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# Transition Readiness and Health Literacy in Adolescents/emerging Adults with Sickle Cell Disease

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TRANSITION READINESS AND HEALTH LITERACY IN  
ADOLESCENTS/EMERGING ADULTS WITH SICKLE CELL DISEASE

by

Lisa M. Burks

Thesis Defense Submitted in  
Partial Fulfillment of the  
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at

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May 2013

ABSTRACT  
TRANSITION READINESS AND HEALTH LITERACY IN  
ADOLESCENTS/EMERGING ADULTS WITH SICKLE CELL DISEASE

by

Lisa M. Burks

The University of Wisconsin-Milwaukee, 2013  
Under the Supervision of Professor W. Hobart Davies, Ph.D.

Approximately 90,000 Americans, primarily African American, are affected by sickle cell disease (SCD). With medical advancements allowing youth with SCD to have increased longevity and survive well into adulthood, adequate preparation in overall disease management is necessary to facilitate a successful transition from pediatric to adult health care. Research has shown that health literacy affects health outcomes (e.g., factors related to disease management) and patients with SCD possess multiple characteristics found to be associated with low health literacy. Thus, it is important to investigate the effects health literacy has on the transition experience of youth with SCD so that we can optimize the chances of a successful transition to adult care. The purpose of this study was to examine transition readiness and health literacy among adolescent and emerging adult patients with SCD and to examine the cross-sectional relationship between health literacy and transition readiness within the SCD population. Results from this study found that patients with SCD had similar self-reported transition readiness relative to other chronic illness populations; similar healthy literacy to overall healthy peers and significantly higher health literacy than healthy Black peers. Assessed health literacy performance was not significantly associated with transition readiness. Finally, patients who had already transferred to adult care had significantly higher transition

readiness skills than patients still receiving pediatric care. Future research should examine other methods of assessing health literacy in this population as well as potential variables affecting SCD patients' ability to manage their disease before and after transitioning to adult care.

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## **Introduction**

Research indicates 133 million Americans (Wu & Green, 2000), including approximately 44% of youth (van der Lee, Mookink, Grootenhuis, Heymans, & Offringa, 2007), are currently living with at least one chronic health condition. Over the past 40 years, medical advancements have enabled increasing numbers of children with chronic medical conditions to survive into adulthood and approximately 500,000 youth with a special health care need turn 18 years of age each year (Lotstein, McPherson, Strickland, & Newacheck, 2005). The effects of growing up with a chronic illness can have many implications. Recently, a national longitudinal study found that young adults living with a lifelong chronic illness were significantly less likely to achieve important milestones (i.e., education, financial, and vocation) in adulthood compared to healthy peers (Maslow, Haydon, Ford, & Halpern, 2011).

There has been increasing attention to the needs of pediatric patients with chronic illness as they transition to adult roles and adult medical care. Chronic illnesses can vary in demands related to disease management and barriers to optimal functioning, which creates a need for research within specific disease populations to optimize our understanding of variables affecting youth with a specific chronic illness. Sickle cell disease is one pediatric chronic illness that has been associated with numerous complications in disease management and barriers in functioning across the lifespan.

### **Sickle Cell Disease**

Sickle cell disease (SCD) is an inherited blood disorder found primarily in individuals of African or Mediterranean descent (Platt et al., 1994). Within the United States, approximately 1 in 12 African-Americans are carriers of the sickle cell gene and 1

in 600 African Americans have SCD (Steinburg & Embury, 1994). SCD refers to the presence of a variation in the beta-globin gene that causes the production of hemoglobin, and causes the hemoglobin cell, when deoxygenated, to change from the natural cell shape to a “sickle” cell shape (Ashley-Koch, Yang, & Olney, 2000). The homozygotic combination of this variation (HbSS) produces sickle cell anemia, the most severe form of SCD (Ashley-Koch et al., 2000). The other major heterozygotic combinations that result in SCD include HbSC, HbS $\beta^+$ -thalassemia, and HbS $\beta^0$ -thalassemia (Stuart & Nagle, 2004). These changes in the beta globin gene result in permanent damage from hemolysis, which is responsible for a variety of medical complications including recurrent pain that can cause acute chest syndrome (i.e., complication often caused by severe sickling of red blood cells in the lungs), priapism, damage to the spleen and kidneys, short stature, delayed puberty, and gallstones (Brozovic, Davies, & Brownell, 1987; Carroll, 2000; Dampier et al., 2004; Lemanek, Ranalli, Green, Biega, & Lupia, 2003; NHLBI, 1995; Platt et al., 1994).

