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Validating the Construct of Resiliency in the Health Literacy and Resiliency Scale (HLRS-Y) with the Child and Youth Resiliency Measure (CYRM-28)

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Validating the Construct of Resiliency in the Health Literacy and Resiliency Scale (HLRS-Y)
with the Child and Youth Resiliency Measure (CYRM-28)

by

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A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy in School Psychology
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Abstract

Chronic health conditions in youth have increased over the last several decades. It is estimated that within the United States there are between 15% to 18% of youth who are living with a chronic health condition (Centers for Disease Control and Prevention [CDC], 2010). The CDC defines a chronic health condition as an illness that lasts for three months or longer that can be managed, but not cured (CDC, 2010). Although there is some research on youth living with chronic illnesses, there are minimal studies that assess the constructs of health literacy, resiliency, and support/advocacy within this population. The current investigation was a validity study of the Health Literacy and Resiliency Scale (HLRS). This is a newly developed 37-item measure that assesses the level of health literacy, resiliency, and support/self-advocacy among chronically ill youth (Bradley-Klug, Shaffer-Hudkins, Lynn, DeLoatche, & Montgomery, 2017). Specifically, the study correlated the construct of resiliency in the HLRS with the resiliency construct from the Child Youth and Resiliency Measure (CYRM; Ungar & Liebenberg, 2011). This measure is a 28-item measure that assesses levels of resiliency among youth and young adults. The goals for this study included: 1) determining the extent to which the results of the factor analysis from the current study are consistent with the three-factor model from the original study, 2) assessing the relationship between the HLRS and the CYRM, and 3) determining the reliability (internal consistency) of the scores of the HLRS. More importantly, since there have only been preliminary analyses conducted on the psychometric properties for the HLRS, this study was the first step towards providing validation for this measure. Participants were recruited through several methods including community-based organizations and online outlets. There were a total of 226

participants, with 54% identifying as White, 31% African American, and the remaining identifying as other. Sixty-one percent were female. The participants were English-speaking with a diagnosis of a chronic health condition given at least six months prior. Some of the conditions that were frequently identified among the sample included: diabetes, HIV, lupus, cystic fibrosis, ADHD, and asthma. Individuals were asked to complete the HLRS, CYRM, and a demographic survey online. The results indicated that the reliability of the values of the three factors in the HLRS ranged from acceptable to excellent. The results also included a correlation between the scores from the HLRS and CYRM. For the HLRS there were strong correlations between the resiliency and support/self-advocacy factors and health literacy and support/self-advocacy factors. For the CYRM, there was a strong correlation ($r = .954$) with the resiliency factor indicating that the resiliency factor within the HLRS aligns with the resiliency construct that is measured in the CYRM. Some items on the HLRS loaded on more than one factor indicating the need for further consideration of particular items on that scale. Overall, these data provide additional support for the HLRS scale and suggest that the scale may be a step closer to being utilized in applied settings.

Chapter One

Introduction

Statement of the Problem

Chronic health conditions in youth have increased over the last several decades. It is estimated that within the United States there are between 15% to 18% of youth who are living with a chronic health condition (Centers for Disease Control and Prevention [CDC], 2010). The CDC defines a chronic health condition as an illness that lasts for three months or longer that can be managed, but not cured (CDC, 2010). For youth, some of these conditions include juvenile rheumatoid arthritis, sickle cell anemia, cystic fibrosis, type 1 diabetes, and neonatal human immunodeficiency virus. According to Van Cleave, Gortmaker and Perrin (2010), health conditions such as obesity, asthma, and behavior/learning problems (e.g., attention-deficit/hyperactivity disorder) are currently the leading health conditions among youth.

When exploring the rise of chronic illnesses among youth, it also is necessary to consider the overall influence that these conditions may have on daily functioning. Although illnesses can vary in severity, most have at least some impact on the physical, mental, and emotional stability of youth. As a result, these illnesses often affect the academic outcomes and social-emotional adjustment of individuals living with a health disorder. For example, Boutelle and colleagues (2010) conducted a study examining how obesity may be considered as a possible predictor of depression in adolescent females. They found that those participants who were considered obese also identified with more depressive symptoms than those who fell in the overweight or normal range. This is an example of how chronic health conditions can have a social-emotional impact on

youth. Additionally, educational outcomes can also be affected when living with a chronic illness. Quach and Barnett (2015) examined this in an 8-year longitudinal study. For this study there were a total of 4983 children included between the ages of 4 to 5 years. Of these participants, 1108 were identified with having a chronic health condition. In order to measure the educational impact of the chronic illness on the students, several measures were completed by the parents/guardians. Measures used collected data on quality of life, behavior (teacher and parent report), child learning, child–teacher relationship, nonverbal and verbal cognition and parent self-report of mental health. Youth were assessed four times over the course of eight years. Based on the results it was found that those participants who had a chronic health condition had poorer outcomes at all time frames on all of the measures in the study in comparison to their typically healthy counterparts. Although this is not necessarily the case for all youth with chronic health conditions, this demonstrates the potential impact that chronic health conditions can have on educational outcomes.

Conceptual Framework

When considering the outcomes that chronic health conditions can have on an individual, it is typical to focus on the symptomatology of that particular disorder. In turn it makes sense for individuals to be anxious about the possible negative effects of the chronic illness and how this may impact daily living. This study seeks to explore those factors that help to contribute to a more “successful” life, rather than focus on the negative aspects associated with illness.

The framework for this study was based on the conceptual model of health promotion and prevention. The health promotion and prevention model examines how factors such as different systems (e.g., health care, community, schools), availability of resources, mental health, family background and environment can impact the daily life of individuals living with chronic health condition (Bauer, Briss, Goodman, & Bowman, 2014). It takes an integrated approach to prevent

the occurrence of chronic illnesses, increase early detection, reduce disease development in people with chronic conditions, minimize health related difficulties, improve quality of life, and reduce the demand on health-care systems. When considering the current study, it also explores how different factors such as health literacy, resiliency and support/ self-advocacy play a role for youth who are living with a chronic health condition. These factors are important to consider because they tend to have positive relationships with outcomes including treatment adherence, optimism and transition readiness. In parallel to the model of health promotion and prevention, this study seeks out solutions through examining health literacy, resiliency, and support/self- advocacy that will help to provide support for individuals living with chronic illnesses.

Health Literacy

Discussing health literacy is imperative when examining youth with health conditions. Although there are a variety of definitions for health literacy, the definition that is most aligned with the current study is “the capacity to make sound health decisions in the context of everyday life” (Kickbusch, 2008, p. 2). Throughout the literature, it has been found that health literacy is correlated with more positive outcomes. For example, individuals with higher levels of health literacy may exhibit characteristics such as increased levels of treatment adherence, better knowledge of fundamental health information, and positive health decision-making in comparison to those with lower levels of health literacy (Trout, Hoffman, Epstein, Nelson, & Thompson, 2014). Particularly, health literacy becomes even more critical when considering youth who are living with chronic health conditions. An example of this is illustrated in a study by Patel, Ferris, and Rak (2016) who explored the association between health literacy and medication adherence. From this study it was found that health literacy, along with nutritional behavior, were significant predictors of medication adherence. More importantly this study also demonstrates the overall

positive influence that health literacy can have on future outcomes for youth with chronic health conditions.

Resiliency

Resiliency, along with health literacy, also is an important factor that should be discussed when examining youth with chronic health conditions. The idea of resiliency has been researched across a range of disciplines. However, within this study, it can be defined as the ability to recover quickly from change, hardship or a difficult situation (Center for Creative Leadership, 2011). This is important because when considering youth with chronic conditions it is necessary to identify those factors that will promote a more positive lifestyle. Although resiliency has been identified as being a valuable trait for most individuals, it is especially crucial for those individuals living with a health condition. An example of this is illustrated in the study by Flett and Hewitt (2014) who investigated youth who are chronically ill and found that those who demonstrated high levels of resiliency tended to have decreased stress levels, increased levels of self-confidence and reliance, and more optimistic perspectives on stressful situations. This is critical because it showcases the positive impact that resiliency can have on a child's life while they're living with a chronic illness.

Support/Self-Advocacy

In addition to resiliency and health literacy, it is essential that youth with chronic health conditions also develop self-advocacy skills. Within this study, self-advocacy can be 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" (Tuttle et al., 2007, p. 1). Although self-advocacy and support have been researched in other domains, it is important to note that these concepts also are important to explore for youth living with chronic health conditions. Previous research has indicated that promoting self-advocacy and support for this population can lead to more positive future outcomes. For example, Maslow, Polluck and Hill (2016) explored how skills

such as self-advocacy and self-regulation can aid in promoting transition readiness for youth with chronic health conditions. Overall, they found positive relationships between self-advocacy and self-regulation and self-advocacy and life expectations. This is important to acknowledge because it demonstrates how fostering a skill such as self-advocacy among youth with chronic health conditions can promote making self-regulatory decisions and also can influence an individual's ability to complete major life milestones such as graduating from college. Support/self-advocacy, along with health literacy and resiliency, will be further investigated through the Health Literacy and Resiliency Scale.

Health Literacy and Resiliency Scale (HLRS)

The HLRS is a 37-item scale that examines the constructs of health literacy, resiliency, and support/self-advocacy in youth with chronic health conditions (Bradley-Klug, Shaffer-Hudkins, Lynn, DeLoatche, & Montgomery, 2017). It is a newer measure that was created to help practitioners identify areas in need of intervention in order to promote positive outcomes for chronically ill youth. However, there have only been preliminary analyses conducted of its psychometric properties. Therefore, the focus of this study was to provide additional data on the validity of the HLRS.

Sources of Validity

When examining the HLRS there were some sources of validity that were considered. Examining sources of validity based on test content, internal structure, relations to other variables and response processes will be helpful in evaluating validity (American Educational Research Association, 2014).

One source of validity is test content validity, which is the extent to which a measure is representative of the construct. Scale content validity is important for factors such as domain representation, relevance, and appropriateness. For the HLRS it would be making sure that health

literacy, resiliency, and support/advocacy are clearly defined and that the items fall within one of these constructs. Additionally, this measure can be compared with other measures that have the same construct. For example, comparing the resiliency construct in the HLRS with the Child Youth Resiliency measure. Another source of validity is internal structure of validity. To examine the internal structure it is important to look at factors such as dimensionality, measurement invariance, and reliability. This can be accomplished by conducting factor analyses, examining invariance at the scale-and-item levels, and examining the internal consistency reliability (Cronbach's alpha). Response processes of validity is another form of evidence of validity. This source of evidence can be collected by questioning test takers, monitoring the development of a response, measuring eye movement, determining cognitive base level, and checking response times. Additional evidence can be collected from qualitative feedback from test takers on the HLRS and examining data such as the amount of time it takes for participants to complete the items (American Educational Research Association, 2014).

For the purpose of this study, examining the relationship between the variables of the HLRS and the CYRM was important. Within this study, the construct of resiliency was the main focus. Examining the relationship between these two measures helps to determine if these selected scales are measuring similar factors among participants who are completing the scales. Additionally, this process provides convergent and discriminant evidence. Ideally there should be convergent evidence among the resiliency constructs between the two scales. This would determine how similar the participants perform on each of the resiliency portions of the measures. In contrast, it is crucial to also provide discriminant evidence between the resiliency construct and the other constructs of health literacy and support/self- advocacy. This was done by analyzing the correlations between the three subscales.

In addition to examining the validity of the HLRS through its relationship to other variables, it also is important to specifically explore construct validity by completing a factor analysis. The purpose of completing the factor analysis was to assess the validity of the questions that make up the HLRS to determine the extent to which the items are measuring the same concepts. Specifically, a confirmatory factor analysis was completed. This provides more evidence for the constructs of health literacy, resiliency and support/self-advocacy. Also, this provides an opportunity to compare the results from the previously calculated exploratory factor analysis with the results from the confirmatory factor analysis within this study.

Purpose and Research Questions

The current study was a follow-up validity study to provide additional data on the psychometric properties of the HLRS. The original study explored, using a sample of youth with three different categories of chronic illness, the relationships between the factors of resiliency, health literacy and self-advocacy/support. In the original study, the HLRS (Bradley- Klug et al., 2017) was used to investigate these relationships. The current study served as a follow-up investigation that used newly collected data. In addition to examining the relationship between chronic health conditions and the three factors, the main purpose of this study was to validate the resiliency construct by utilizing the Child Youth and Resiliency Measure (CYRM). The CYRM is a measure that was created to assess levels of resiliency among youth and young adults. The scale identifies common themes that can be found among resilient youth. This scale was selected to validate the construct of resiliency for the HLRS because of the extensive data that have been collected over the past several years. When developing the scale and defining the construct of resiliency, Ungar and Liebenberg (2011) gathered data domestically and internationally in order to provide a well-defined and representative definition for resiliency.

Rationale

By evaluating the validity of the resiliency construct within the HLRS, this strengthened the value of the scale. Research has indicated that factors such as resiliency, health literacy, and support/self-advocacy are correlated with positive outcomes that include positive mental health, high treatment adherence, and positive quality of life. This current study not only examined the relationship between these factors with youth with chronic health conditions, but it also evaluated the construct validity of the resiliency factor. Resiliency is important because it is related to higher levels of optimism, lower levels of stress and overall increased quality of life as compared to those who may lack resiliency. By evaluating the validity of this construct with the HLRS helped strengthen the overall value and use of the scale.

Research questions

- To what extent are the results of the confirmatory factor analysis from the current study consistent with the three-factor model from the original study?
- What is the relationship between the Health Literacy and Resiliency Scale (HLRS) and the Child Youth Resiliency Measure (CYRM)?
- What is the reliability (internal consistency) of the scores of the Health Literacy and Resiliency Scale?

Significance of the Study

Over the past several decades the traditional role of the school psychologist has progressed from a primary role of determining the need for special education services to an extended role of promoting physical and mental health for all youth, including those with chronic illnesses (Tan, 2015). Due to the influence that chronic health conditions can have on a child academically, physically, and socio-emotionally, it is necessary that school psychologists are aware of this impact so that these children can be fully supported. This study addressed some of these broader

concerns. Specifically, it contributed to the validation of the Health Literacy and Resiliency Scale, which can be used to identify important factors such as health literacy, resiliency, and support/self-advocacy. Rather than viewing these students as being a product of the medical diagnosis, school psychologists can use the HLRS to identify student needs and implement resources through a multi-tiered system (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 school psychologists gain more access to pediatric school psychology research it can eventually lead to implementing more specific prevention and intervention approaches within the schools to support positive outcomes for youth and young adults living with a chronic health condition.

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. The ability to recoup rapidly from change, adversity or a difficult situation. For the HLRS scale the definition for resiliency is described as interpersonal resources that buffer the stress of living with a health condition including competence, positive coping styles, sense of humor, connectedness, and knowledge of health behaviors and health risks.

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” (Tuttle et al., 2007, p. 1).

Validity- “The degree to which evidence and theory support the interpretations of the test score for proposed use of the test” (American Educational Research Association, 2014, p.11).

Sources of Validity Evidence- These sources reflect the different aspects of validity but do not specifically represent distinct types of validity. These sources consist of: evidence based on test content, relations to other variables, Internal structure, response processes and consequences of testing (American Educational Research Association, 2014).

