can be seen in a study conducted by Adams (2015) on youth living with ADHD. This researcher created a self-advocacy tool and found that as patients increased in age they demonstrated greater abilities to advocate for themselves. Ideally as children develop over time, they should become more independent. When considering the results of the current study, it is important to note that this particular construct is comprised of both support and self-advocacy. Therefore, it is possible that the responses from younger students are more reflective of the fact that they may require more outside supports (e.g. family, friends, etc.) than older students. Overall, it is important to acknowledge the relationship that age may have on the reported levels of support/self-advocacy. This in turn can potentially spearhead interventions that are tailored towards providing supports for older patients with chronic health conditions.

However as noted, questions in the support/self-advocacy category were not answered as frequently. A possible rationale for this is that individuals were currently not in school and therefore either indicated that the question was not applicable or selected the response of ‘significantly disagreed’. Scores for this construct could be lower due to this. Future studies should examine this relationship of respondents who are not in school and their specific responses to the responses in the support/self/advocacy category.

Additional Findings

Aside from the three original research questions there were also other findings within this study. As mentioned, correlational data analyses were run for the dependent variables and age. There was a positive moderate correlation ($r = .40$) between the dependent variables of health literacy and resiliency and also between health literacy and support/ self-advocacy ($r = .34$). Although there is limited research on this topic, it is important to mention because it suggests that there may be a relationship between individuals reported levels of health literacy and their levels resiliency and support/self-advocacy.

Limitations of the Study

There are several limitations that should be noted for this current study. One major limitation of the study is the scale used for data collection. The HLRS-Y scale is new and efforts to provide validity evidence are in the early stages. The current study is incorporating a secondary analysis of the original data collected from this scale. In addition, the sample for the study also was very limited, particularly in the area of diversity. Specifically, the majority of the participants identified themselves as being Caucasian and female. This is important to note because this may have had an impact on the types of chronic illnesses represented in the sample. For example, chronic health conditions such as sickle cell anemia were under represented, which may have resulted from the lack of diversity within the sample (i.e., sickle cell disease is most commonly reported in Africans and African Americans). Another limitation is that many of the conditions that were included in the larger sample, were not included in this current study. Ideally it is helpful to have a range of conditions represented in the sample; however, for analyses purposes it was difficult to ensure that these participants were represented in the larger sample. There was not an equal distribution of the chronic illnesses, with some conditions (e.g., type 1 diabetes) being more prevalent than others in the sample of respondents. Due to the variety of health conditions, participants in the current study were grouped into categories using the ICD-9-CM (International Classification of Diseases, 9th edition, Clinical Modification) code to minimize this limitation. Many chronic health conditions were identified in the original sample, however some of these conditions had very few participants. Therefore it was necessary to group the conditions into larger categories. This posed another limitation because only those participants who fell in the three largest categories were included in the present study. This in turn decreased the sample size of the study. Despite that the categories were created for the analyses, this posed another limitation. Due to the fact that the chronic health conditions were grouped, the researcher was unable to determine if there were differences within these groups. This is important to note because although illnesses were categorized based on their similarities, there are still differences in symptomatology, treatment and overall management. In addition, there also were limitations when performing the analyses. Of those participants who fell into one of the three selected categories, it was found that not all of these participants responded to all of the questions. The survey enabled individuals to skip questions; therefore there were a number of participants who did not answer all of the questions. This poses a limitation in that the researcher was not able to receive a full assessment of the individuals on all of the constructs.

Recommendations for Future Research

There is a significant need for additional research with youth living with chronic health conditions. More specifically, there is a need for research on how to foster attributes such as health literacy, resiliency, and support/self advocacy in this population of youth.

This current study sought to determine if there was a relationship between respondents who were classified into three different categories of chronic health conditions and the constructs of health literacy, resiliency and support/self-advocacy. One recommendation is to replicate this study with a larger, more diverse sample of participants. The reason for this is because this was the first investigation outside of the pilot study utilizing data from this scale. Prior to replicating the study, a power analysis should be conducted to determine the number of participants needed to identify group differences.

In addition, it also may be beneficial to avoid separating participants into large categories and to simply group them by specific chronic health disorder. Perhaps the sample can be geared towards those individuals with the most prevalent chronic health conditions. Researchers can then examine if there are varying levels in the constructs based on the exact disorder. This can be helpful because the results will focus on the chronic diseases that most youth are facing today. For example, chronic illnesses such as obesity and asthma were not represented in the current study sample. A follow up study should include these groups. This also is important because the outcomes could then be directly connected to a specific condition, rather than a group of conditions. There a many illnesses that can be found within one ICD-9 category therefore it becomes difficult to generalize the results to specific condition.