In addition to medical complications, individuals with SCD can experience cognitive and academic deficits. Cognitively, individuals with SCD are at risk for deficits in global intellectual functioning, attention/executive functioning, verbal ability, language skills, visual-motor and visual-spatial processing, and memory (Kral, Brown, & Hynd, 2001; Schatz, Finke, Kellett, & Kramer, 2002; White & DeBaun, 1998). Individuals with SCD have also been found to display deficits in reading, writing, arithmetic, and spelling relative to healthy peers and siblings (Armstrong et al., 1996; Fowler et al., 1988; Noll, Stith, & Gartstein, 2001; Schatz et al., 2002; Swift et al., 1989; Wang et al., 2001; Wasserman, Wilimas, Fairclough, Mulhern, & Wang, 1991).

There are many behaviors that are involved in effective management of SCD such as adjusting to symptoms, maintaining adequate relationships with health care providers, and managing emotional and social consequences of the disease (Moos & Schaefer, 1984). As such, potential factors hindering a patient's ability to manage their disease effectively should be considered within the SCD population. Specifically, neurological complications have been associated with poor coping skills related to disease management which could be due to the difficulties in attention and executive function problems that result from these cognitive and academic deficits (Anie, 2005). Given the complex demands of treatment and cognitive and academic deficits that often are found within the SCD population, the ability to manage their disease can be impaired and potentially lead to further difficulty surrounding health care utilization and adherence to treatment.

### **Health Care Transition from Pediatric to Adult Care**

Due to advancements in disease management over the past 40 years, such as newborn screening and close follow up early in life (Serjeant, 2010), children with SCD are being diagnosed at birth and advances in medical treatment (i.e., penicillin, vaccinations, hydroxyurea therapy) have lead to improved survival and quality of life (Morris, Singer, & Walters, 2006; Steinberg et al., 2003). Consequently, an estimated 90 percent of patients with SCD survive beyond 21 years of age and over 50 percent survive beyond 40 years of age (Castro, Chicoye, Greenberg, Hayned, & Peterson, 1994). As such, the need for adult health care services for patients with SCD and further understanding of health care transition has increased substantially over the years.

Transition refers to the “purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-

orientated health care systems” (Blum et al., 1993). While transition does not refer to the actual movement or “transfer” from pediatric to adult care, it does refer to the process in which parents/caregivers gradually shift disease management skills over to the child (DeWalt & Hink, 2009; Giordano, Petrila, Banion, & Neuenkirchen, 1992; Wysocki et al., 1996). Over time, increasing responsibility in disease management is transferred from the parent/caregiver to the adolescent/emerging adult, resulting in the eventual transition into an adult health care setting. The time period in adolescence/emerging adulthood associated with medical care transitioning is related to a variety of developmental issues, including the transition from high school to college, obtaining employment, and establishing independence from parents/caregivers. Thus, the transition process can be affected by a variety of factors related to developmental adjustments, which may result in a difficult or potentially unsuccessful transition (Pai & Schwartz, 2011). Additionally, research examining perspectives of patients, caregivers, and health care providers has found that factors such as poor communication between patients/families and health care providers and lack of skill development in patients have been noted as potential barriers to successfully transitioning to adult health care, while successful transition was associated with collaborated support in disease management and independent living between the patient, their family, and health care providers (Treadwell, Telfair, Gibson, Johnson, Osunkwo, 2011). The successful transition to adult-focused healthcare providers will set the stage for continuing care by professionals with expertise in SCD, which would likely create the best opportunities for optimal long-term management of the disease.

Furthermore, transition-related research has found that unsuccessful transition is associated with a variety of negative health outcomes in various chronically ill populations (Annunziato et al., 2011; De Beaufort, Jarosz-Chobot, Frank, De Bart, & Deja, 2010; Fredericks et al., 2010; Hauser & Dorn, 1999; Reiss, Gibson, & Walker, 2005; McLaughlin et al., 2008; Telfair, Myers & Drezner, 1994; Wiener, Kohrt, Battles, & Poa, 2011; Wojciechowski, Hurtig, & Dorn, 2002). For instance, Wiener et al. (2011) assessed transitioning among young adults with HIV. These researchers found that only 7% of the patients (ages 18-31 years) actually transferred from pediatric to adult-based care and 71% of the patients were not receiving any HIV care at the time of follow-up, highlighting an unsuccessful transition to adult care. Annunziato et al. (2011) examined the level of understanding in regards to health care management in patients receiving liver transplantation and found that only half of this emerging adult sample (18 years and older) were consistently managing their disease independently, making their own appointments, and understanding insurance issues. Wojciechowski et al. (2002) examined transition in adolescent/emerging adults with SCD and found that patients who maintained follow-up appointments after transfer to adult care demonstrated more efficient disease management; however, most ceased attending follow-up appointments after young adulthood as patients transitioned to adult care. These studies highlight the need for further examination of transition readiness in the young adult population, as unsuccessful transition can result in negative health outcomes.