Chapter Two

Literature Review

Chronic health conditions

Chronic health conditions among youth have gradually increased over the last several decades. Currently within the United States approximately 15% to 18% of youth are living with a chronic health condition (Centers for Disease Control and Prevention [CDC], 2010). A chronic health condition can be defined as an illness that persists for three months or longer that can be managed, but not cured (CDC, 2010). For youth, some of these conditions include diabetes, sickle cell anemia, cystic fibrosis, cancer, and neonatal human immunodeficiency virus. However, according to Van Cleave, Gortmaker and Perrin (2010), health conditions such as obesity, asthma, and behavior/learning problems (e.g., attention-deficit/hyperactivity disorder) have currently become the most common health disorders among youth. These researchers conducted a longitudinal study that consisted of tracking three cohorts of children over a 6-year period. Cohort 1 ($n=2337$) was tracked from 1988 to 1994, cohort 2 ($n=1759$) was tracked from 1994 to 2000 and cohort 3 ($n=905$) was tracked from 2000 to 2006. At the beginning of each 6-year period all participants were in the 2-8 year age range, and each cohort had approximately 7% of its participants identified with an already existing chronic health condition. Data were collected in the form of parent report at the beginning and end of the 6-year time frame. Parents were expected to identify health conditions that “limited activities or schooling, required medicine, special equipment, or specialized health services and that lasted at least 12 months” (Van Cleave et al.,

2010, p.624). Based on the data, it was found that chronic health conditions among youth increased drastically not only from 1988 to 2006, but also within each of the 6-year cohort time frames. More specifically, these researchers found that the original 7% of participants with a chronic health condition increased to 12.8% for cohort 1, 25% for cohort 2, and 26.6% for cohort 3. This is important to note because this demonstrates the rise of chronic health conditions within youth over time. With this increase of childhood chronic illnesses, it is imperative to examine the overall impact that may be associated with living with a chronic health condition.

Impact of chronic health conditions

In addition to exploring the increase of chronic health conditions among youth, it also is necessary to consider the overall impact these conditions may have on daily functioning. Although different illnesses can range in severity, they still can affect the physical, mental, and emotional stability of youth. This can in turn impact the educational outcomes, social adjustment, and overall quality of life of individuals living with a health disorder.

Physical

Maintaining physical health is critical for all stages of life. More so, it is necessary during the childhood and adolescent stages (Xiangli Gu, Mei, & Solmon, 2016). Physical activity and physical health during childhood are important to acknowledge because they can lead to positive outcomes, such as physical fitness, increased self-esteem, and better health related choices in the future. More importantly, it has been found that physical activity and physical health are also associated with higher levels of health-related quality of life (Xiangli et al., 2016). This is critical because having health related quality of life is especially important for youth with chronic health conditions. Health related quality of life (HRQOL) can be described as the mental and physical perceptions of one's own life and the relationship that it has with one's health condition, social support, socioeconomic status and functional status (Centers for Disease Control and Prevention

[CDC], 2000). Ideally, children should be given the opportunity to engage in physical activity. However, when considering youth with chronic health conditions, physical activity may be more difficult to engage in due to the specific symptoms that a patient may be experiencing. Lam, Li, Chiu, and Chan (2016), conducted a study examining the physical impact that cancer had on youth in comparison to their typically healthy counterparts. Specifically, they examined how the relationship between physical activity and constructs such as quality of life and self-efficacy, differed between these cancer patients and typically healthy youth. The researchers conducted a cross-sectional study that consisted of a total of 224 participants between the ages of 9-18 years. Seventy-six were cancer patients currently admitted in the pediatric oncology unit for treatment and the remaining were identified as typically healthy. Forty-six of the participants were female. Participants were rated by researchers on their physical activity levels using The Chinese University of Hong Kong: Physical Activity Rating for Children and Youth (CUHK-PARCY) (Chung et al., 2014; Kong et al., 2010). They were then asked to complete the Physical Activity Self-Efficacy (PASES; Matheson et al., 2004), and The Pediatric Quality-of-life Inventory Cancer Module (PedsQLTM; Varni et al., 2002). Based on the data collected, it was found that in comparison to their healthy counterparts, the participants with cancer demonstrated overall lower intensity levels of physical activity. Additionally, the individuals with cancer also reported considerably lower levels of self-efficacy and quality of life in comparison to the typically healthy participants. This is critical because it demonstrates how living with a certain chronic health condition can affect an individual's ability to be physically active. Additionally, it also demonstrates how having lower levels of physical engagement can influence factors such as health related quality of life. This is important because it demonstrates how impactful engaging in physical activity can be for youth in this subgroup. As stakeholders, it is critical to identify ways

that youth living with a chronic health condition can routinely participate in physical activity that is aligned with their health condition.

In parallel, it is believed that having physical impairments, especially during the childhood stages can have a negative impact on youth. Although all chronic health conditions have some form of symptomatology (mild or severe) it is important to understand that there are some that may directly impact the physical activity of youth. A common chronic health condition that is present among youth is juvenile rheumatoid arthritis (JRA) or juvenile idiopathic arthritis (JIA). JIA, although previously largely identified as JRA, is a condition found in youth that affects the joints and muscle tissue. There are a range of symptoms that can consist of joint misalignment, soft and muscle tissue tightening, and bone erosion (<http://www.kidsgetarthritisoo.org/>). There are various subsets of this condition that may specifically affect the knees and the ankles.

Although different youth may have varying experiences, there is often some form of pain that is associated with the illness. Tarakci, Yeldan, Kaya, Baydogan, and Kasapcopur (2011) examined the relationship between physical activity of youth living with JIA and the potential impact that it had on their individual anxiety, depression, and functional ability. The researchers conducted a cross-sectional study that consisted of participants ranging in age from 8 to 17 years. Fifty-two patients identified with having JIA, while the 48 participants were included in the control group. In order to assess the participants, physical activity was measured using a 1-day activity diary, while anxiety, depression, and functional ability were measured using The Screen for Child Anxiety Related Emotional Disorders (SCARED) questionnaire (Muris, Dreessen, Bögels, Weckx, & Van Melick, 2004), Children's Depression Inventory (CDI; Kovacs, 1992) and Childhood Health Assessment Questionnaire (CHAQ; Guillemin, Bombardier, Beaton, 1993), respectively. The participants also were asked to assess their levels of pain and well-being. This was done using a visual analog scale (VAS; Aitken, 1969). The results demonstrated significant differences

between the JIA group and the control. As expected, those individuals with JIA recorded much less physical activity and much higher levels of pain in comparison to the control group. There also was another interesting finding when exploring the results from the depression inventory. There was a high correlation between participants with JIA and higher scores on the CDI. Additionally, for those JIA participants who reported higher scores on the CDI there also was a positive relationship with levels of anxiety, and an inverse relationship with functional ability and overall well-being, suggesting that among youth this condition may be related to negative mental health outcomes (Tarakci et al., 2011).

Mental Health

As previously mentioned another factor that should be considered along with physical health is mental health functioning. Positive mental health is associated with having better emotional stability, better quality of life and more positive social interactions (McDougall & Wright, 2014). When considering youth living with a mental health disorder, some of the more common conditions include depression, anxiety, and posttraumatic stress disorder (PTSD). For children and adolescents living with a chronic health condition, the risk for having a comorbid mental health condition is higher than for those who are physically healthy. An example of this can be seen in the study conducted by Boutelle and colleagues (2010) that examined how obesity can be considered as a possible predictor of depression in adolescent girls. These researchers conducted a longitudinal study consisting of 496 female students ages 11 to 15 years. Participants completed The Schedule for Affective Disorders and Schizophrenia for School-Age Children (K-SADS; Puig-Antich & Chambers, 1983), a survey developed for the study, and also had their height and weight measured at baseline and for three consecutive yearly follow-ups. Results indicated that those participants who fell within the obese category tended to express more depressed symptoms than those who fell in the overweight or normal range.

Additionally it has also been found that having a chronic illness not only correlates with depression during adolescence, but it also can continue into adulthood as well. In a longitudinal study, Ferro, Gorter, and Boyle (2015) examined 2825 youth over the course of 15 years. Participants ranged from 10 to 11 years of age. Seven-hundred and fifty three participants were identified with at least one chronic health condition and the remaining were classified as typically healthy youth. A self-report measure and Center for Epidemiological Studies Depression Scale (Poulin et al., 2005; Radloff, 1977) were used to identify this chronic health condition and measure the level of depression over the span of the study. Chronic health conditions that were present included asthma, cerebral palsy, food allergies, and heart conditions. Participants were asked to complete these measures in eight cycles, with the final cycle ending while the participants were between the ages of 24-25 years. Based on the results from the entire study, it was found that youth who identified with having a chronic health condition expressed significantly higher levels of depression in comparison to their typically healthy counterparts. More specifically, youth with chronic health conditions displayed higher levels of depression during the ages of 16-19 years, suggesting that there may be increased stress during the transitional years to adulthood.

These outcomes are important to understand because they demonstrate a relationship with chronic illnesses such as obesity and mental health disorders. Understanding the severity of the comorbidity of these conditions can help stakeholders to implement prevention strategies.

Educational Outcomes

Educational and school outcomes are also factors that can be impacted when living with a chronic health condition. Doctors' visits, pain management, physical limitations, and absenteeism are examples of a cross-cutting issue that can play a role in the overall educational experience of youth with chronic illnesses. Currently, the academic expectations for students may be considered challenging even for healthy children. Although having a chronic condition does not suggest that a

child may automatically fall behind their peers in the classroom, it does pose a potential risk factor. Quach and Barnett (2015) examined this in an 8-year longitudinal study. For this study there were a total of 4983 children included between the ages of 4 to 5 years old. Of these participants, 1108 identified with having a chronic health condition. In order to measure the educational impact of the chronic illness on the students several measures were completed by the parents/guardians. Measures used collected data on quality of life, behavior (teacher and parent report), child learning, child–teacher relationship, nonverbal and verbal cognition, and parent self-report of mental health. Youth were assessed four times over the course of eight years. Based on the results it was found that those participants who had a chronic health condition had poorer outcomes at all time frames on all of the measures in the study in comparison to their typically healthy counterparts.

As mentioned, there may be several challenges that result from living with a chronic health condition. Two examples of this are lower educational attainment and absenteeism (Champaloux & Young, 2014). Educational attainment can be described as the highest level or degree of education an individual has completed, as defined by the US Census Bureau Glossary (U.S. Census Bureau, 2012). For this study the researchers conducted a secondary analysis using the National Longitudinal Survey of Youth-Cohort 1997. The survey included 8,984 participants from ages 12 to 16 years. Preliminary reports were collected in 1997, but were later assessed yearly to identify any significant changes during the transitional years from childhood into adulthood. Measures were comprised of both parent and child interviews in which both parties were asked to classify and describe the chronic health condition of the student. Chronic health conditions were grouped into four categories: (1) cancer, diabetes or epilepsy; (2) asthma; (3) heart and cardiovascular conditions; and (4) other. These categories were created based on previously conducted research noting that non-asthmatic chronic health conditions such as cancer, diabetes,

or epilepsy may have a more significant impact on educational attainment compared to asthma (Champaloux & Young, 2014). Due to the small sample sizes of individuals with cancer, diabetes, and epilepsy these conditions were combined into one separate category. Heart and cardiovascular conditions also were merged in a separate category, but this was due to the lack of current literature regarding the relationship between these specific conditions and educational attainment. The remaining chronic health conditions were grouped separately because there was an incomplete record of the illnesses reported. Overall, the study concluded that in fact specific disorders did have an overall impact on absenteeism among youth living with chronic illnesses. More specifically those individuals who reported having conditions such as epilepsy, cancer, or diabetes displayed higher school absences in comparison to the participants in the other groups. This in turn also resulted in higher rates of retention and higher depressive symptoms for these students in comparison to those in the other health condition groups (Champaloux & Young, 2014).

Overall, it is clear that having a chronic health condition can lead to educational barriers during various stages of childhood and adolescence. These barriers can be noticed from as early as kindergarten, while also extending into the secondary education setting. With this knowledge researchers can work to provide prevention and intervention supports for these students within the schools.

Health Literacy

Health literacy is important to consider when discussing youth with chronic health conditions. Although there are several different definitions for health literacy, the definition that is most aligned with the current study is “the capacity to make sound health decisions in the context of everyday life” (Kickbusch, 2008, p. 2). Somewhat differently, the CDC utilizes the definition from The Patient Protection and Affordable Care Act of 2010, which defines health literacy as the degree to which an individual has the capacity to obtain, communicate, process, and understand

basic health information and services to make appropriate health decisions (Centers for Disease Control and Prevention [CDC], 2010). However, more simply, some perceive health literacy as being very literal. For example, another definition consists of the ability to read, understand, and implement medical terminology that is displayed on a prescription bottle or written in a medical journal (Sukka et al., 2015). Additionally, there also are different forms of health literacy. These forms include basic/functional health literacy, interactive/communicative health literacy, and critical health literacy. Having an understanding of these forms of health literacy can help youth living with a chronic condition to be more aware of their own individual health.

Types of Health literacy

Functional health literacy is the most common type of health literacy that can be seen within the literature and interventions. Essentially, functionally health literacy is defined as having the basic literacy comprehension skills (reading and writing) to effectively deal with health concerns (Heijmans, Waverijn, Rademakers, van der Vaart, & Rijken, 2015). Functional health literacy is critical because it enables patients to have a basic understanding of how to cope with not only their chronic health condition but also maintaining their basic health.

Despite the fact that functional health literacy is the most frequently referenced type of health literacy within the literature, there is still a dearth in research when exploring this concept among youth and adolescents. In response, Chisolm, and Buchanan (2007) sought to determine if measuring functional health literacy in adolescents would provide similar results as the studies involving adults. For their study they recruited 50 participants aged 13 to 17 years. Among these youth 26% identified as female and 80% identified as White. In order to test their levels of health literacy they were asked to complete three literacy measures including The Test of Functional Health Literacy in Adults (TOFHLA), the Rapid Estimate of Adult Literacy in Medicine-Teen (REALM; Davis, Wolf, Arnold, Byrd, Long, Springer & Bocchini, 2006), and the Wide Ranging

Achievement Test (WRAT-3; Wilkerson, 1993). Results demonstrated that the TOFLHLA, WRAT-3 and REALM-T scores from the participants did correlate. This is suggesting that the questions from the different measures have similar constructs and produced consistent responses from each of the individual participants. However, despite the similarities of these scores for the adolescents, they were still considerably lower when comparing them to adult scores. This is important to note because it suggests that youth in general have low functional health literacy scores. Although this can be attributed to many different reasons, such as developmental stage, life experience and education level, it still indicates that there should be some form of intervention put in place to increase these levels. Scales such as the ones utilized in this study help to measure constructs such as overall information seeking, disease self-management, and decision-making. These are all good qualities that are important for both adults and youth to have when managing a chronic condition. More so, this becomes especially important for adolescents living with a chronic health condition who are close to transitioning into independent adulthood.