In addition to expanding on the sample, another suggestion for future research may be to include qualitative data from the participants. More specifically, if there are some significant differences in any of the constructs among the different chronic health conditions, it may be useful to identify why there are differences. This can be done by utilizing a semi-structured interview that allows students to specifically indicate the strategies and resources that help contribute to their high levels of health literacy resiliency and support/advocacy. As researchers, the goal is to seek as much information as possible to help spearhead interventions and supports for those individuals who may be lacking these resources.

Finally, it will be important to explore the feasibility of using this tool in a clinical setting. This scale was originally developed with the intent of having youth and young adults complete it as part of a clinical evaluation. Therefore, the utility of this scale for this type of setting will be critical to explore.

Implications and Considerations for Practice

Within the study it was found that when controlling for the specific categories of illnesses, age had a significant negative relation to the reported levels of support/self-advocacy. This is important to consider when implementing in practice because this information demonstrates that older individuals may be lacking in the area of this construct. As researchers we want to consider this because this can help to determine if there should be an intervention implemented for older youth, to help foster more support and self-advocacy. Support/ self-advocacy is defined as “the extent to which young people advocate on behalf of the accommodations and care they need and whether those around them are supportive of these needs” (Tutle et al., 2007, p. 1). Helping all youth within this population to develop this skill is vital because it does help aspects such as transitioning to adult care, developing positive relationships with healthcare providers, and extracting resources across different systems. It may be helpful to implement a preliminary intervention on how to promote support/self-advocacy in older patients. One example of an intervention that can be used with older patients is the TAKECHARGE for the Future curriculum (Powers, Turner, Westwood, Matuszewski, Wilson, & Phillips, 2001). This program is geared to towards providing supports and fostering self-advocacy skills for older youth with special health needs and disabilities. More specifically the program focuses empowering students so that they can become advocates for their own needs. The program provides an extra layer of social support, while also teaching youth how to access a variety of resources for their needs. Additionally in practice, it is necessary to take into account the developmental aspect of the situation. For example support/self-advocacy will look different for a 13-year old patient than for a 20-year-old patient. It is critical that the environment and developmental aspects of the youth are considered prior to implementing a particular intervention. Also factors such as whether a child is either receiving inpatient or outpatient care will also determine the direction of the intervention.

In addition, another implication for practice can be to promote health literacy as a prevention strategy. Based on the positive relationship between health literacy and resiliency and support/self advocacy, increasing levels of health literacy may be beneficial in increasing the levels of these other two constructs. Increasing health literacy can be targeted through education of those with chronic health conditions. This education could be offered through health educators, support groups, family members who are knowledgeable of the health condition, as well as evidence-based online resources. Health literacy can be measured using instruments such as the The Health Literacy Assessment Scale for Adolescents (HAS-A; (Manganello, DeVellis, Davis, & Schottler-Thai, 2015)). Addressing health literacy is crucial for practitioners because providing knowledge to youth with chronic health conditions is feasible and may serve to increase resiliency and support/self-advocacy.

Conclusion

The current study examined if there was a relationship between the independent variables of different categories of chronic health conditions and the dependent variables of levels of health literacy, resiliency and support/self advocacy. In addition this study also sought to determine if the interaction of age and health condition also had an impact on the recorded levels of the dependent variables. In contrast to the literature, the results indicated that there was not a significant difference between the three categories of chronic health conditions and the three dependent variables. Also there were not any significant findings when examining age as a moderator variable of the relation between health condition and the three dependent variables. However there was a significant finding between age and the level of support/ self-advocacy. Those individuals who were younger tended to report higher levels of support/self-advocacy. However, questions in the support/self-advocacy category had a lower response rate. It is hypothesized that some of the respondents were not in school and thus several of the items in this categories did not apply to them. In addition there was also a positive correlation between the dependent variables. Those individuals who had higher levels of health literacy also had higher levels of resiliency and support/ self-advocacy. These significant finding should be taken into consideration when implementing interventions for youth with chorine health conditions.