### **Assessment of Transition**

Recognizing that age does not necessarily translate into successful transition to adult care, experts have recommended that transfer to adult care be based on alternative

metrics, such as a patient's level of independent disease management (Rosen, Blum, Britton, Sawyer, & Siegel, 2003; Reiss et al., 2005). To date, assessment of transition readiness has primarily utilized checklists, often unpublished, that ask respondents to answer "yes" or "no" to questions regarding health-related knowledge. However, these measures often fail to describe the different levels of readiness resulting in acquisition and mastery of the skills. To address these issues, the Transition Readiness Assessment Questionnaire (TRAQ) was developed to assess transition readiness among youth in all stages of the transition process with special healthcare needs (Sawicki et al., 2011).

The TRAQ was developed using data on patients age 16-26 years with a variety of complex health conditions, including cerebral palsy, diabetes, cystic fibrosis, and sickle cell disease. This tool consists of 33 items requiring a respondent to rate the frequency and likelihood to engage in a particular task regarding their health care. The measure is divided into two domains, self-management and self-advocacy. Measuring an individual's level of self-management in regards to their special health care needs can assist providers in understanding how well the patient is able to independently handle the complex responsibilities of their disease (e.g., management of prescription refills, medical payments, and attending appointments). Furthermore, measuring a patient's ability to utilize beneficial resources and advocate independently within the adult health care system (e.g., utilizing necessary community and financial support services and communicating needs to the health care staff) is instrumental in facilitating successful transition. The TRAQ has demonstrated adequate validity and acceptability (Sawicki et al., 2011), and appears to be an acceptable measure for assessing transition readiness within the health care system. However, it is important to consider and further understand

the theoretical foundation of the transition process and the potential influences and outcomes within the health care system.

### **Theoretical Modeling of the Transition Process**

The development and progression of transition is frequently framed within the Diffusion of Innovation Theory (Rogers, 1962). The theory proposes several elements (i.e., innovation, communication channels, time, and social system) that affect an individual's decision to accept a new idea or innovation. The theory suggests that individuals progress through five stages when interpreting and determining the acceptance of the innovation; knowledge, persuasion, decision, implementation, and confirmation when interpreting a new idea or innovation (Figure 1). Therefore, this theory indicates that an individual's knowledge towards the innovation will ultimately influence their decision to accept or reject the new idea. The theory has guided research examining various disease management factors and interventions in both pediatric and adult chronic illness populations including asthma, diabetes, and HIV (Britto, Pandzik, Meeks, & Kotagal, 2006; Ferris, Kuhlthau, Ausiello, Perrin, & Kahn, 2006). In order to understand the origins surrounding a patient's decision to accept or reject the innovation (i.e., managing disease treatment when transitioning to adult care), the examination of potential variables impacting a patient's knowledge is warranted.

### **Health Literacy**

As previously noted, the examination of variables that can affect successful transition to adult care is necessary. One potential variable that may impact an individual's ability to manage his or her disease and utilize the health care system appropriately is health literacy. Health literacy is defined as "the degree to which

individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Nielsen-Bohlman, Panzer, & Kindig, 2004).

An estimated 90 million American adults exhibit limited health literacy (DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004). Individuals with low socioeconomic status, less than high school education, poor English proficiency, black race, and birth outside of the United States appear to be at the greatest risk for limited health literacy (Nielsen-Bohlman et al., 2004; Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman, & Rudd, 2005; Yin, Johnson, Mendelsohn, Abrams, Sanders, & Dreyer, 2009). Consequently, limited health literacy is associated with problems completing medical forms, difficulty understanding instructions for prescription medications, and difficulties comprehending provider instructions (Baker, Parker, Williams, Clark, & Nurss, 1997; Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs American Medical Association, 1999). As such, low health literacy has been associated with higher use of health services and greater health care costs (Baker et al., 1997; Baker, Parker, Williams, & Clark 1998; Baker et al., 2004; Lee, 1999; Weiss & Palmer, 2004). Overall, these findings suggest that health literacy is associated with negative health outcomes and could potentially impact the transition to adult care.

To date, the assessment of health literacy in adolescents/young adults has been minimal (Manganello, 2008). DeWalt and Hink (2009) completed a systematic review examining health literacy and child health outcomes. Findings from this review revealed an inconsistent relationship between impaired health literacy and child health outcomes. For instance, Conwell et al. (2003) investigated adolescent tobacco smoking and found



that low health literacy was significantly related to a greater likelihood of smoking. Further, Davis et al. (2006) found a significant relationship between low health literacy and less knowledge about oral contraceptive pills in adolescents. Conversely, Andrasik et al. (1988) found no relationship between low health literacy and increased frequency of headaches in children with migraine headaches. As such, the relationship between limited health literacy and potential negative health outcomes within the adolescent/young adult population has not been completely delineated, thus necessitating additional research.