In addition to functional health literacy, there also is interactive/communicative health literacy. This form of health literacy is slightly more complex than functional health literacy and requires a higher form of literary and cognitive abilities. It involves not only basic reading and writing skills, but also social skills to help individuals actively participate in everyday health related activities and tasks. Individuals are required to incorporate different forms of communication skills in order to seek out and apply new information for their current health circumstances (Heijmans, Waverijn, Rademakers, van der Vaart, & Rijken, 2015). This form of health literacy is critical because it helps individuals to vocalize and advocate on the behalf of their needs. More specifically, it comes in handy during doctor visits, and at work places, and school environments.

Huang, Tobin, and Tompane (2012) sought to explore the interactive health literacy abilities among youth in a recent study. The researchers recruited 74 youth with inflammatory bowel disease in a pediatric hospital setting. Patients were at least 10 years of age (mean= 15) and had not been admitted into the hospital within the last 30 days. Youth were tested on both their functional and interactive health literacy. For the functional literacy, youth who were close to transitioning into adulthood were given the Test of Functional Health Literacy in Adults (TOFHLA), which is described in Table 1. For the interactive health literacy measure all of the participants were given the Crohn's and Colitis Knowledge (CCKNOW) scale, a self-report self-efficacy scale and personal medical history knowledge scale. The CCKNOW helped to assess the patients' current knowledge regarding the management of inflammatory bowel disease, while a self-efficacy scale (5-point Likert scale) was used to determine patients' ability to complete everyday disease related responsibilities with minimal parental assistance (e.g., communicating with a medical professional regarding chronic health condition, scheduling appointments, seeking necessary medical attention, and calling in to fill prescriptions). The results indicated that overall most youth did not display high levels of interactive health literacy. When looking at participants, ages 15 years and above, they scored an average of 83% on the functional health measure. However, in contrast, these same participants only scored an average of 22% on the (CCKNOW) scale, which measured participants' abilities to manage their chronic health condition. In addition, these same participants only scored on average of 61% on the self-efficacy scale. Although the self-efficacy average is much higher than the average CCKNOW scores, it is still lower in comparison to the functional health literacy score. This is critical because more often individuals are tested on their functional health literacy rather than their interactive health literacy (Heijmans, Waverijn, Rademakers, van der Vaart, & Rijken, 2015). However, this study indicates that just testing functional health literacy is not adequate. The reason for this is that although most of these

youth demonstrated having sufficient understanding of basic reading and writing of medical concepts, they did not have the applied knowledge along with it. This is crucial because it is this applied knowledge that helps individuals to receive the actual medical help that they may need. This knowledge allows for patients to communicate effectively with others (especially medical professionals) regarding their current medical needs.

The third type of health literacy is critical health literacy. This form is the most complicated type to fulfill. This involves having a deeper understanding of health-related issues and one's own individual needs. Individuals also are expected to critically analyze and interpret information to help influence and stimulate action within the community (Sykes, Wills, Rowlands, & Popple, 2013). This form of health literacy has the least amount of research, due to its varying and vague definitions. Although the concept is more loosely defined than both functional and communicative/interactive health literacy, it does appear to serve a noticeable purpose. Sykes and colleagues (2013) explored the concept of critical health literacy through a "theoretical and colloquial evolutionary concept analysis method" (p. 7) in order to develop a deeper understanding of how this construct is defined and viewed by various stakeholders. This study is unique in that it not only synthesizes the literature, but it also combines a range of interviews from practitioners, policy makers and those in academia. Based on the previous research and the newly collected data, the researchers were able to conclude that there were distinct characteristics that were associated with the concept of critical health literacy. These specific characteristics were comprised of health awareness, information skills, functional communication and collaboration between service providers and users, knowledgeable decision making, and advocacy through political action (Sykes et al., 2013). The following table (Table 1) consists of current scales within the literature that assess various characteristics of health literacy.

Table 1

Health Literacy Measures for Youth and Young Adults

Brief Health Literacy Screener	A three-item measure that is used to identify inadequate health literacy (Chew, Bradley, & Boyko, 2004).
Rapid Estimate of Adolescent Literacy in Medicine (REALM-Teen)	A 66 item word recognition test in English that can be used as a health literacy-screening tool in pediatric care settings (Davis, Wolf, Arnold, Byrd, Long, Springer, & ... Bocchini, 2006).
Health Literacy Assessment Scale for Adolescents - HAS-A	A 15-item self-report health literacy measure that examines adolescents' ability to acquire, communicate, comprehend, and analyze health related information (Manganello, DeVellis, Davis, Schottler-Thal, 2015).
Health Literacy Measure for High School Students	A 47-item health literacy measure that evaluates how well high school students comprehend and interpret health information (Wu, Begoray, Macdonald, Wharf Higgins, Frankish, Kwan, Fung, & Rootman, 2010)
Media Health Literacy Measure - MHL	A 6-item measure developed to assess the concept of Media Health Literacy among youth (Levin-Zamir, Lemish, & Gofin, 2011).
Test of Functional Health Literacy in Adolescents - TOFHL	A 36-item scale adapted from the TOFHL-Adult that measures health literacy in Chinese students (Chang, Hsieh, & Liu, 2012).
Health Literacy and Resiliency Scale-HLRS-Y	A 37-item scale that examines the measures healthy literacy, resiliency, and support/self-advocacy in youth with chronic health conditions (Bradley-Klug, Shaffer-Hudkins, Lynn, DeLoatche, & Montgomery, 2017).

Within the literature, it has been found that health literacy is associated with positive outcomes for individuals living with a chronic health condition. It has been shown that having certain types of health literacy, such as communicative health literacy is more effective and having some form of knowledge about health-related information is always positive. For example, individuals with high levels of health literacy may exhibit characteristics such as better treatment adherence, better understanding of basic health information, making positive health decision, overall quality of life, and more factors.

Navarra, Neu, Toussi, Nelson, and Larson (2014) chose to explore health literacy and the impact on youth living with HIV/AIDS. The researchers conducted a cross-sectional study with 50 HIV infected youth. The participants were sampled from multiple clinical sites and were from 13 to 24 years old. They were all currently in treatment when they were prescribed antiretroviral therapy (ART) for a minimum of six months. Participants also were screened prior to the study for mental health (Mini-Mental Health State Exam- MMSE) and visual sufficiency. Participants were admitted into the study where they completed several measures over the course of three days. In order to assess health literacy, patients completed the Test of Functional Health Literacy in Adults (TOFHLA) and the Rapid Estimate of Adult Literacy in Medicine-teen (REALM-teen). Participants completed the Beliefs About Medication Scale (BAMS; Riekert & Drotar, 2002), which measures an individual's perceptions of threat to their illness, positive and negative outcome expectancy and thoughts towards treatment adherence. Additionally, participants completed the Media Use Questionnaire, which measures the amount of time spent utilizing any form of media devices. Lastly, participants were asked to self-report their treatment adherence for their medication over the course of the last three days. In addition, participant medical records also were available to track HIV biomarkers for preceding adherence. After data collection was

complete and data were analyzed, it was found that having basic fundamental health literacy skills was predictive of higher levels of self-report adherence in comparison to other forms of health literacy. This is crucial because treatment adherence is vital for youth living with chronic health conditions, especially those living with HIV. In the case of youth living with HIV, if they do not have consistent treatment adherence it can lead to them becoming immune to that specific medication. Therefore, it is clear why promoting health literacy can be beneficial for those living with a chronic illness.

Similarly, Patel, Ferris, and Rak (2016) explored the relationship between health literacy and medication adherence. They conducted a study that included 74 participants between the ages of 7-29 years. Participants had a diagnosis of chronic/end-stage kidney disease and hypertension. Within the study they assessed nutrition literacy, health literacy, nutrition behavior, and medication adherence. This was done using the Disease-Specific Nutrition Knowledge Test, Newest Vital Sign Scale, Nutrition Knowledge-Behavior Concordance Scale and Morisky Medication Adherence Scale, respectively. Based on the data that were collected, it was found that health literacy along with nutritional behavior were significant predictors of medication adherence. This demonstrates more evidence of the positive effects that health literacy can have on children and young adults living with a chronic health condition. As individuals become more knowledgeable about their personal health and disease, they are more likely to make positive choices regarding their health.

Health literacy can have a positive impact on an individual's life. This indicates that the lack of health literacy might in turn lead to negative effects. Sparapani, Jacob, and Nascimento (2015) explored some of these outcomes with youth living with diabetes. Within the study researchers sought to examine some of the daily effects that type one diabetes can have on youth and their overall management of their chronic illness. To conduct this study the researchers

recruited 19 youth (13 girls and 6 boys) ages 7 to 12 years. It was a qualitative study that involved the participants being interviewed through the use of puppets and participation in the construction of a scenario. Interviews lasted for a minimum of 40 minutes up to a maximum of 120 minutes and were transcribed and coded for data analysis. Based on the results, found from the interviews and scenarios, the participants expressed a range of negative emotions and experiences from living with diabetes mellitus. Patients expressed having conflicting desires with adhering to their dietary restrictions due to not being able to eat all the things that other children could eat. More common themes consisted of patients feeling insecurity, fear and pain. This was specifically associated with the administration of daily insulin shots. Participants expressed that they had difficulties with both receiving and independently administering the insulin shot. They reported feeling scared during this process and also having anxiety about how they will continue to cope with the illness in the future. More interestingly, one factor that was correlated with all of these outcomes among the participants was the inadequate knowledge about the actual condition. Youth did not have any knowledge of the disease and how it works within their body. They expressed that they did not like to ask many questions and did not like talking about the disease with their families. This is critical because it demonstrates how the absence of health literacy can impact the lives of youth dealing with a chronic disease. The relationship between health literacy and future outcomes is necessary to acknowledge. Due to their lack of understanding, they have experienced increased levels of anxiety, insecurity, rejection and many other negative outcomes.

The next section of this literature review provides a brief overview of The Health Literacy and Resiliency Scale (HLRS; described in Table 2) and how it is applicable to the current study. The HLRS (Bradley-Klug et al., 2017) is a measure that was constructed to assess the overall health literacy and resiliency in youth and young adults (aged 12-25 years old) with chronic health conditions. The measure was designed as a broad measure that could be used for youth with any

chronic illness. Along with health literacy and resiliency, the scale also examines levels of support/self-advocacy. These three constructs are collectively examined through a 37-item Likert scale. Originally the scale consisted of 102 items and was eventually narrowed down to 37 items. There was a factor analysis conducted in order to determine the three subscales of health literacy, resiliency and support/self-advocacy. Because this scale will be utilized in the current study, there will be a resiliency and support/self-advocacy section also included in the literature review.

Initial Development of the HLRS

The development of the HLRS was completed in four phases. The procedures explained by DeVellis (2012) were used to determine the overall purpose of the measure. Within Phase 1 of the scale development, the researchers defined the initial 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 was 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 deciding on these definitions, two focus groups were conducted in order to gain a better perspective of what is it like for youth living with a chronic health condition. (Bradley-Klug et al., 2017). Through these focus groups, common themes were established. Using these themes along with information gathered during the literature review process, 101 items were created for the initial scale. 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).

During Phase 2, the scale was reviewed and the number of items were reduced. Part of the phase included an examination by an expert team of four individuals in the fields of measurement and scale development, health literacy, resiliency, and pediatric psychology. Based upon their feedback, the number of items in the scale was reduced to 80 at the end of Phase 2.

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 prior. Participants were offered a \$25 electronic gift card for finishing the survey. Participants took the measure online through a Survey Monkey website. To get additional qualitative feedback regarding the format and relevance of the items, participants also were asked if each item was too hard to understand or whether the item should be considered for deletion. The overall purpose of Phase 3 was to further 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 1-5). 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 also were considered for deletion if the absolute value of the corrected item-total correlation was 0.10 or lower or the alpha coefficient increased by 0.05 or more when the item was deleted. Any items with large amounts of non-response in the form of missing data or responses of Does Not Apply also were flagged for removal from the scale. The final scale contained 37 items across the three areas of health literacy (10 Items), resiliency (13 Items), and support/self-advocacy (14 Items).

Phase 4 included participant recruitment on a national level, scale administration, scale analyses, and scale item finalization. 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.

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%). 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-10) 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%).

An exploratory factor analysis (EFA) was conducted. The purpose of this analysis was to determine the underlining constructs associated with each of the items identified. In order to be included under a specific construct, items had to have pattern coefficients that were greater than or equal to 0.40. Items were removed if they did not fit these criteria for any of the factors and also if there were cross loadings greater than 0.35 with more than one construct (Bradley Klug et al.,

2015). 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; $\alpha = .88$), resiliency (13 items; $\alpha = .93$) and support/self-advocacy (14 items; $\alpha = .94$).

Resiliency

The concept of resiliency has been discussed across a variety of disciplines. Essentially it can be defined as the ability to recuperate rapidly during difficult situations. It also involves the capacity in which individuals navigate the resources (e.g., family, community, culture, individuality) around them to help maintain a positive and productive life (Ungar & Liebenberg). Resilient people are flexible during times of change and hardship and tend to be well adjusted in comparison to other typically developing individuals. In particular, resiliency can be beneficial for youth living with a chronic health condition. Recent research has shown that youth who demonstrate high levels of resiliency tend to have decreased levels of stress, a more optimistic perspective on stressful situations, and higher levels self-confidence and reliance (Flett & Hewitt, 2014).

Models for Resiliency

When examining the concept of resiliency, it is important to note that there are several models of resiliency for youth. Specifically, these models can be reflected in youth living with chronic health conditions. Examples of these models include the Wanderlander and Varni's Disability-Stress-Coping model (Wallerander et al., 1989), Thompson and Gustafson's Transactional Stress and Coping Model (Thompson, Gustafson and George, 1994), and Kazak's Social Ecological Model (Kazak, 2001).

The Wandlander and Varni's Disability-Stress-Coping model for resiliency is a model that emphasizes the impact of environmental factors on the parent and the child's adjustment to living with a chronic health condition. More specifically, this model indicates that there are conflicting risk factors such as low socio-economic status and lack of family support that can be detrimental. These factors can actually lead to more psychological maladjustment and therefore can be harmful and impact both the parent and the child's ability to cope with the chronic health condition. However, in contrast to this, it was found that resistance factors were more effective for producing psychologically adjusted families (Wandlander et al., 1989). This model suggests that increasing factors such as social support, family cohesion, and adaptive coping strategies can be helpful in increasing better adjustment and emotionality. In contrast, increasing the amount of stress within an environment can be more harmful rather than strengthening.

Another model that examines resiliency within youth is the Thompson and Gustafson's Transactional Stress and Coping Model (Thompson, Gustafson and George, 1994). This model examines how the chronic health condition specifically impacts the child and family directly. Particularly, this model indicates that the overall adjustment of chronically ill youth is influenced by illness-related variables (e.g., disease type, diagnosis, and illness severity), demographic variables (e.g., socioeconomic status, gender, and age), or a combination of the two. This model suggests that stressors associated with the symptoms and treatment of the chronic condition can impede the child and the family's ability to cope with the disorder in an effective way. In contrast, this model indicates that those families who had more "control" over the child's condition tended to be more adjusted. Examples of control consisted of having a consistent schedule for treatment adherence and designated treatment plans for the child. These factors appear to aid in overall family coping and adapting. This model has been explored with a variety of chronic health conditions in youth including pediatric cancer, diabetes, sickle cell disease, and asthma.