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Appendix A

HLRS- Y Final 37 Items

Item #	Question	Factor
1	I know the common symptoms of my health condition	1
2	I recognize when my health symptoms are severe and when they are not	1
3	I understand my health condition well	1
5	I know what medication(s) I need to take to manage my health condition	1
6	I know the correct dosage for my medication(s)	1
8	I know which types of physical activity can be potentially harmful to my health	1
9	I know when to tell my friends or family about my health limitations	1
11	I know the different ways my health impacts my performance in school or work	1
12	I understand the different ways my health impacts my relationship with my family	1
13	I understand the different ways my health impacts my relationships with my friends	1
18	I tell others when I am not feeling well	2
21	I learn about my health condition from my health care team	2
32	I limit or modify my daily activities based on my body’s symptoms	2
33	I get extra rest or ‘take it easy’ when needed for my health	2

	condition	
36	I have people around who love me	2
42	I accept help from my family and friends in managing my health condition	2
43	I accept help from my teachers and other personnel at school in managing my health condition	2
57	My parents help me adapt by learning as much as possible about my health condition	2
58	There is at least one person in my life who keeps an eye on me in case I need support with my health condition	2
59	I have a social support system (e g , family, friends) I can count on when I need to attend health-related events	2
60	I receive accommodations related to my health condition to allow me to be successful in school	2
62	Adults at my school understand my health-related needs	2
63	Adults at my school know about my health condition	2
22	I learn about my health condition from talking with others who have personally experienced the same condition	3
35	I am strong enough to live with the challenges that come with my health condition	3
38	I try to find the positive or funny aspects in difficult health situations	3
39	I focus on the positive aspects of my life	3
40	I am optimistic about my future	3
41	I’ve accepted my health condition as part of who I am	3
46	I find ways to do my normal routine activities while living with my health condition	3
47	I find ways to do fun activities with friends or family while living with my health condition	3

48	I believe something good will come out of my experiences with my health condition	3
51	Seeing others successfully managing a similar health condition helps me to manage my condition	3
52	Interacting with other teens or young adults with health conditions helps me feel better	3
53	Others help me cope by finding humor in situations related to my health condition	3
54	Others help me feel like I am living a normal life by including me in activities and events	3
56	I am able to adapt to my health condition when I can talk about my experiences with someone	3

Appendix B

HLRS Response Rankings

Resiliency			
Item #	Question	Rank	N
53	Others help me cope by finding humor in situations related to my health condition	2.97	133
22	I learn about my health condition from talking with others who have personally experienced the same condition	3.06	137
56	I am able to adapt to my health condition when I can talk about my experiences with someone	3.16	130
48	I believe something good will come out of my experiences with my health condition	3.16	134
40	I am optimistic about my future	3.19	136
51	Seeing others successfully managing a similar health condition helps me to manage my condition	3.19	122
52	Interacting with other teens or young adults with health conditions helps me feel better	3.26	122
54	Others help me feel like I am living a normal life by including me in activities and events	3.30	132
38	I try to find the positive or funny aspects in difficult health situations	3.31	136

41	I’ve accepted my health condition as part of who I am	3.33	135
47	I find ways to do fun activities with friends or family while living with my health condition	3.34	135
35	I am strong enough to live with the challenges that come with my health condition	3.34	136
46	I find ways to do my normal routine activities while living with my health condition	3.37	135
Support/Self Advocacy			
Item #	Question	Rank	N
62	Adults at my school understand my health-related needs	2.52	117
43	I accept help from my teachers and other personnel at school in managing my health condition	2.74	121
18	I tell others when I am not feeling well	2.78	139
63	Adults at my school know about my health condition	2.89	119
21	I learn about my health condition from my health care team	2.94	136
42	I accept help from my family and friends in managing my health condition	3.00	133
33	I get extra rest or ‘take it easy’ when needed for my health condition	3.03	134
60	I receive accommodations related to my health condition to allow me to be successful in school	3.04	114
57	My parents help me adapt by learning as much as possible about my health condition	3.13	131
32	I limit or modify my daily activities based on my body’s symptoms	3.19	135
59	I have a social support system (e g , family, friends) I can count on when I need to attend health-related events	3.33	131
58	There is at least one person in my life who keeps an eye on me in case I need support with my health condition	3.42	133
36	I have people around who love me	3.61	135
Health Literacy			
Item #	Question	Rank	N
9	I know when to tell my friends or family about my health limitations	3.29	139
13	I understand the different ways my health impacts my relationships with my friends	3.34	132
12	I understand the different ways my health impacts my relationship with my family	3.35	131

8	I know which types of physical activity can be potentially harmful to my health	3.38	134
6	I know the correct dosage for my medication(s)	3.44	129
3	I understand my health condition well	3.48	141
11	I know the different ways my health impacts my performance in school or work	3.52	132
5	I know what medication(s) I need to take to manage my health condition	3.55	129
2	I recognize when my health symptoms are severe and when they are not	3.59	139
1	I know the common symptoms of my health condition	3.76	141