### **Health Literacy Assessment**

As health literacy is thought to be a multi-faceted concept composed of an individual's ability to read, comprehend, and take action with health-related materials, measures assessing health literacy need to address these components (Nielsen-Bohlman et al., 2004; Rudd, 2007). To date, a variety of health literacy measures have been developed. For instance, the Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis et al., 1991) and later the adolescent version (REALM-Teen) (Davis et al., 2011) were developed to screen adult and adolescent patients' ability to read common medical words and lay terms for body parts and illnesses. The individual is asked to read the words and is scored if they pronounce the word correctly. The individual's score is then categorized based on reading level (e.g., 3<sup>rd</sup> grade and below, 4<sup>th</sup>-6<sup>th</sup> grade, 7<sup>th</sup>-8<sup>th</sup> grade, 9<sup>th</sup> grade and above). The REALM demonstrated strong test-retest reliability ( $r = .98$ ), inter-rater reliability ( $r = .99$ ), and high positive correlations were found when compared to the Slosson Oral Reading Test Revised (SORT-R) ( $r = .95$ ) and the Peabody Individual Achievement Test-Revised (PIAT-R) ( $r = .94$ ). The REALM-Teen demonstrated excellent internal consistency (Cronbach's  $\alpha$ : .94), strong re-test reliability ( $r = 0.98$ ), and

high criterion validity in correlation with both the Wide Range Achievement Test 3 (WRAT-3) ( $r = 0.83$ ) and the SORT-R ( $r = 0.93$ ) (Davis et al., 2011). Another common measure of health literacy is the Test of Functional Health Literacy (TOFHLA) (Parker, Baker, Williams, & Nurss, 1995) which assesses the functional literacy level of patients using real-life health care materials. For example, individuals are asked to read patient education information, prescription bottle labels, registration forms, and instructions for diagnostic tests. Both reading comprehension and numeracy are assessed using this tool and individuals are categorized as having inadequate, marginal, or functional health literacy. The TOFHLA demonstrated strong reliability (Cronbach's  $\alpha$ : .98) and was significantly correlated to both the REALM ( $r = .84$ ) and the WRAT-R ( $r = .74$ ).

Although these tools assess readability, print literacy, and numeracy (i.e., comprehension of fundamental math skills) these measures have been criticized by the Institute of Medicine (IOM) for primarily focusing on reading skills and state the need for developing health literacy measures that provide a comprehensive assessment (Nielson-Bohlman et al., 2004). Specifically, the IOM calls for the development and testing of innovative measures that additionally include culturally appropriate materials and a broader scope of health literacy assessment beyond readability, such as the use of media and topics more directly and comprehensively related to health care utilization. As a result of these criticisms and call for innovative and comprehensive health literacy assessments, the Health Literacy Skills Instrument (HLSI) was developed as a practical, user-friendly, and comprehensive assessment of health literacy (McCormack et al., 2010). This measure moves beyond traditional health literacy assessments testing print literacy to also examining print literacy as well as non-print stimuli, oral information, and

internet-based information-seeking skills (McCormack et al., 2010). The domains explored within this measure include health-related issues across the life span for health promotion and disease prevention (e.g., stroke, nutrition, health care maintenance and treatment, and health system navigation) (McCormack et al., 2010). All of these domains serve as very important measurements to consider when exploring transition within a chronically-ill transition population.

### **Need for Assessment of Transition Readiness and Health Literacy within SCD**

As SCD is associated with various complications requiring medical care from multiple subspecialties from childhood through adulthood, the transition to adult care is instrumental within this population. Furthermore, individuals with SCD frequently come from low socio-economic backgrounds and are predominantly of Black race (Chau, Thampi, & Wright, 2010; Radcliffe, Barakat, & Boyd, 2006), both characteristics known to be associated with risk for limited health literacy, which may further complicate the transition to adult care. Health literacy, therefore, deserves careful attention as a potentially important mediator of successful transition to adult care in SCD.