A third model of resiliency for youth is Kazak's Social Ecological Model (Kazak, 2001). This model indicates that there are a range of systems (i.e., child, family, school, school, community, and culture) that collectively impact the parent and the children's ability to cope with their chronic health condition. Kazak's model underlines the importance of continuous connections between system levels and how this impacts the child's perspective on his or her illness at each system level (Kazak, 2001). Despite the child remaining at the center of all of these systematic levels, the Social Ecological Model hypothesizes that better emotionality and psychological adjustment can be understood by examining how these subsystems interconnect with the family and the child living with the chronic health condition (Kazak, 2001).

After examining these models it is clear that there are some common features present throughout each them. One major factor that was consistent within each model is the impact of parents on the adjustment of youth chronically ill youth. For example, parents' ability to help provide a stable environment seems to have a great impact on how well the child is able to cope with their chronic health condition. Additionally, it seems that there are specific risk factors related to levels of resiliency. There appears to be a relationship between less resiliency and more risk factors, and higher resiliency with more protective factors. Table 2 provides a range of resiliency measures that assess for some of those risk and protective factors.

Table 2

Resiliency Measures for Youth and Young Adults

Measures of Resiliency	Description of Measures
Resiliency Scales for Children and Adolescents (RSCA)	This scale is for children and youth ages 9 to 18 years. It measures individual factors related to resilience. The scales focus on strengths as well as current symptoms and vulnerabilities. There are three major subscales: sense of Mastery, Sense of Relatedness and emotional reactivity. (Prince-Embury, 2005, 2006)
Resilience and Youth Development Module (RYDM)- Health Kids Survey	This measure is a comprehensive student self-report tool for monitoring the school environment and student health risks. This tool assesses environmental and internal assets associated with positive youth development and school success. External factors seeks to identify meaningful and pro-social bonding to community, school, family, and peers. Internal assets identify individuals' resilience traits, such as self-efficacy and problem-solving skills. (Constantine & Benard, 2001; Constantine, Benard, & Diaz, 1999)
The Adolescent Resilience Questionnaire (ARQ)	This scale examines resilience in youth with chronic illness. It is for teens and secondary school students (ages 11-19). It examines strengths within the adolescent, but also the family, peer group, school and community. This tool measures the ability to reach positive outcomes while facing life challenges. It has 74 items and contains 13 subscales in 5 domains. (Gartland et al., 2006)

Table 2 (Continued)

Brief Resiliency Checklist (BRS)	This measure is a 6-item assessment instrument that has been created to identify the presence of all risk and protective factors within the child or family. It was tested on large high-risk cohorts. (Smith, B. Dalen, Wiggins, Tooley, Christopher and Bernard, 2008).
Resiliency Scale for Adolescents (READ)	This measure looks to examine all three higher order categories of resilience. It contains 5 factors: (1) personal competence, 2) social competence, 3) structured style, 4) family cohesion, 5) social resources. This scale uses a Likert scale. (Hjemdal et al., 2006)
The Resiliency Attitudes and Skills Profile	This 34-item measure was designed to measure resiliency attitudes in various dimensions. These include insight, independence, creativity, humour, initiative, relationships and values orientation. The scale is for youth ages 12-19 years and can be helpful for creating interventions.
The Connor Davidson Resiliency Scale (CD-RISC and CD-RISC2)	This is a self-report measure designed for older adolescents and young adults. It consists of 25 items, each rated on a 5-point Likert scale, with higher scores reflecting indicating higher resilience. The scale has been administered in primary care, general psychiatric outpatients, etc.
The Ego Resilience 89 Scale (ER 89)	This 14-item self-report measure is designed to assess ego resiliency (a stable personality characteristic) in older adolescents/young adults (study groups: 18 and 23 years; Block & Kremen, 1996)

Support/ Self-Advocacy

Along with resiliency and health literacy it is important that youth with chronic health conditions also have self-advocacy skills. Self-advocacy can be 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” (Tuttle et al., 2007, p. 1). Self-advocacy is different from resiliency in that individuals are explicitly vocalizing their health issues and concerns in order to gather support from key individuals in their microsystem (e.g., family, friends, physicians). In contrast to this, the type of support that is described with resiliency comes from the child’s natural environment. Specifically, the resiliency support does not stem from the child seeking out and advocating for their needs, but rather it is available to a child through their ecosystem. In many cases advocacy for children with chronic illnesses can be seen in the form of local or national organizations and support groups (e.g., The Children’s ‘Heart Foundation, Children’s Diabetes Foundation and Childs Sickle Cell Foundation). In other instances, advocacy can also be displayed through parents/guardians and teachers of the child with a chronic illness. Additionally, it is important to note that along with developing self-advocacy, youth must also develop both knowledge of self and knowledge of rights (Test, Fowler, Wood, Brewer, & Eddy, 2005). Knowledge of self describes the ability that individuals must understand their own identity in relation to their chronic illness. Similarly, knowledge of rights can be described as the capacity to which an individual can convey and communicate essential needs that are related to one’s own disorder. These concepts are fundamental because in order for youth to effectively convey to others their needs and rights, they must have an understanding of themselves (Test et al., 2005). Additionally, it is critical to note that along with knowledge of self and knowledge of rights, self-management is a contributing factor to one’s ability to self-advocate.

Self-management

When discussing the concept of self-advocacy, it also is necessary to include the importance of self-management. Self-management and self-advocacy both play a large role in how youth with chronic health conditions cope with their illnesses. More specifically, self-management is crucial because it helps youth with the transitioning process from pediatric to adult care. In order to examine this relationship more closely Gibson-Scipio, Gourdi and Krouse (2015) conducted a study of African American youth with asthma. Within the study there were 13 youth between the ages of 14 to 18 years. The researchers conducted focus groups that sought to identify the participants' beliefs and overall self-management goals. Within the focus groups they questioned the participants about major themes of medication self-management, social support, independence vs. interdependence, and self-advocacy. The researchers identified eight questions on asthma self-management goals that were used to help guide the focus groups. Based on the results from the sessions it was found that self-management skills were useful for promoting independence, autonomy and increased self-advocacy.

Self-advocacy and transitioning

When examining self-advocacy, it is necessary to discuss the impact that it can have on youth transitioning from childhood to adulthood. Transitioning to adult care from pediatric care can be a difficult process. However, there are certain characteristics that are helpful in fostering transition readiness. In the literature Hart, Polluck, Hill and Maslow (2016) conducted a study that examined how skills such as self-advocacy and self-regulation are helpful in promoting transition readiness. Within this study researchers recruited 174 participants from the ages of 13 to 17 years. All youth had a chronic health condition (e.g., sickle cell disease, inflammatory bowel disease, lupus and juvenile inflammatory arthritis) and were given the survey to complete while at a clinic or online after their clinic visit. There were several measures that were used to measure the

constructs of self-advocacy, self-regulation and overall “readiness”. These measures consisted of the TRAQ (Sawicki, Lukens-Bull, & Yin, 2011), which are explicitly described in Table 3., the Intentional Self-Regulation measure (Freund & Baltes, 2002) and the Hopeful Future Expectation measure (Schmid, Phelps, Kiely, Napolitano, Boyd, & Lerner, 2011). The TRAQ is 5 point-Likert scale that was utilized to assess transition readiness. In order to evaluate this construct, the scale consists of domains such self-management and self-advocacy. The Intentional Self-Regulation measure also was utilized and served as a way to examine self-regulation among these youth. This tool is 9 items and consists of individuals answering questions by making a choice between two options. Ideally the person would pick the scenario that best describes them. For example “I think about exactly how I can best realize my plans” versus “I don’t think long about how to realize my plans, I just try it”. This measure is somewhat reliable with a Cronbach’s alpha of .63. Lastly participants completed the Hopeful Future’s Expectations measure. This tool is a 13-item scale where participants are asked rate the probability of them completing certain life milestones (e.g., getting married, maintain a job, etc.). The result concluded that (after controlling for age, gender and SES) there was a positive relationship between overall self-advocacy, self-regulation, self-advocacy, and life expectations. This is important because it indicates the potential impact that self-advocacy can have on the process of transitioning from pediatric to adult care. Fostering self-advocacy among youth with chronic health conditions can help with making self-regulatory decisions, and also can impact one’s ability to complete major life milestones such as attending college. As clinicians it is important to understand this significance and seek out ways to increase self-advocacy skills among chronically ill youth.

Additionally, the TRAQ measure has also been used in other studies to help examine self-advocacy in youth with chronic health conditions. Jensen and colleagues (2017) conducted a longitudinal study that involved 89 participants ranging from ages 16 to 23 years. Of these

individuals 65% were female and 81% identified as Caucasian and non-Hispanic. The majority of the conditions among these youth consisted of rheumatic conditions (e.g., inflammatory arthritis, Sjogren's syndrome) and endocrinologic conditions (e.g., diabetes, polycystic ovarian syndrome). Participants were asked to complete the TRAQ at a baseline point and then again during a follow-up procedure to determine if their self-advocacy and self-management scores were impacted by their interactions with the medical providers. More specifically they wanted to determine if factors such as having conversations with providers about transitioning and attending doctor visits alone help increase overall transition readiness scores. The results from the TRAC scores indicated that youth, regardless of condition, did not exhibit sufficient readiness for adult care. However, there was a relationship with age, specifically indicating that older participants tended to have higher scores on the self-management and self-advocacy domains. Additionally, although the results were not significant, there also was an increase in self-management and self-advocacy scores among those participants who indicated that they had previous conversations with their physician about transitioning and those who occasionally attended doctor's visits alone. This is important to recognize because these results indicate the need for intervention. It is possible that youth with chronic health conditions are not receiving enough support and education on how to manage their illness independently. This is important because as stakeholders it is critical for us to put supports in place for these youth.

Fostering self-advocacy is critical for youth with chronic health conditions. Research has shown that advocacy among this subgroup of individuals can have some positive effects. In 2017, Yi and Nam conducted a study to examine the impact of advocacy on childhood cancer survivors. They specifically wanted to investigate the influence that self-advocacy had on helping individuals with childhood cancer to overcome stigmas related to their condition. The investigators implemented a mixed-methods approach that involved conducting qualitative interviews and

collecting quantitative surveys from participants. The participants ranged from 18-35 years, with the average being 23 years of age. Most participants received their cancer diagnosis by 9.20 years ($SD= 4.72$). During the data collection process, the researchers sought information on the how these individuals dealt with issues of discrimination, secrecy, and overall self-stigma. Participants were asked to reflect on how their experiences of having cancer throughout childhood impacted their overall decision making in adulthood. Based on the results, it was found that promoting self-advocacy had a positive influence on individuals as they entered into adulthood. Those individuals who participated in advocacy support groups while growing up described this experience as being helpful in increasing positive aspects such as knowledge of their chronic health condition, self-worth, sense of accomplishment, and social interactions. They showed that by making efforts to increase their own self-advocacy, they became more comfortable with sharing their experiences of living with childhood cancer. In contrast, those individuals who did not have the same opportunities to foster self-advocacy tended to have more difficulty with disclosing their diagnosis, building a social circle and dealing with the stigma of having been a childhood cancer survivor. This is important to understand because it shows how having self-advocacy can lead to more positive outcomes for those living with a chronic health condition. Having a chronic health condition can be extremely stigmatizing; however, increasing self-advocacy during childhood has been shown as a positive way to combat some of those negative experiences. Table 3 consists of current measures within the literature that examine aspects of support/ self-advocacy.

Table 3

Self-Advocacy Measures for Youth and Young Adults

Measures of Self- Advocacy	Description of Measure
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).
<i>Self-Advocacy Interview for Students</i>	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).
Transition Readiness Assessment Questionnaire (TRAC)	The Transition Readiness Assessment Questionnaire (TRAC) is 20 item measure that is used to assess transition readiness among youth with chronic health conditions. There are two domains within the scale that consist of self-management and self-advocacy. This measure also utilizes a 5-point Likert scale (Sawicki, Lukens-Bull, & Yin, 2011).

Selection of Measures for Current Validity Study

After examining the existing measures within the literature for the three subscales of health literacy, resiliency and support/self-advocacy, it was determined that exploring the construct of resiliency would be the most logical. The reason for this is because although there are multiple

measures for all three constructs, it is important to choose a measure for youth that aligns with the questions that are in the HLRS.

Currently, many of the health literacy measures examine basic functional health literacy rather than looking at the more complex definition of health literacy used for the HLRS. Only one measure of support/self-advocacy was found that aligned with the items in the HLRS; however, this measure was for adults rather than youth. Therefore, it was decided that among the scales within the literature for these constructs that the Child Youth Resiliency Measure was the best selection for conducting this validity study.

Sources of Validity

When conducting a validity study it is important to discuss the various sources of evidence of validity that have been identified in the literature. Validity can be described as the extent to which evidence and theory align with the interpretation of test scores for the anticipated uses of tests. Essentially, validity is the most fundamental aspect of creating and evaluating tests. These sources of evidence include test content, internal structure, response processes, relationship to other variables, and consequences of testing. When examining the HLRS, it is critical to understand how these sources of can impact the overall validity of the scale (American Educational Research Association, 2014).

One source of validity is test content validity. In order to examine the scale content validity it would be important to examine factors such domain representation, relevance, and appropriateness of the items used to measure the construct. Domain is specifically referred to as the actual construct that the test is measuring. These factors can be examined by clearly defining the construct, assessing individual question items to determine if they align with other questions (factor analysis) and testing items to see if they are representative of the population. For the HLRS this would require making sure that health literacy, resiliency or support/advocacy are clearly

defined and that the items fall within one of these constructs. Additionally, this measure can be compared by looking at its relationship to other variables such as comparing the resiliency construct in the HLRS with the Child Youth Resiliency Measure. Another source of validity is based on internal structure of the items. When examining the internal structure of an instrument it is important to look at factors such as dimensionality, measurement invariance, and reliability.

These factors help to distinguish the variability among items and how these items are similar or different from each other. This can be done also by conducting factor analyses, examining invariance at the scale- and item levels and examining internal consistency reliability (Cronbach's alpha).

To examine response processes validity methods, it is necessary to question test takers, monitor the development of a response, look at eye movement, determine cognitive base level, and check response times. This can be done collecting qualitative feedback from test takers on the HLRS and examining data such as the amount of time it takes for participants to complete the items.

Additionally, consequences of testing are considered a source of validity. This validation method involves collecting data to assess the accuracy of the interpretations given by those designated for that role. It also takes into account the unintended consequences that may come from participants completing a measure, by assessing the amount of error. This is important to consider, especially for test results that require interpretation from a specified individual. The reason for this is because measures can have high reliability and validity, but still be deemed as ineffective due to incorrect interpretation (American Educational Research Association, 2014).

Relations to other variables is another form of evidence of validity. This examines how variables are related to each other between measures and to the overall testing outcomes. It is important to note that evidence based on relationships with other variables provides details

regarding the degree to which these relationships are consistent with the underlying construct. This is critical to consider for this study because the resiliency construct within the HLRS was analyzed with the constructs of health literacy and support/self-advocacy and also with the resiliency construct from the CYRM.

The Child and Youth Resilience Measure (CYRM) is a tool that assesses how different factors (e.g., individual, relational, communal and cultural) may influence and foster resilience in youth. This measure was created as part of the International Resilience Project (IRP) at the Resilience Research Centre (RRC). It was originally created in 14 communities across the world. The IRP was created in 2002 by Dr. Michael Ungar at the School of Social Work, at Dalhousie University and was financially supported by the Social Sciences and Humanities Research Council and the Nova Scotia Health Research Foundation (Ungar & Liebenberg, 2011).

The CYRM was initially created for youth and young adults between the ages 9 to 23 years. Over time the measure also has been modified into several other versions. One version is 26-items and is used with children ages 5 to 9 years, another version is 28-items and is used to obtain data from a Person Most Knowledgeable (PMK) (e.g., parent, teacher) regarding a child's life, and another version is 28-items and is used with adults (ages 24 and older). For all available versions of the CYRM (child, youth, adult, and PMK), there is a short form version that aligns with the measure. These versions are on either a three-point or five-point Likert response scale. Specifically, the PMK version can be used in conjunction with the other versions of the measure (i.e., child and adult). It is meant to provide the researcher with more insight.

A Confirmatory Factor Analysis was conducted on all the measures using data from three international sites and it confirmed three sub-scales: individual capacities/resources, relationships with primary caregivers and contextual factors that facilitate a sense of belonging that all combine to help measure resiliency. The individual subscale specifically asks questions regarding personal

skills, peer support, and social skills, while the relationship with primary caregiver examines physical caregiving and psychological caregiving. Lastly the context subsets consist of spiritual, education and culture perspectives.

Administration

The CYRM can be administered to participants in both group settings or individually. If permitted, the researcher should ideally read the questions to the participants, however if this isn't possible the measure can be completed individually by youth. Completion of the CYRM-28 takes approximately 15 minutes and the CYRM-12 takes a little less amount of time.

Previous Literature on CYRM

There have been a variety of studies that have been conducted utilizing the Child Youth Resiliency Measure. Originally the measure was created in order to help assess and understand resiliency in youth. The researchers wanted to understand the extent to which specific factors help to promote better adjustment and functionality in children. Ungar and Liebenberg (2011) explored this by assembling an international team of researchers interested in the topic of resiliency. In order to construct this measure the researchers used a mixed methods design that sought to identify both common and unique characteristics of resilience across different cultures. Through this collaborative process the original version of the CYRM containing 58 items was constructed. These test items were created by individuals from countries including Gambia, China, Russia, United States, India and several other countries. Additionally, there also were interview questions that were created to collect qualitative data. Researchers from each of these countries returned to their home country and collected data for the initial pilot study. At each chosen site across the world, researchers had a minimum of 60 youth participate in the quantitative measure and between 2 to 24 participants complete the qualitative questions. These participants consisted of a total of 89 individuals for the qualitative portion and 1451 for the quantitative portion. Of these youth, 47.9%

were male and the mean age was 16 years. Participants resided in countries including Russia, Tanzania, Palestine, China, Israel, Columbia, India, South Africa, Canada, Palestine and southern parts of the United States. Once the data were collected a confirmatory factor analysis was conducted in order to determine what major themes of resiliency were present. It was found that there were three major overarching concepts within the seven themes of resiliency that stood out. These themes as mentioned were individual, familial relationships and context. Items that weighed heavily on the factor analysis under one of these themes were included in the final 28-item version of the CYRM. They also found that the concept of resiliency is continuous and expands across various cultures. Although customs range from country to country, resiliency seems to have common themes that expand beyond cultures. From this original pilot study the CYRM-28 was constructed and tested across the world. This enabled researchers to conduct further studies to help validate this scale.

Following the construction of the CYRM-28, more validation studies were conducted utilizing the newly constructed scale. Liebenberg, Ungar and Fons Van de Vijver (2012) proceeded to conduct a study with Canadian youth. They administered the scale to two groups in the Atlantic Canada area. Group one had a total of 497 participants and group 2 had a total of 410 participants. The scale was administered to youth either individually or in small groups of five or less. Administration ranged from 45 to 60 min and all questions were read aloud to participants. The average age for youth was 16.8 years and (56.5%) of the participants identified as male; approximately (44.3%) of participants self-identified as minorities. The results indicated that youth scored relatively similar to those students in the original study. Additionally, they found that the eigenvalues of the eight variables of personal skills, peer support, social skills, physical caregiving, psychological caregiving, spiritual, educational and cultural background heavily reflected their designated categories within the original factorial analysis. Interestingly, there was

some variation of the different categories of participants. Females and those who identified as minorities tended to have higher scores of resiliency in comparison to males and “non visible” minorities. This demonstrates how the CYRM helps researchers to understand some of hierarchical concepts of resiliency. It not only indicates the strong presence of individual, contextual and familial support resiliency, but it also provides information on the subgroups within these major categories. Having this information can potentially provide insight on resiliency deficits among the youth. For example, if a child scores low on items related to caregiver support and peer support this can help stakeholders to identify some ways to provide assistance for these youth.

In addition to creating the 28-item version of the CYRM, there also is a shortened version that consists of only 12 items. Liebenberg, Ungar and Leblanc (2013), conducted a study in order to detail the reduction of the CYRM. They implemented this study with two groups of youth. Group one consisted of multiple-service-using youth ($n=122$; mean age = 18) and Group two consisted of a school-based sample of youth ($n=1494$; mean age = 15). Collectively there were 1,616 students from rural and urban public schools in one Atlantic Canadian province, attending grades 7 to 12. They ranged from ages 10 and 18 years and 53% were females. Based on the results they were able to eliminate 16 of the items in order to create the final shorten form version. Three repetitions of an Exploratory Factor Analysis were conducted on data from the first sample of youth to identify items for inclusion in the CYRM-12. In the third analysis, a varimax rotated factor analysis of the 12 items resulted in a four-factor solution, with 10 of the items loading strongly within one of these factors. Reliability for these items were sufficient ($\alpha=.754$). A confirmatory factor analysis was then conducted on the second sample of youth, which indicated satisfactory goodness of fit. Cronbach’s alpha was completed for these final 12 items ($\alpha=.840$). This indicated that the CYRM-12 demonstrated sufficient validity to serve as a screener for

resiliency. Although the CYRM-28 provides a more comprehensive reflection of the various dimensions of resiliency, the 12-item measure is well designed to provide broad indicators of these very same constructs.

Overall is it important to understand how factors such as health literacy, resiliency and support/ self-advocacy can impact the well-being of youth living with chronic health conditions. The HLRS was created to assess these constructs across a variety of settings. However, in order to increase the use of the scale it is necessary to collect additional sources of evidence to evaluate the validity of the HLRS scores. The purpose of this study was to specifically provide validation for the resiliency construct. The following chapter will outline the methods for completing this process.

Chapter Three

Method

A quantitative approach utilizing newly collected data was implemented for the current study. This chapter provides an overall discussion of the methods for this study. The first section describes the sources of validity that were examined, then the research design and the selected measures are presented, followed by the detailed procedures for data collection. The next section includes a data analysis plan. To explore the validity of the HLRS measure the following research questions were examined:

- To what extent are the results of the factor analysis from the current study consistent with the three-factor model from the original study?
- What is the relationship between the Health Literacy and Resiliency Scale (HLRS) and the Child Youth Resiliency Measure (CYRM)?
- What is the reliability (internal consistency) of the scores of the Health Literacy and Resiliency Scale?

Research Design

This quantitative study utilized data collected from the Health Literacy and Resiliency Scale (HLRS-Y version) and the Child Youth Resiliency Measure (CYRM). To evaluate the validity of the HLRS-Y version measure, two sources of validity evidence were collected: relationship of the Health Literacy and Resiliency Scale to other variables (i.e., Child Youth Resiliency Measure) and the internal structure of the Health Literacy and Resiliency Scale. These sources of validity were evaluated using confirmatory factor analysis. Additionally, internal consistency reliability was evaluated for the HLRS-Y version.

In order to assess the validity of the HLRS scale, examining the relationship of the variables of the HLRS to the CYRM was important. Within this study, the construct of resiliency was the main focus. Examining the relationship between these two measures helped determine if these selected scales were measuring similar factors among participants who were completing the scales. Additionally, this process helped provide convergent and discriminant evidence. Ideally there should be convergent evidence among the resiliency constructs between the two scales. This should determine how similarly the participants perform on each of the resiliency portions of the measures. In contrast, it was crucial to also provide discriminant evidence between the resiliency construct and the other constructs of health literacy and support/self-advocacy. This was completed by analyzing the correlations between the constructs of resiliency with health literacy and support/self-advocacy.

In addition to examining the validity of the HLRS scores through its relationship to other variables, it also was important to explore construct validity by conducting a confirmatory factor analysis. The purpose of completing the confirmatory factor analysis was to assess the validity of the items that make up the HLRS to determine the extent to which the items are measuring their intended constructs. This analysis offered more evidence for the three constructs underlying the HLRS: health literacy, resiliency, and support/self-advocacy. This also provided an opportunity to compare the results from the previously conducted exploratory factor analysis with the results from the confirmatory factor analysis within this study.

Another way that the validity of the measure was assessed was through testing the internal consistency reliability of the measure. This was important to explore because if a measure is said to have construct validity, the scores of the scale's items should correlate highly with the overall sum of the scale's scores. This also provided additional evidence that the scale is measuring the

specific constructs that have been identified. In order to complete this process for this study, Cronbach's alpha was calculated.

The Current Study

Data Collection

Data were collected through an online survey method called Qualtrics. Participants had access to a link that enabled them to complete the tool from a technology device (e.g., laptop, iPad, smartphone).

Participants

Youth who completed the survey were required to be between ages 13-21 years and have a primary diagnosis of a chronic health condition. The diagnosis should have been given at least six months prior. Additionally participants were English-speaking due to the fact that both of the scales instruments used in the study were only available in English. The sample consisted of 226 participants, with 54% identifying as White and 31% African American. Sixty-one percent identified as female. The participants were English-speaking with a diagnosis of a chronic health condition given at least six months prior. Some of the conditions that were frequently identified among the sample included: diabetes, HIV, lupus, cystic fibrosis, ADHD, and asthma. Originally the goal was to recruit approximately 400 participants, however due to a plateau in data collection this number was reduced to 226. The majority of the participants, approximately 170, were recruited within the first two months of data collection. Participation slowed down within the third month even with intensive recruitment efforts such as multiple postings on social media. As a result, a decision was made to stop data collection. In comparison, the original study had a total of 204 participants. Table 4 provides a comparison of the participants in the original study to the current study. Regarding gender, there were more females that responded than males. Also the majority of the participants identified as white, however this sample was more diverse than the

original study. The conditions listed in the table represent the top 10 conditions within both the original and current study. In some cases (i.e., ADHD, Ehlers Danlos) there was a discrepancy between the two studies. Additionally, the large majority of students from both studies were enrolled in school.

Table 4.

Demographic Characteristics of the Sample in the Initial Instrument Development Study and Current Validation Study

	Initial Instrument Development Study (n=204)	Current Validation Study (n=226)
Gender		
Female	76%	61%
Male	24%	35%
Transgender	-----	4%
Race/Ethnicity		
White	86%	54%
Hispanic or Latino	-----	18%
Black or African American	12%	31%
Asian	-----	12%
Other	2%	3%
Condition^a		
Type 1 Diabetes	22%	15%
Cystic Fibrosis	6%	8%
Human Immunodeficiency Virus	4%	6%
Juvenile rheumatoid arthritis	8%	7%
Sickle Cell	3%	11%
Asthma	1%	5%
ADHD	1%	15%
Elhers Danlos	10%	2%
Scoliosis	12%	5%
Hemophilia	5%	<1%
Lupus	<1%	4%
Epilepsy	3%	4%
Currently enrolled in school		
No	19%	21%
Yes	81%	79%

^aSome participants chose more than one option (e.g., Hispanic/white)

Recruitment

Following approval by the University Institutional Review Board, participants were recruited through several methods including community-based organizations and online outlets. Verbal recruitment and paper flyers were utilized in the community-based settings within Hillsborough, Pasco, and Pinellas Florida counties (e.g., medical facilities, hospitals, clinics). Recruitment in medical settings were done through other medical professionals and approval by the facilities. Social media was utilized as a form of online recruitment (e.g., Facebook, email). Online recruitment flyers were placed on various health pages on Facebook and Instagram that were created for youth with different chronic health conditions (e.g., Sickle Cell Foundation Inc. page). The time frame for recruiting these participants took approximately 3 and a half months. For the duration of this recruitment phase, the primary investigator consistently had to repost the survey link multiple times throughout the week to various social media sites for childhood chronic health conditions. Additionally, weekly recruitment in pediatric settings continued throughout this phase of the study.

Participants were required to complete informed consent. There was informed consent for those participants who were 18 years and over, and a parent permission and assent form for those youth who were under the age of 18 years. Once this was completed individuals were directed to complete the measures. The measures included basic demographic information along with the Health Literacy and Resiliency Scale and the Child Youth Resiliency Scale (CYRM-28). The HLRS and the CYRM were randomly counterbalanced throughout the data collection process. Overall it took participants approximately 15 to 18 minutes to complete the survey. The demographic section consisted of participants providing information on their gender, type of chronic health condition(s), time frame when individuals found out about their condition, race/ethnicity, spirituality, and geographical region (see Demographic Survey in Appendix C).

Measures and Procedures

There were two measures that participants completed, and both of these measures are described in detail in Chapter Two. The first measure was the Health Literacy and Resiliency Scale. This measure is a 37-item scale that examines the constructs of healthy literacy, resiliency, and support/self-advocacy in youth with chronic health conditions (Bradley-Klug et al., 2017). It requires individuals to speak English and takes approximately 20 minutes or less to complete. The second measure was the Child Youth and Resiliency Measure (CYRM-12), which is a tool that assesses how different factors (e.g., individual, relational, communal, and cultural) may influence and foster resilience in youth (Ungar & Liebenberg, 2011). It is a 28-item measure that can be taken in under 20 minutes. It is self-administered and produces an overall score of resiliency.

Analysis Plan

Descriptive analyses

All data analyses were conducted using the program Statistical Package for the Social Sciences (SPSS, Version 25) and Mplus (version 7.3). SPSS was used to conduct the descriptive analyses for this study, which consisted of means, standard deviations, and normality (skewness and kurtosis). Mplus was used to conduct the factor analysis.

Confirmatory Factor Analysis

A confirmatory factor analysis (CFA) was conducted in order to further examine the constructs of the health literacy, resiliency, and support/self-advocacy within the HLRS. A confirmatory factor analysis was also conducted for the CYRM. For both measures, this provided an opportunity to compare the results of the CFA with the outcomes from the original exploratory factor analyses in the pilot studies. The CFA depicts the factor loadings of each of the items from the new sample of participants. The acceptability of the three-factor model was evaluated by the goodness of fit and by the overall strength of the parameter estimates. Weighted least squares

mean and variance adjusted estimation was used. Additionally, any issues such as modifications to the original model, convergence problems, or improper solutions (e.g., correlations between latent variables greater than 1), were evaluated.

Univariate Analysis

Prior to completing the univariate analyses, Cronbach's alpha was computed for each of the three constructs within the HLRS. This helped to analyze the item-to-total correlations. These data are presented in Table 5. Univariate analyses were conducted for both the HLRS and the CYRM. A frequency count for each of the items was also produced, providing information about central tendencies and dispersion among the data. Additionally, correlational analyses were conducted to evaluate the relationships that were present between the three constructs from the HLRS scale and the CYRM. These data are depicted in Table 11 in Chapter Four.