### **Objective**

The following study aimed to evaluate transition readiness and health literacy of adolescents/emerging adults with SCD as well as the relationship between these two variables. The current study is supported by the Diffusions of Innovation Theory, which suggests an individual's knowledge (i.e., transition readiness and health literacy) will ultimately affect their ability to manage this disease following transition to adult care. First, this study compared transition readiness ratings of adolescents/emerging adults with SCD to normative data from chronically-ill peers. It was hypothesized that

adolescents/emerging adults with SCD would demonstrate poorer transition readiness ratings than their chronically-ill peers, given the cognitive and academic deficits often found in patients with SCD. Second, this study compared health literacy ratings of adolescents/emerging adults with SCD to overall healthy and similar race healthy normative data. It was hypothesized that adolescents/emerging adults with SCD would demonstrate reduced health literacy relative to overall healthy norms and healthy similar race norms, given that factors associated with low health literacy are more common within patients with SCD and the high prevalence of cognitive and academic deficits in the SCD population. Third, the relationship between transition readiness and health literacy in adolescents/emerging adults with SCD was examined. It was hypothesized that individuals with limited health literacy would demonstrate poorer transition readiness. Lastly, the study included an exploratory aim to examine transition readiness and health literacy performance differences between patients receiving pediatric or adult care at the time of the study.

## **Method**

### **Participants**

Thirty adolescent/emerging adult patients with SCD, ages 16-21 years, were recruited from Children's Hospital of Wisconsin and Froedtert Memorial Lutheran Hospital in Milwaukee, Wisconsin. To maximize the representativeness of the sample, participants were not excluded based on factors such as frequent hospitalizations for vaso-occlusive painful episodes, history of stroke, or current requirement of chronic therapy (e.g., routine blood transfusions or hydroxyurea therapy). Additionally, adult patients who had not yet transitioned to adult care were eligible for the study as well. As such, participants recruited in the pediatric clinic ranged from 16 to 21 years of age, while the participant age range was 18 to 21 years within the adult health care setting. Patients were recruited during both their visits for routine care within the clinic and during hospital admissions to capture the most representative sample.

### **Inclusion/Exclusion Criteria**

Participants were included in the sample if they were between the ages of 16 and 21 years of age and had a diagnosis of SCD (any genotype). Participants were excluded if they were non-English speaking or experiencing acute disease complications at the time of the assessment (e.g. pain severity levels greater than 7/10 or were experiencing significant medical complication).

### **Procedure**

Potential participants were identified through electronic scheduling and medical records and were approached for recruitment if patients were in the appropriate age range. The primary recruiters were the principal investigator and a research assistant that

recruited clinic patients weekly during primary clinic visit hours, while potential inpatient participants were approached during time of their hospitalization. Researchers obtained informed consent and provided a standard introduction to the study and instructions for the measures. Participants initially completed a demographic questionnaire. Participants then completed the Transition Readiness Assessment Questionnaire (TRAQ) and the Health Literacy Skills Instrument-Short Form (HLSI-SF). The TRAQ and HLSI-SF was administered in alternating order throughout the study to control for possible order effects.

### **Measures**

***Demographic/Health Information.*** A demographic/health questionnaire was completed to document demographic and medical variables, such as age, gender, sickle cell genotype, and current pain severity. Pain intensity was measured using the Numeric Rating Scale (NRS) which has been commonly used in both pediatric and adult populations (von Baeyer et al., 2009) and specifically within the SCD population (Jacob et al., 2005). The NRS has demonstrated good evidence of acceptability, reliability, and validity in assessing pain intensity (Bijur, Latimer, & Gallagher, 2003; Jensen, Karoly, & Braver, 1986; Williamson & Hoggart, 2005). The NRS asks the patient to choose a pain score on a 10 point anchored scale, ranging from 0 (no pain) to 10 (worst pain possible).

***Transition Readiness.*** The Transition Readiness Assessment Questionnaire (TRAQ; Sawicki et al., 2011) was given to assess transition readiness in adolescents/emerging adults with SCD. The TRAQ was developed for individuals between ages 16 and 26 with special health care needs to measure readiness for transition from a pediatric to an adult health care setting. The measure was assessed among several

populations with complex health conditions (Sawicki et al., 2011). The most common diagnoses were cystic fibrosis (40%), sickle cell disease (8%), diabetes (7%), and cerebral palsy (5%). Additionally, a primary diagnosis of cognitive impairment was found in 9% of the overall sample. The TRAQ consists of 33 items related to the optimal process of transition and requires the participant to rate the level at which they utilize each item in the transition process on a 0-5 rating scale (0 = Not needed for my care; 1 = No, I do not know how, 2 = No, I do not know how but I want to learn, 3 = No, but I am learning to do this, 4 = Yes, I have started doing this, 5 = Yes, I always do this when I need to). Two composite domains are calculated based on the participant ratings: Self-Management and Self-Advocacy. Scores were computed by summing the responses for all items on that scale and then dividing by the number of items. Additionally, a response of 0 was considered not applicable and was not included in the total score. The Self-Management domain covers skills needed for management of the participant's chronic medical condition (e.g., "Do you fill a prescription when you need to?"). The Self-Advocacy domain covers skills pertaining to participant self-advocacy and health care utilization (e.g., "Do you request the accommodations and received the support you need at school or work?"). The two domains are moderately correlated ( $r = .46$ ,  $p < .0001$ ) and have high internal consistency (Cronbach's  $\alpha = .92$  for Self-Management and Cronbach's  $\alpha = .82$  for Self-Advocacy) (Sawicki et al., 2011).