Chapter Four

Results

This chapter includes the results of the analyses conducted to answer the research questions. The overall purpose of this study was to evaluate the validity of the Health Literacy Resiliency Scale. First, the results from the preliminary analyses and descriptive statistics are discussed, followed by the confirmatory factor analysis, including Cronbach's alpha. These analyses helped to answer the research questions.

Preliminary Analysis

Data entry

All data were collected online using Qualtrics and were automatically downloaded into an Excel spreadsheet. Data were then transformed and uploaded into SPSS and Mplus 7.3 for further analyses. Descriptive analyses for this current study consisted of means, normality (skewness and kurtosis), and correlations for the resiliency, health literacy, and support/advocacy subscales from the HLRS along with the CYRM.

Distribution of data

Utilizing SPSS, descriptive statistics were calculated for the data and are shown in Table 5. For health literacy the sample of participants scored an average of 2.80 on a 4-point scale. For resiliency and self-advocacy/support participants scored an average of 3.21 and 3.08, respectively. In order to examine the normality of each of the three variables, skewness and kurtosis were calculated. For both skewness and kurtosis, all of the values fell in the range between -2.0 and 2.0, which indicate that there were no extreme departures from normality.

Table 5.

Descriptive Statistics for Health Literacy, Resiliency and Support/Self-Advocacy (n =169)

Subscale	# of items	Cronbach's alpha	<i>M</i>	<i>SD</i>	Skewness	Kurtosis
Health Literacy	10	.87	2.80	0.78	-0.62	-0.58
Resiliency	13	.93	3.21	0.66	-1.66	1.96
Self-Advocacy/Support	14	.79	3.08	0.73	-0.95	1.94

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

Missing Data (Does Not Apply)

Of the 226 participants who responded to the survey, 169 (74%) answered all of the questions for the Health Literacy Resiliency Scale. For the health literacy category, the applicable response rate of participants was 80% across all questions. For the resiliency category, the applicable response rate was 96% across questions, and for the support/self-advocacy category, the applicable response rate was 74.8% across questions. Items 11 “Adults at my school know about my health condition”, 25 “I accept help from my teachers and other personnel at school in managing my health condition”, 29 “I receive accommodations related to my health condition to allow me to be successful in school”, and 30 “Adults in my school understand my health-related needs” had the most responses of “Does Not Apply” from participants; all of these items are in the support/self-advocacy category. For statistical purposes “Does Not Apply” was treated as missing data when participants completed the survey. For the Child Youth Resiliency Measure, all participants responded to the questions.

Confirmatory Factor Analysis

A confirmatory factor analysis was conducted for the HLRS using Mplus 7.3. Analyses included 226 participants and “Does Not Apply” responses (treated as missing data) among these

participants were accounted for using the pairwise deletion method. The matrix of association was a polychoric matrix. The method of estimation was weighted least squares mean and variance adjusted estimation. Various fit indices, such as the comparative fit index (CFI), χ^2 , and root mean square error of approximation (RMSEA), were used to examine model fit. However, it should be noted that the chi-square value is extremely sensitive to sample size. The results consisted of CFA, $\chi^2 (626, N = 226) = 2366.83, p < .001, CFI = .851, RMSEA = .113$. Within the literature there are acceptable values that determine if the model is a good fit. It is reported that if the CFI is above .95 (Hu & Bentler, 1999) and RMSEA is below .06 (Browne & Cudeck, 1993), that indicates good model fit. Additionally, χ^2 values that are closer to 0 indicate good fit (Byrne, 1998). Based on these recommendations in the literature, the fit of this model was not considered acceptable. There were no modifications made to the original model despite there being some items that loaded heavily on two factors. Table 6 shows the factor loadings for the CFA of the constructs from the Health Literacy and Resiliency Scale. Additionally, Figure 1 is a visual representation of the factor loadings and how they align with each category.

Table 6.

Unstandardized and Standardized Factor Loadings for the Confirmatory Factor Analysis of the Constructs from the Health Literacy and Resiliency Scale (n = 169)

Item	Unstandardized	S.Error	Standardized	S. Error
	Loading		Loading	
Health				
1	1.00	0.00	0.89	0.02
2	0.99	0.03	0.89	0.02
3	0.89	0.03	0.79	0.02
4	0.97	0.03	0.86	0.02
5	0.88	0.04	0.80	0.03
6	0.86	0.03	0.76	0.03
7	0.98	0.04	0.87	0.02
8	0.68	0.05	0.60	0.05
10	0.71	0.05	0.63	0.05
12	0.82	0.05	0.72	0.04
Resiliency				
13	1.00	0.00	0.97	0.01
14	0.91	0.02	0.89	0.01
15	0.87	0.03	0.85	0.02
18	0.72	0.04	0.70	0.03
20	0.90	0.02	0.87	0.04
21	0.94	0.03	0.91	0.02
31	0.78	0.03	0.76	0.02
32	0.81	0.03	0.78	0.03
33	0.71	0.03	0.69	0.03
34	0.74	0.04	0.72	0.03
35	0.78	0.03	0.75	0.03
36	0.81	0.03	0.79	0.03
37	0.78	0.03	0.76	0.03
Support/Self-Advocacy				
9	1.00	0.00	0.50	0.05
16	1.28	0.17	0.64	0.05
17	1.77	0.19	0.89	0.04
11	0.89	0.14	0.45	0.05
19	1.16	0.14	0.58	0.05
22	1.33	0.18	0.67	0.05
23	1.36	0.17	0.68	0.05
24	1.40	0.17	0.70	0.05
25	0.94	0.13	0.47	0.05
26	1.24	0.15	0.62	0.05
27	1.05	0.15	0.53	0.05
28	1.46	0.17	0.73	0.04
29	1.19	0.15	0.60	0.05
30	1.22	0.15	0.61	0.0

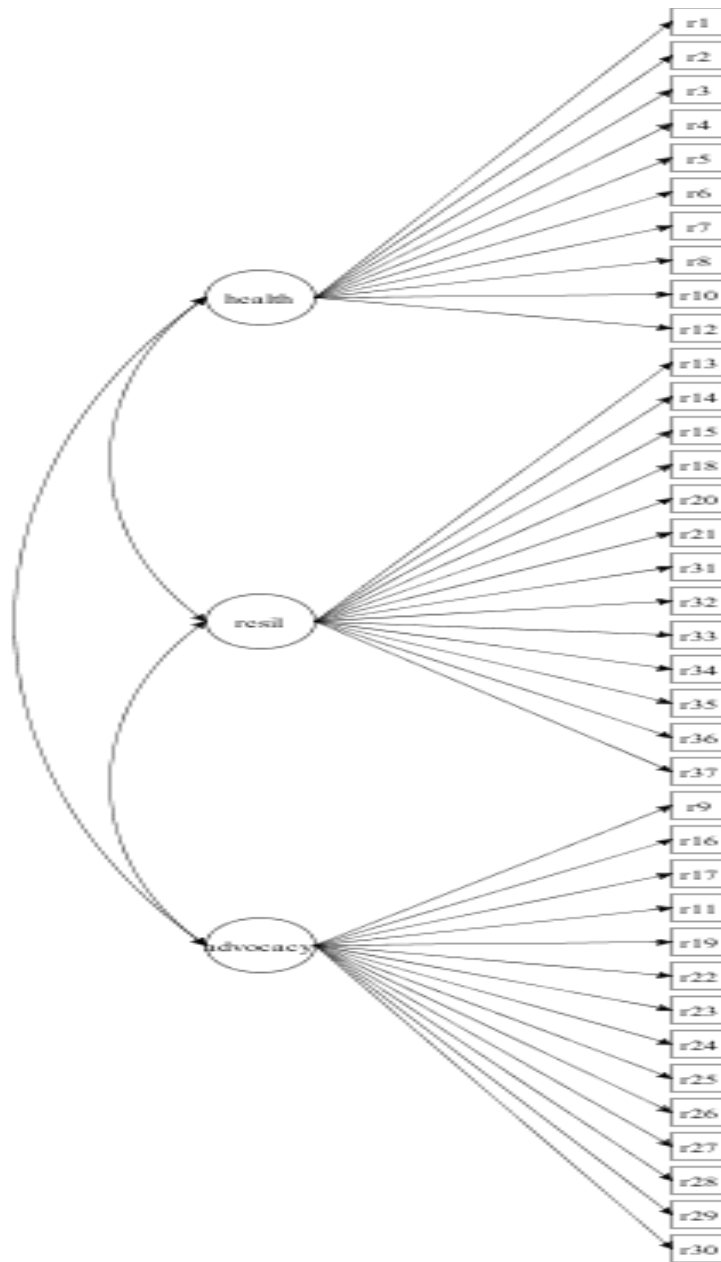


Figure 1. *Three-Factor Model for Health Literacy and Resiliency Scale*

Table 7 depicts the modification indices for the secondary loadings. This table illustrates the items within the HLRS that loaded heavily on more than one construct, meaning that although an item was designated for one construct it also loaded on one or more other constructs. Twenty

one of the items had modification indices that ranged from 10.1 to 276. This is important to consider when thinking about the fit of the model for the HLRS because this indicates that multiple items want to fall in two or more categories. Ideally within a measure the items should be loading under their specific construct. For example, item 17 “I learn about my health condition from my health care team” and item 18 “I learn about my health condition from talking with others who have personally experienced the same condition” are items that are in the resiliency category and the support/self-advocacy category that also want to fall into the health literacy category. Other items that also had high loadings on two factors include #9 “I understand the different ways my health impacts my relationship with my family” and #19 “I limit or modify my daily activities based on my body’s symptoms”. These items are both in support/self-advocacy category but also load highly with health literacy.

There were 16 items that did not show evidence of secondary loadings. Specifically, for health literacy there were 60% that did not load on another construct, 54% for resiliency, and 21% for support/self-advocacy.

Additionally when considering the fit of the Health Literacy and Resiliency Scale, it is also important to consider the modification indices for the correlated errors. Appendix G depicts the errors for the items that are highly correlated with each other. This specifically means that there are many items that participants answered very similarly to each other. This is important to note because there should be some variation between each of the items. Chapter 5 discusses further details regarding these data.

Table 7.

Modification Indices for Secondary Loadings

Item	Health	Resilience	Advocacy
Health			
1			
2			
3			
4		27.319	39.242
5		18.873	30.963
6			
7			
8			
10		10.936	
12		40.449	58.538
Resilience			
13			
14			
15	16.927		
18	276.045		221.205
20	10.074		11.990
21			
31			
32	11.399		13.771
33	18.584		
34			
35			
36			
37	12.927		
Advocacy			
9	80.217	33.158	
16			
17	215.775	29.759	
11	11.826	15.533	
19	66.652		
22		16.007	
23			
24	45.093	14.556	
25	41.126		
26			
27	56.339		
28	33.741		
29	24.527	12.286	
30	76.971		

Table 8 represents the summary of the standardized loadings for the Health Literacy and Resiliency Scale. Overall the values for the average loadings indicated that there were strong loadings among the items for each of the three factors. Additionally, the minimum and maximum values indicate that all of the items loaded with their designated factor. This is important to note because it demonstrates that the participants answered the questions how they were intended to be answered. Additionally Table 9 depicts the pairs of correlated errors between items with modification indices above 50.

Table 8.

Summary of Standardized Loadings for the Three-Factor Health Literacy and Resiliency Scale

Scale	Minimum	Maximum	Average Loading
Health Literacy	0.60	0.89	0.78
Resiliency	0.69	0.97	0.80
Support/Self-Advocacy	0.45	0.89	0.61

Table 9.

Pairs of Correlated Errors between Items with Modification Indices Above 50

Pairs	Items	Modification Index
Pair 1 (H5, H4)	I understand my health condition well. I know what medication(s) I need to take to manage my health condition.	109.923
Pair 2 (S29, S30)	I receive accommodations related to my health condition to allow me to be successful in school. Adults at my school understand my health-related needs.	99.988
Pair 3 (S30, S11)	Adults at my school know about my health condition. Adults at my school understand my health-related needs.	73.491
Pair 4 (H10, S9)	I understand the different ways my health impacts my relationship with my family I understand the different ways my health impacts my relationships with my friends	66.192
Pair 5 (S17, H12)	I learn about my health condition from talking with others who have personally experienced the same condition. I learn about my health condition from my health care team.	63.992

A confirmatory factor analysis also was conducted for the CYRM using Mplus 7.3. This analysis was completed to validate the CYRM and to also compare the fit between the two measures. Analyses included 226 participants with no missing data. The matrix of association was a polychoric matrix. The method of estimation was weighted least squares mean and variance adjusted estimation. Various fit indices, such as CFI, χ^2 , and RMSEA, were used to examine the model fit. The results for the CFA were χ^2 (2009, $N = 226$) = 4008.10, $p < .001$, CFI = .918,

RMSEA = .06. Based on the results from the RMSEA it is noted that this model may be of acceptable fit. Table 10 provides the factor loadings for the CFA of the CYRM.

Table 10.

Unstandardized and Standardized Factor Loadings for the Confirmatory Factor Analysis of the Child Youth Resiliency Measure (n =226)

Item	Unstandardized Loading	S.Error	Standardized Loading	S. Error
1A	1.00	0.00	0.92	0.02
2A	0.87	0.04	0.81	0.04
3A	0.80	0.04	0.74	0.04
4A	0.66	0.05	0.61	0.05
5A	0.47	0.06	0.43	0.06
6A	0.65	0.05	0.60	0.05
7A	0.93	0.08	0.87	0.08
8A	0.50	0.06	0.47	0.06
9A	0.45	0.06	0.42	0.06
10A	0.85	0.03	0.79	0.03
11A	0.94	0.03	0.87	0.03
12A	0.76	0.04	0.70	0.04
13A	0.77	0.04	0.72	0.04
14A	0.95	0.03	0.88	0.05
15A	0.94	0.06	0.87	0.06
16A	0.82	0.04	0.76	0.04
17A	1.16	0.03	0.76	0.02
18A	1.13	0.03	1.04	0.02
19A	0.75	0.02	0.70	0.02
20A	0.72	0.05	0.67	0.05
21A	0.86	0.03	0.80	0.03
22A	0.53	0.05	0.49	0.05
23A	0.80	0.04	0.74	0.04
24A	0.92	0.06	0.85	0.05
25A	0.69	0.07	0.64	0.06
26A	1.03	0.03	0.95	0.03
27A	0.86	0.03	0.80	0.03
28A	0.62	0.04	0.58	0.05

Correlations were calculated for the variables of health literacy, resiliency, and support/self-advocacy, along with the CYRM. Among the HLRS factors of health literacy and resiliency there was a positive moderate correlation ($r = .37$). For the resiliency and support/self-advocacy and health literacy and support/self-advocacy there were strong correlations of ($r = .72$)

and ($r = .55$), respectively. This suggests that individuals who had higher responses on support/self-advocacy items also had higher responses on the resiliency and the health literacy items. To get the correlation for the CYRM and the resiliency scale of the HLRS, a third CFA with the 37 items from the HLRS and the 28 items from the CYRM was conducted. For model fit $RMSEA = .06$ indicated fit was in the acceptable range. The correlations of the CYRM and health literacy was $r = .20$, CYRM and support/self-advocacy $r = .72$, and for the CYRM and resiliency $r = .95$. These results can be found in Table 11.