***Health Literacy.*** The Health Literacy Skills Instrument-Short Form (HLSI-SF) was given to assess health literacy in young adult participants with SCD (McCormack et al., 2010). The HLSI-SF is a computer-based test that measures print literacy, oral literacy, and Internet-based information-seeking skills. The HLSI-SF consists of 10

questions covering five domains within health literacy; print-prose ( $n = 2$ ), print-document ( $n = 3$ ), print-quantitative ( $n = 2$ ), Internet ( $n = 1$ ), and oral ( $n = 2$ ). Instructions and an introduction to the test automatically displayed electronically before the participant began the test, which asked participants to answer 10 questions on information related to general health. Print-prose questions included information regarding cholesterol (e.g., provided information in text format about low density lipoprotein and high density lipoprotein) and stroke (e.g., provided an electronic pamphlet on the signs to identify a stroke). Print-document questions included information regarding hospital navigation using maps (e.g., provided electronic image of a hospital map), the use of medication recording (e.g., provided electronic image of a medication record form), and food portion control (e.g., provided information in text format on food serving sizes for various foods). Print-quantitative questions included information regarding the use of nutrition labels (e.g., provided electronic image of nutrition label) and prostate cancer (e.g., provided electronic bar graph comparing the number of men that die from prostate cancer to other diseases). Oral questions consisted of information on hospital telephone recording instructions (e.g., provided audio clip of hospital telephone recording message). Internet questions included information regarding calories (e.g., provided link to interactive web site that identifies the amount of calories burned for various activities customized to weight and height) and exercise (e.g., provided a link to an instructional video clip about the appropriate movements of a lung exercise). Intended advantages of the measure were the use of health-related interactive stimuli for the participant and coverage of a breadth of general health information.



Administration of the HLSI-SF takes approximately 15 minutes. The measure has been validated for use in participants 18 years and older and utilized a racially diverse validation sample. Although the ages of our current sample (16-21 years old) range beyond that of the validated measure (18 and older), health literacy measures within youth are limited and are still in development (Manganello, 2008). Therefore, the current measure appears to be the best available measurement at this time for adolescents/emerging young adults and health literacy results should be interpreted as preliminary findings within this age group. The HLSI-SF demonstrated adequate internal consistency (Cronbach's  $\alpha = .70$ ) and correct responses range from 24% to 90% with an overall average of 67% ( $SD = 23\%$ ) items answered correctly in the norming sample (McComack et al., 2010). The HLSI-SF correlated highly with the long form of the HLSI ( $r = .90$ ), which suggests reliability of the brief version (McCormack et al., 2010). Cutoffs were empirically derived from the HLSI-SF including adequate literacy for scores of 70% correct or higher and inadequate literacy for scores of 60% or below correct (McCormack et al., 2010). The HLSI-SF had a moderate correlation with the TOFHLA ( $r = 0.36$ ), which was anticipated given the measure assessed constructs beyond readability to additionally include interactive stimuli such as oral, document, and internet-based questions.

### **Study Aims**

*Aim I:* This study aimed to describe and compare transition readiness in adolescent/emerging adults with SCD to chronically-ill norms. To achieve this aim, the TRAQ was administered to adolescents/emerging adults with SCD. Norms from the TRAQ were used for comparison (Sawicki et al., 2011). It was hypothesized that

adolescents/emerging adults with SCD would have lower transition readiness than their chronically ill peers.

***Aim II:*** This study aimed to describe and compare the health literacy in adolescent/emerging adults with SCD to established healthy norms and healthy Black race norms from the HLSI-SF. To achieve this aim, the HLSI-SF was administered to adolescents/emerging adults with SCD. It was hypothesized that adolescents/emerging adults with SCD would demonstrate lower health literacy than both overall norms and physically healthy Black race norms.

***Aim III:*** This study aimed to identify the relationship between health literacy and transition readiness in adolescents/emerging adults with SCD. It was hypothesized that health literacy would positively correlate with transition readiness.

***Exploratory Aim:*** The study aimed to explore potential differences in both transition readiness and health literacy as a function of patients' health care setting (i.e., pediatric or adult) at the time of the study.

### **Data Analysis**

Demographic/descriptive data are presented as means and standard deviations, when appropriate. A Pearson's correlation was used to examine the relationship between age and both transition readiness and health literacy performances. Independent sample t-tests were used to examine the differences gender differences in both transition readiness and health literacy performances. Internal consistency reliability was tested using Cronbach's alpha for the TRAQ measure. The Guttman Scale (Guttman, 1950) was used for the HLSI-SF to measure scalability. Scalability was measured by rank ordering questions by difficulty (based on percentage answered correctly) and identifying

the highest difficulty question that was answered correctly by each participant within that scale.