Table 11.

Pearson Product-Moment Correlations between HLRS Subscales and CYRM Subscale

Subscale	Health	Resiliency	Support	CYRM
Health	1.0	.36	.54	.20
Resilience		1.0	.71	.95
Support			1.0	.72
CYRM				1.0

The Cronbach's alphas for each of the three factors within the Health Literacy and Resiliency Scale were calculated (see Table 5). The Cronbach's alphas for the CYRM was considered excellent, with a value and .94 (Hatte, 1985). Within the HLRS the Cronbach's alpha was calculated for each of the three factors with Health Literacy being .87, Resiliency .93, and Support/Self-advocacy .79. These values ranged from acceptable to excellent. These Cronbach's alpha values differ from the values calculated in the original sample.

Summary of Findings

After completing the data analysis, it was concluded that the model for the Health Literacy and Resiliency Scale was not a good fit. These conclusions were drawn using a confirmatory

factor analysis and examining the values of the CFI, χ^2 and RMSEA. In contrast, the subscales appear to have high internal consistency. Cronbach's alpha was used to report the reliability of the three factors within the HLRS. The values for the three factors ranged from acceptable to excellent. The results also included correlational data for the Health Literacy and Resiliency Scale and Child Youth Resiliency Measure. Among the HLRS there were strong correlations for the resiliency and support/self-advocacy factors and health literacy and support/self-advocacy factors. While for the CYRM there was a strong correlation with the resiliency factor indicating that the resiliency factor within the HLRS tends aligns with the resiliency construct that is measured in the CYRM.

Chapter Five

Discussion

The overall purpose of this study was to provide validity and reliability evidence for the HLRS. In the original study in which the HLRS was developed, the researchers explored the presence of relationships between three different categories of youth chronic illness and the factors of resiliency, health literacy, and self-advocacy/support. In the original study, the HLRS (Bradley-Klug et al., 2017) was used to investigate these relationships. This study served as a follow-up investigation with newly collected data. In addition to examining the relationship between the three factors for individuals with chronic health conditions, the main purpose of this study was to collect validity evidence of the resiliency construct by correlating the resiliency scale on the HLRS with the resiliency scores from the Child Youth and Resiliency Measure (CYRM).

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

Overview of the Study

Chronic health conditions in youth have increased over the last several decades. It is estimated that within the United States there are between 15% to 18% of youth who are living with a chronic health condition (Centers for Disease Control and Prevention [CDC], 2010). The CDC defines a chronic health condition as an illness that lasts for three months or longer that can be managed, but not cured (CDC, 2010). Although there is some research on youth living with chronic illnesses, there are minimal studies that assess the constructs of health literacy, resiliency, and support/self-advocacy within this population. The current study was a validity study of the

Health Literacy and Resiliency Scale (HLRS). This is a newly developed 37-item measure that assesses the level of health literacy, resiliency, and support/self-advocacy among chronically ill youth (Bradley-Klug, Shaffer-Hudkins, Lynn, DeLoatche, & Montgomery, 2017). Specifically, the study analyzed the construct of resiliency in the HLRS with the resiliency construct from the Child Youth and Resiliency Measure (CYRM; Ungar & Liebenberg, 2011). This measure is a 28-item measure that assesses levels of resiliency among youth and young adults. The goals for this study included: 1) determining the extent to which the results of the factor analysis from the current study are consistent with the three-factor model from the original study, 2) assessing the relationship between the HLRS and the CYRM, and 3) determining the reliability (internal consistency) of the scores of the HLRS. Findings from this study provide information on the validity of the HLRS and also have the potential to drive prevention and interventions. More specifically, when individuals take this measure it can help to screen for any weaknesses in the areas of health literacy, resiliency, and support/self-advocacy. This in turn can help stakeholders to implement interventions or provide resources that will promote more positive outcomes (e.g., better mental health, treatment adherence).

When examining the HLRS, two sources of validity evidence were considered. Specifically, this study examined the sources of internal structure and relations to other variables (American Educational Research Association, 2014). When considering relations to other variables, this study examined how variables are related to each other and to the overall testing outcomes. It is important to note that evidence based on relationships with other variables provided details regarding the degree to which these relationships were consistent with the underlying construct. This was critical to consider for this study because the resiliency construct within the HLRS was analyzed with the constructs of health literacy and support/self-advocacy and also with the resiliency construct from the CYRM.

Discussion of Results

Research question one. To what extent are the results of the factor analysis from the current study consistent with the three-factor model from the original study?

Based on the results from the confirmatory factor analysis the HLRS still depicts a three-factor model that aligns with the original study. Although the model did not have acceptable fit, the majority of the items tended to be strongly related to their designated factor. However, in addition to those results, the confirmatory factor analysis also suggested that the errors for some pairs of items were highly correlated with each other; errors for pairs of items are assumed to be uncorrelated so to the extent that these errors are correlated there will be misfit in the model. For example, the errors for items #4 “I know what medication(s) I need to take to manage my health condition” and #5 “I know the correct dosage for my medication(s)” were highly correlated with each other. This indicates that individuals tended to answer these questions almost identically. As a researcher looking to increase the validity of a measure, it is important to consider whether these questions are too similar. Perhaps for adolescents and young adults it may be more difficult to notice if there is a difference between these items. In contrast, just because someone knows the name of the medication they should take, does not necessarily mean that the individual knows the exact dosage they should take of that particular medication. Although individuals within this data set did answer these two questions similarly, it may still be helpful to keep both questions. Some of the pros to keeping both questions are that when administered in a clinical setting it can possibly provide more specific insight about an individual’s health literacy. When administering this measure in a therapeutic setting the practitioner has the opportunity to ask follow-up questions. Thus, by keeping both of these questions it enables the practitioner to explain more in depth the differences between knowing the name of the medication one should take and also knowing the correct dosage. However, it is important to note that in cases such as administering

the measure online, this provides a con when analyzing the data. Keeping two questions that appear to be extremely similar can be problematic when trying to create a highly valid and reliable measure. In addition to some items having errors that were highly correlated with each other, there also were some items that loaded heavily on two factors. Items #17 “I learn about my health condition from my health care team” and #18 “I learn about my health condition from talking with others who have personally experienced the same condition” both loaded highly on two factors. Originally, item #17 was designated to be in the support/self-advocacy construct, but within this current dataset this item also loaded highly on the health literacy construct. Although the item is meant to examine how the health care team “helps” the individual, it also emphasizes the point of the learning more about one’s own health condition, which may explain the strong loading on the health literacy construct. Similarly, item #18 is considered to be a resiliency item; however, this item also loaded heavily on the health literacy factor. This item targets the idea of building capacity through understanding another individual’s experiences. However, the item also inquires about learning more about one’s own health condition. When examining these questions, it is necessary for the researchers to consider how these questions are worded. It is important to have questions that are clear and concise. It is possible that a potential solution to address questions such as those listed above is to reword the items so that they do not align with two factors or to remove them. The advantages of rewording the questions are that this allows the researchers an opportunity to create questions that are more clear and direct. When creating a measure it is necessary to ensure that the items best capture the constructs. Although it seems like the ideal solution, there also are some cons to this idea. For example, rewording the questions can be a long process. It may require gathering the research team to ensure that everyone agrees with the rewording of the questions. It also may require additional focus group testing to determine how this population responds to the new items in comparison to the previous items. In addition, this

may also be the same case when choosing to remove the items. Removing the items that load heavily on two constructs can be advantageous because it reduces the length of the measure. Currently the measure is 37 items total, so for some individuals it may be too long to complete. Also, removing these items may help to provide a better overall model fit for the measure. However, in contrast a disadvantage to removing these items is that it may reduce content validity.

Research question two. What is the relationship between the Health Literacy and Resiliency Scale (HLRS) and the Child Youth Resiliency Measure (CYRM)?

Based on the results from the analyses there were some noteworthy correlations between the HLRS and the CYRM. One anticipated finding was that there was a low correlation between the CYRM and the health literacy construct. However, when examining the correlation between the CYRM and the resiliency factor there was a strong positive correlation. This is important to note because this helps to contribute to the construct validity of the HLRS. Because the CYRM is an instrument that measures resiliency it is helpful that the factor of resiliency is highly related to that of the HLRS. This is essential because, one of the goals of this study is to evaluate the validity of the scale. However, although having a strong positive correlation between the resiliency construct and the CYRM is preferred, it is necessary to note that having correlations that are “too high” can be considered problematic (Boateng, Neilands, Frongillo, Melgar-Quinonez, & Young, 2018). A correlation of .954 indicates that there is little difference between the CYRM and the resiliency construct in the HLRS. Having a correlation that’s approximately .7 to .8 would have been ideal because this indicates that the measures are similar but still have some unique qualities that yield distinct value to clinical and/or research settings (Boateng et al., 2018). However, in this specific case, the resiliency construct that is being validated is actually part of a larger scale that measures other constructs. Therefore, having a correlation of .954 is not as problematic

because the scale measures more than just resiliency. It also measures health literacy and support/self-advocacy.

Additionally, this evidence also shows that there is convergent validity between the resiliency construct and the CYRM. This specifically means that the construct of resiliency in the HLRS and the CYRM appear to be highly related to each other, whereas this was not necessarily the case for the other factors in the HLRS. It is important that the CYRM is not strongly correlated with the other factors such as health literacy. This means that the resiliency set of questions created for the HLRS are consistent with the construct of resiliency as defined in the literature. Although the questions are designed to specifically look at the resiliency for youth with chronic health conditions, data indicate that the items still align with the overall universal definition of interpersonal resources that buffer the stress of living with a health condition, which include competence, positive coping styles, sense of humor, connectedness, and knowledge of health behaviors and health risks (Rew & Horner, 2003). Additionally, it also involves the capacity to which individuals navigate the resources (e.g., family, community, culture, individuality) around them to help maintain a positive and productive lifestyle (Ungar & Liebenberg, 2011).

In addition, there also was a positive correlation with the CYRM and the support/self-advocacy construct. When examining this relationship, it is crucial to pinpoint the connection it has with Kazak's Social Ecological Model for resiliency (Kazak, 2001). As mentioned, this model indicates that there are a range of systems (i.e., child, family, school, school, community, and culture) that collectively impact the parent and the children's ability to cope with their chronic health condition. Kazak's model underlines the importance of continuous connections between system levels and how this impacts the child's perspective on his or her illness at each system level (Kazak, 2001). With the child remaining at the center of all these systematic levels, the Kazak Social Ecological Model hypothesizes that better emotionality and psychological

adjustment as related to resiliency can be understood by examining how these subsystems interconnect with both the family and the child living with the chronic health condition (Kazak, 2001). Therefore, this provides some justification as to why there is such a high correlation between the CYRM and the support/self-advocacy construct within the HLRS.

Research question three. What is the reliability (internal consistency) of the scores of the Health Literacy and Resiliency Scale?

The reliability of the HLRS was analyzed by computing the internal consistency of the three subscales. When examining the Cronbach's alpha of the subscales (health literacy $\alpha=.87$, resiliency $\alpha=.93$ and self-advocacy $\alpha=.79$), internal consistency was somewhat lower, specifically for the support/self-advocacy factor.

When examining the data on the HLRS it was noted that the support/self-advocacy factor had the highest number of responses recorded as "Does Not Apply" in comparison to the other factors, with only 74.8% applicable responses, meaning that these participants did not select the "does not apply" option. The categories of Health Literacy and Resiliency had 80% and 96% applicable responses, respectively. This is important to pinpoint because it indicates that there may have been specific questions that were not applicable for many of the participants. For example, after examining the questions with the highest responses of "Does Not Apply", it was found that all of them were in the support/self-advocacy category. More specifically, these questions were all related to school and feeling supported in the school setting (e.g., "Adults at my school understand my health-related needs" and "Adults at my school know about my health condition"). This is critical because the survey is targeted for the adolescent and young adult population, which includes individuals from ages 18-21 who may not be currently attending school. As a potential solution for this in the future, it is possible that these questions can be reworded to include both school and work (e.g., "Adults at my school and/or work understand my health-related needs").

However, to avoid double-barreled questions, it may be better to include questions that are specifically related only to work (e.g., Adults at my work understand my health-related needs). Although there may still be some individuals who may not work or attend school due to health-related reasons, it is hypothesized that rewording these questions to include work or adding specific work-related questions will be more inclusive.

In addition to examining the internal consistency of the subscales, it is also important to compare the values of previous studies that also utilized this measure. Bradley-Klug et al. (2017) conducted the original exploratory factor analysis with the HLRS and reported good internal consistency values as well: health literacy ($\alpha=.86$), resilience ($\alpha=.85$), and self-advocacy/support ($\alpha=.88$). For this scale, it is helpful to have consistent reliability scores across the studies. As this measure becomes utilized in future practice, it is important that it remains reliable. There was also a follow-up study that was conducted utilizing some of the data from the original exploratory factor analysis. Cambric (2017) utilized these data and separated individuals into three major ICD-9 categories. The Cronbach's alphas for this study were health literacy ($\alpha=.88$), resilience ($\alpha=.88$), and self-advocacy/support ($\alpha=.87$). These values were very similar to those from the original study, most likely due to utilizing participants from the same dataset.

Limitations

Certain limitations of the study should be considered when interpreting the results. The study was conducted completely online, which limits participation to only youth who have online access to complete the study. For example, it may be more difficult for an individual from a lower social economic background to complete the survey. It may also be difficult for individuals with debilitating chronic conditions to complete the survey as well. Another limitation that was considered is underrepresentation of specific health conditions within the study. Most of the advertisement for the study was done via social media to online health groups on websites such as

Facebook (e.g., Juvenile Diabetes Type 1 support Facebook group). Not all youth health conditions have an online presence on social media, and it is noted that some of the more common conditions such as cancer and cerebral palsy had limited representation in this study sample. Additionally, when analyzing the data, it was noted that approximately 75% of individuals completed the questions within the support/self-advocacy. Specifically, questions involving school had the highest responses of “Does Not Apply”. This is viewed as a potential limitation because the questions did not inquire about participants who may “work” rather than attend school.

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 continuous research on how this population can foster and maintain attributes such as health literacy, resiliency, and support/self-advocacy.

The current goal of this study was to help validate the resiliency factor of the HLRS with the CYRM and to provide validity for the entire HLRS. Based on these results, there was a correlation between the resiliency factor and the resiliency measure from the CYRM. One recommendation for the future would be to complete this validation process for the other factors of health literacy and support/self-advocacy. It is important for researchers to know if these other factors are also providing accurate reflections of these constructs. The goal of this measure is to eventually be used in practice, however prior to this it necessary to ensure that the scores from the scale are valid.

Another recommendation based on the analyses would be to consider eliminating and rewording some of the items to help strengthen the overall fit of the model for the scale. This is important because the measure should have an overall good structural model that indicates that the observed model is aligned with the theorized model. After completing this process, more data can be collected to determine if fit improves for the measure. Completing another confirmatory factor

analysis for the revised measure will also determine if there are still three factors and how the items load to their designated factor.