One sample t-tests were completed to compare transition readiness and health literacy scores to reference means. A Pearson's correlation was used to assess the relationship between transition readiness and health literacy. Exploratory analyses were performed using independent-sample t-tests to examine differences between patient's setting of health care (i.e., pediatric or adult) at the time of their study and both transition readiness and health literacy scores.

## Results

A total of 34 participants were approached for the study and 30 participants completed the study (Table 1). As the principal investigator and research assistant were the two recruiters and were not based on site, the researchers were notified when patients within the target age range (16-21) were scheduled for clinic during the time periods that were staffed for recruiting or had been hospitalized. Reasons for not completing the study included declining to participate ( $n = 2$ ) and high levels of pain reported by the physician ( $n = 2$ ). Gender was split equally (female:  $n = 15$ , 50%) and ages of the participants ranged from 16 to 21 years ( $M = 18.63$ ,  $SD = 1.77$ ). Furthermore, no significant differences were found between age and gender ( $p > .163$ ). Nearly half of the participants ( $n = 14$ ) reported having pain at the time of the study, with an average rating of 5.07 out of a 0-10 range among participants reporting pain. Fewer than half of the participants ( $n = 12$ ) had transferred to adult care, while the remainder ( $n = 18$ ) were still receiving care in a pediatric setting. Ages of patients that were seen in pediatric care ranged from 16 to 18 years ( $n = 12$ ), while patients seen in adult care ranged from 19 to 21 years ( $n = 12$ ), and patients that were eligible to transfer but were still receiving pediatric care (due to services in adult health care setting were not available at this time in recruitment) ranged from 19 to 21 years-old ( $n = 6$ ). Frequencies of demographic characteristics can be found in Table 1.

### Transition Readiness

The TRAQ consists of two domains: Self-Management and Self-Advocacy. Responses in the Self-Management domain were distributed in a moderately skewed manner (Dover, 1979; moment coefficient of skewness =  $-.567$ , SEskewness =  $.427$ ) and

spanned the entire range of possible responses, from 1-5 ( $M = 3.29$ ,  $SD = 0.94$ ). Within the Self-Advocacy domain, responses were distributed approximately symmetrically (moment coefficient of skewness =  $-.351$ ,  $SE_{skewness} = .427$ ) and spanned a more limited range (2-5) of the possible responses, ( $M = 3.80$ ,  $SD = 0.60$ ). The reliability for the 16-item Self-Management domain was  $\alpha = .857$  and the reliability for the 13-item Self-Advocacy domain was  $\alpha = .633$ . However, dropping two items for the Self-Advocacy domain (i.e., “Do you help plan or prepare meals/food” and “Do you keep home/room clean or clean-up after meals”) increased reliability to the acceptable level ( $\alpha = .708$ ).

Therefore the adjusted Self-Advocacy domain included 11 items ( $M = 3.74$ ;  $SD = .68$ ). In regards to age, results found that older patients’ scores were significantly higher in both Self-Management ( $r = .448$ ;  $p < .013$ ) and Self-Advocacy ( $r = .488$ ;  $p < .006$ ) domains of transition readiness. In regards to gender, females ( $M = 3.90$ ;  $SD = .38$ ) had significantly higher scores than males ( $M = 3.60$ ;  $SD = .85$ ) in the Self-Management domain ( $t(28) = 2.340$ ;  $p < .027$ ). Additionally, significant gender differences were found between females ( $M = 3.97$ ;  $SD = .71$ ) and males ( $M = 3.62$ ;  $SD = .18$ ) within the Self-Advocacy domain ( $t(28) = 1.303$ ;  $p = .007$ ).

**Aim I:** Using a one-sample t-test, Self-Management scores within patients with SCD were not significantly different than the chronically-ill norms. Similarly, the Self-Advocacy domain scores in patients with SCD were not significantly different than chronically-ill norms. As such, mean score differences in both Self-Management ( $MD = -.232$ ) and Self-Advocacy ( $MD = -.062$ ) domains of transition readiness did not

demonstrate significant discrepancies between patients with SCD and chronically-ill norms. Results for these findings can be found in Table 2.