Additionally, another recommendation may be to consider expanding the use of this scale to include youth with mental health conditions (e.g., anxiety, depression). When considering the questions on the scale, many of them are applicable for those who are living with mental health disorders (e.g., “I understand my health condition well”, “I understand the different ways my health impacts my relationship with my family”, “I’ve accepted my health condition as part of who I am”). The overall goal of this scale is to help assess the levels of health literacy, resiliency and support/self-advocacy among youth so that interventions can be put in place. This same process may be helpful for those with chronic health conditions and those with mental conditions.

Lastly, it can be helpful to explore the feasibility of utilizing the HLRS in a clinical and school setting. This measure was originally created for the purpose of having youth and young adults complete it as part of a clinical evaluation. Therefore, the utility of this scale within these particular settings should be explored.

Implications and Considerations for Practice

Within this study there was support for the validity of the resiliency scores from the Health Literacy and Resiliency Scale based on the correlation with the resiliency scores from the Child Youth Resiliency Measure. This is important, because one of the key goals for this measure is for it to be utilized in a clinical and practical setting. Utilizing the HLRS in practice can help school and pediatric psychologists to assess and review the levels of health literacy, resiliency, and support/self-advocacy of youth living with chronic health conditions. Rather than viewing these students as being a product of the medical diagnosis, school psychologists can use the HLRS to identify student needs and implement resources through a multi-tiered system (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 school psychologists gain more access to pediatric school psychology research it can eventually lead to implementing more specific prevention and intervention approaches within clinical and school settings to support positive outcomes for youth and young adults living with a chronic health condition.

Contributions to the Literature

This study contributed 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. Specifically, this study helped to validate one of the constructs of the HLRS. By doing this, the scale will ideally become more sought-after by practitioners to use with youth with chronic health conditions. Because the scale is relatively new, it is important to demonstrate that there is some validity to the overall measure so that practitioners feel comfortable using it in applied settings. This in turn is helpful because the scale is intended to be used across a variety of settings. Since the validity is strengthened, hopefully there will be an increase in the use of the scale in the future, which will eventually be helpful in driving interventions, particularly for those groups who may have lower levels of these three factors.

Conclusion

The overall goals for the study were to: 1) determine the extent to which the results of the factor analysis from the current study are consistent with the three-factor model from the original study, 2) assess the relationship between the HLRS and the CYRM, and 3) determine the reliability (internal consistency) of the scores of the HLRS. More broadly, another goal was to contribute 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 related to resiliency and health literacy. Specifically, this study helped to validate

one of the constructs of the HLRS. Based on the analyses, the resiliency construct was shown to be strongly correlated with the CYRM. These results help to move the HLRS a step closer to being utilized in a practical setting. This can be helpful in driving interventions, particularly for those groups who may have lower levels of these three factors. However, prior to using the scale in practice it is recommended that the authors consider the results of this study when perhaps revising some of the items. Because multiple items either loaded on two of the constructs or the errors for pairs of items were highly correlated with each other, it may be helpful to further investigate these items on the scale. Reassembling a team of experts to review these items will be helpful in determining if some of the items should either be eliminated or reworded to create a better fit. Overall, it is recognized that these constructs (resiliency, health literacy, and support/self-advocacy) are important, and that fostering these skills in youth can lead to positive outcomes such as increased levels of treatment adherence, self-regulation skills, and self-confidence (Epstein, Nelson, & Thompson, 2014; Flett & Hewitt, 2014; Trout, Hoffman, Maslow, Polluck, & Hill, 2016).

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Appendices

Appendix A: HLRS- Y Final 37 Items

Item #	Question	Factor
1	I know the common symptoms of my health condition.	H
2	I recognize when my health symptoms are severe and when they are not.	H
3	I understand my health condition well.	H
4	I know what medication(s) I need to take to manage my health condition.	H
5	I know the correct dosage for my medication(s).	H
6	I know which types of physical activity can be potentially harmful to my health	H
7	I know when to tell my friends or family about my health limitations	H
8	I know the different ways my health impacts my performance in school or work	H
9	I understand the different ways my health impacts my relationship with my family	S
10	I understand the different ways my health impacts my relationships with my friends	H
11	Adults at my school know about my health condition.	S
12	I learn about my health condition from talking with others who have personally experienced the same condition.	H
13	I am optimistic about my future.	R
14	I've accepted my health condition as part of who I am.	R
15	I find ways to do my normal routine activities while living with my health condition.	R
16	I tell others when I am not feeling well.	S
17	I learn about my health condition from my health care team.	S
18	I learn about my health condition from talking with others who have personally experienced the same condition.	R

19	I limit or modify my daily activities based on my body's symptoms.	S
20	I try to find the positive or funny aspects in difficult health situations.	R
21	I focus on the positive aspects of my life.	R
22	I get extra rest or 'take it easy' when needed for my health condition	S
23	I accept help from my family and friends in managing my health condition	S
24	I have people around who love me	S
25	I accept help from my teachers and other personnel at school in managing my health condition	S
26	My parents help me adapt by learning as much as possible about my health condition.	S
27	There is at least one person in my life who keeps an eye on me in case I need support with my health condition.	S
28	I have a social support system (e.g., family, friends) I can count on when I need to attend health-related events.	S
29	I receive accommodations related to my health condition to allow me to be successful in school.	S
30	Adults at my school understand my health-related needs.	S
31	I find ways to do fun activities with friends or family while living with my health condition.	3
32	I believe something good will come out of my experiences with my health condition.	R
33	Seeing others successfully managing a similar health condition helps me to manage my condition.	R
34	Interacting with other teens or young adults with health conditions helps me feel better.	R
35	Others help me cope by finding humor in situations related to my health condition	R
36	Others help me feel like I am living a normal life by including me in activities and events	R
37	I am able to adapt to my health condition when I can talk about my	R

	experiences with someone	
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Appendix B: Child Youth Resiliency Measure- 28-item

1. I have people I look up to
2. I cooperate with people around me
3. Getting an education is important to me
4. I know how to behave in different social situations
5. My parent(s)/caregiver(s) watch me closely
6. My parent(s)/caregiver(s) know a lot about me
7. If I am hungry, there is enough to eat
8. I try to finish what I start
9. Spiritual beliefs are a source of strength for me
10. I am proud of my ethnic background
11. People think that I am fun to be with
12. I talk to my family/caregiver(s) about how I feel
13. I am able to solve problems without harming myself or others (for example by using drugs and/or being violent)
14. I feel supported by my friends
15. I know where to go in my community to get help
16. I feel I belong at my school
17. My family stands by me during difficult times
18. My friends stand by me during difficult times
19. I am treated fairly in my community
20. I have opportunities to show others that I am becoming an adult and can act responsibly
21. I am aware of my own strengths
22. I participate in organized religious activities
23. I think it is important to serve my community
24. I feel safe when I am with my family/caregiver(s)

25. I have opportunities to develop skills that will be useful later in life (like job skills and skills to care for others)

26. I enjoy my family's/caregiver's cultural and family traditions

27. I enjoy my community's traditions

28. I am proud to be a citizen of _____ (insert country)

Note: Scale is 1-3 (1=No, 2=Sometimes, 3=Yes)

Appendix C: Demographic Questionnaire

How did you find out about this study?

Age: _____

Gender:

- Male
- Female
- Transgender

What state do you live in? (e.g., FL, VA): _____

Race/Ethnicity:

- American Indian or Alaskan Native
- Asian
- Black or African American
- Hispanic or Latino
- Native Hawaiian or Pacific Islander
- White
- Multi-racial
- Other (please specify): _____

Primary Health Condition: _____

Other Diagnosed Health Condition(s): _____

When did you find out about your health condition? (Please answer based on your primary health condition)

- I've known as long as I can remember
- During my preschool years (you were 3 to 5 years old)
- During my elementary school years (you were 6 to 10 years old)
- During my middle school years (you were 11 to 13 years old)
- During my high school years (you were 14 to 17 years old)
- During my early adulthood years (since you have turned 18)

Are you currently enrolled in school?

- Yes
- No

How do you describe your religious/spiritual values?

- Very strong
- Somewhat strong
- Not strong

What year of school are you in? (if you answered “No” to the previous question, choose “Not applicable”)

- Not applicable
- 6th grade
- 7th grade
- 8th grade
- 9th grade
- 10th grade
- 11th grade
- 12th grade
- Freshman in college
- Sophomore in college
- Junior in college
- Senior in college
- Other: _____

Are you currently covered under health insurance?

- Yes
- No
- Not applicable

If you are covered under health insurance, what type of insurance do you have?

- Private
- Public (e.g., Medicaid)
- Not sure

Appendix D: Health Literacy Resiliency Scale Item Frequencies (n = 226)

Item	<i>n</i>	<i>M</i>	<i>SD</i>	1	2	3	4
1	226	2.88	0.66	2	59	129	36
2	226	2.33	0.78	4	64	114	44
3	226	2.60	0.83	24	70	105	27
4	215	3.04	0.77	6	42	104	63
5	217	2.99	0.86	7	60	78	72
6	218	2.74	0.86	13	77	81	47
7	224	2.86	0.74	5	65	110	44
8	218	2.88	0.73	5	58	113	42
9	226	2.99	0.64	1	45	135	45
10	226	2.89	0.69	4	56	126	40
11	195	2.68	0.76	15	52	108	20
12	224	2.80	0.67	1	74	118	31
13	226	3.58	0.72	3	23	41	159
14	226	3.49	0.72	2	25	60	139
15	226	3.38	0.75	5	22	82	117
16	226	3.06	0.60	0	35	143	48
17	226	2.87	0.62	0	60	135	31
18	226	2.84	0.65	3	60	134	29
19	219	2.86	0.84	5	79	86	59
20	226	3.45	0.78	7	21	62	136
21	225	3.51	0.80	10	15	51	149

22	220	3.06	0.71	1	45	111	62
23	225	3.15	0.51	0	16	160	49
24	226	3.50	0.61	2	8	91	125
25	200	3.50	0.70	2	39	107	52
26	224	3.13	0.61	0	30	136	58
27	224	3.38	0.59	0	13	112	99
28	226	3.28	0.58	1	13	133	79
29	198	2.79	0.72	0	77	84	35
30	193	2.68	0.68	7	64	105	17
31	226	3.13	0.58	0	26	145	55
32	224	3.02	0.68	8	26	144	46
33	225	2.99	0.62	1	42	140	42
34	224	2.97	0.63	3	39	144	38
35	222	3.22	0.64	0	27	119	76
36	225	3.15	0.65	3	25	133	64
37	226	3.09	0.59	0	30	146	50

Note: For specific item content refer to Appendix A. Response scale is 1 = strongly disagree, 2 = disagree, 3 = agree, 4 = strongly agree.

Appendix E: CYRM Item Frequencies (n = 226)

Item	<i>M</i>	<i>SD</i>	No %	Sometimes %	Yes %
R1	2.67	0.66	10.6	11.5	77.9
R2	2.73	0.49	2.2	22.6	75.2
R3	2.47	0.77	16.8	19.0	64.2
R4	2.67	0.51	1.8	29.2	69.0
R5	2.42	0.65	8.8	39.8	51.3
R6	2.55	0.62	6.6	31.9	61.5
R7	2.95	0.22	0	5.3	94.7
R8	2.63	0.55	3.5	29.6	66.8
R9	2.31	0.77	19.0	31.4	49.6
R10	2.62	0.59	5.3	27.4	67.3
R11	2.70	0.60	7.5	14.6	77.9
R12	2.49	0.63	7.5	36.3	56.2
R13	2.67	0.50	1.3	30.5	68.1
R14	2.72	0.58	6.6	14.6	78.8
R15	2.87	0.41	2.7	7.5	89.8
R16	2.48	0.78	17.7	16.4	65.9
R17	2.85	0.40	1.8	11.5	86.7
R18	2.82	0.47	3.5	11.1	85.4
R19	2.44	0.66	9.3	37.2	53.5
R20	2.62	0.60	6.2	25.7	68.1
R21	2.68	0.59	6.2	19.9	73.9
R22	2.17	0.81	25.7	31.4	42.9
R23	2.60	0.62	7.1	26.1	66.8
R24	2.85	0.42	2.7	9.3	88.1
R25	2.68	0.56	4.9	22.6	72.6
R26	2.74	0.57	6.6	12.8	80.5
R27	2.48	0.67	9.7	32.3	58.0
R28	2.23	0.70	15.5	46.0	38.5

Appendix F: Descriptive Statistics for Child Youth Resiliency Measure (n=226)

	N	Minimum	Maximum	Mean	Std. Deviation
R1	226	1.00	3.00	2.67	.65
R2	226	1.00	3.00	2.73	.49
R3	226	1.00	3.00	2.47	.76
R4	226	1.00	3.00	2.67	.50
R5	226	1.00	3.00	2.42	.65
R6	226	1.00	3.00	2.54	.61
R7	226	2.00	3.00	2.94	.22
R8	226	1.00	3.00	2.63	.55
R9	226	1.00	3.00	2.30	.77
R10	226	1.00	3.00	2.61	.58
R11	226	1.00	3.00	2.70	.60
R12	226	1.00	3.00	2.48	.63
R13	226	1.00	3.00	2.66	.49
R14	226	1.00	3.00	2.72	.57
R15	226	1.00	3.00	2.87	.40
R16	226	1.00	3.00	2.48	.77
R17	226	1.00	3.00	2.84	.40
R18	226	1.00	3.00	2.81	.46
R19	226	1.00	3.00	2.44	.65
R20	226	1.00	3.00	2.61	.60
R21	226	1.00	3.00	2.67	.58
R22	226	1.00	3.00	2.17	.81
R23	226	1.00	3.00	2.59	.61
R24	226	1.00	3.00	2.85	.42
R25	226	1.00	3.00	2.67	.56
R26	226	1.00	3.00	2.73	.57
R27	226	1.00	3.00	2.48	.66
R28	226	1.00	3.00	2.23	.69

Appendix G: Modification Indices for Correlated Errors

<u>Item Pair</u>	<u>Modification Index</u>
H5,H4	109.923
S30,S29	99.988
S30,S11	73.491
H10, S9	66.192
S17,H12	63.992
R18,H12	44.016
S30, S25	29.057
R18, H1	27.258
H2 ,H1	25.632
S30, H5	24.004
R18, H7	23.888
R18,,H6	23.696
S28, S27	21.926
S17, H6	21.833
R18,H10	20.735
S9, H8	19.088
R18, H2	18.510
S19, H6	17.950
S25, S11	16.313
S29, S11	15.732

R18 , H3	14.747
R18,R14	14.722
S24, S17	14.565
S30, S19	14.241
S17, H7	13.253
S27, S24	13.017
S30,H4	12.889
H10, H8	12.534
R20,R18	12.534
S25, H4	12.513
S29, S5	12.374
S27, H5	11.947
R34,S28	11.828
S30, H6	11.765
S19,H2	11.289
S27, H6	10.668
R20,S17	10.658
H12, H2	10.369
S17,H10	10.222
R30, R2	10.115

Note: H= Health Literacy, R=Resiliency, S= Support/Self-Advocacy
Modification indices are from the Three-Factor Model