### **Health Literacy**

The scores of the HLSI-SF were skewed (Dover 1979; moment coefficient of skewness = -1.112, SEskewness = .427) and spanned the entire range of possible responses from 0-100. The Guttman order demonstrated an 85% fit on the HLSI-SF, with only 45 participant responses out of order from the overall 300 responses analyzed. The HLSI-SF provided cut-off scores to identify individuals that displayed adequate (70-100% correct) and inadequate (<60% correct) health literacy. Using these cut-off score, our results found that among SCD adolescent/emerging adult patients 53.3% demonstrated adequate health literacy ( $n = 16$ ) and 46.7% demonstrated inadequate health literacy ( $n = 14$ ). There was a significant positive relationship between age and health literacy ( $r = .372$ ;  $p < .043$ ). Females ( $M = 71.33$ ;  $SD = 18.07$ ) achieved significantly higher scores than males ( $M = 63.09$ ;  $SD = 19.45$ ) in health literacy ( $t(28) = 2.135$ ;  $p < .042$ ).

*Aim II:* As shown in Table 2, health literacy was found to be similar in patients with SCD relative to overall healthy peers. As such, differences in mean scores between patients with SCD and overall healthy peers ( $MD = .910$ ) were not significantly discrepant. However, patients with SCD demonstrated significantly higher health literacy than healthy Black peers. Therefore, differences in mean scores between patients with SCD and health Black peers ( $MD = -10.30$ ) displayed significant discrepancies. Detailed results for these findings can be found in Table 2.

### **Impact of Health Literacy on Transition Readiness**

***Aim III:*** In order to explore the relationship between health literacy and transition readiness, a Pearson's correlation was performed. Results indicated that health literacy was not significantly associated with Self-Management ( $r = .017$ ;  $p = .929$ ) or Self-Advocacy ( $r = .283$ ;  $p = .129$ ) domains of transition readiness. The effect size for the relationship with Self-Advocacy suggests that there may be a small to medium effect that would be shown to be significant with an adequately powered study.

### **Performance within Pediatric and Adult Samples**

***Exploratory Aim:*** In order to identify if the health care setting (i.e., pediatric or adult) the patient was receiving services at the time of the study had an effect on either transition readiness or health literacy performance; independent-sample t-tests were conducted. In regards to transition readiness, patients that were receiving treatment in an adult care setting scored significantly higher than patients receiving pediatric care in both Self-Management and Self-Advocacy domains (Table 3). In regards to health literacy, patients receiving adult care did not perform significantly differently than patients receiving pediatric care (Table 3).

## **Discussion**

The goal of this study was to examine transition readiness and health literacy among adolescents/emerging adult patients with sickle cell disease. Results may have implications for understanding the associations between health literacy and transition readiness in optimizing the transition experiences for this vulnerable group.

### **Transition Readiness**

Aim I led to the hypothesis that adolescents/emerging adults with SCD would demonstrate significantly lower transition readiness than patients in the general chronic illness population. Results indicated that SCD patients did not significantly differ in transition readiness skills than the overall chronically ill population. There is limited literature to date examining the impact of transition readiness and its comparison to different chronically ill populations and specifically difference within the SCD population. While there is considerable reason to think that health literacy could affect the success of transition to adult care, we are in need of more reliable and disease-specific measures in both areas. There is a pressing need for further investigation in this area. Furthermore, older age and patients receiving care in an adult health care setting was associated with higher transition readiness, which is consistent with the chronically ill norm comparisons (Sawicki et al., 2011) and with previous literature (Annunziato et al., 2011; Wojciechowski et al., 2002). Additionally, females were found to have higher self-management and self-advocacy skills within transition readiness than males. In the study by Sawicki et al. (2011), which included participants with a variety of chronic illnesses, females were found to have higher self-management skills than males. However, no



previous literature has found significant gender differences in self-advocacy skills related to transition readiness.

### **Health Literacy**

Aim II led to the hypothesis that adolescents/emerging adults with SCD would demonstrate lower health literacy than both overall healthy peers and healthy black peers. The results found that SCD patients demonstrated significantly higher health literacy than healthy black peers. However, SCD patients did not display significantly different health literacy scores than overall healthy peers. Previous literature found Black race to be among one the most common risk factors of low health literacy (Paasche-Orlow et al., 2005; Yin et al., 2009). Given that patients with SCD are predominantly of Black race and demonstrated significantly higher health literacy than healthy Black peers, these findings suggest that managing a life-long chronic illness may increase health literacy skills. Overall, nearly half of SCD patients demonstrated inadequate health literacy. However, previous studies (DeWalt et al., 2004), including the comparison study sample (McCormick et al., 2010) have found similar prevalence of limited health literacy within the general population, which demonstrates that the SCD population is demonstrating relatively normative health literacy weaknesses. Therefore, research further examining the impact of health literacy on patients with SCD is needed. Additionally, significantly higher health literacy was found among older patients and female patients. As such, future research should consider the relationship of these variables on patient's health literacy.

### **The Impact of Health Literacy on Transition Readiness**

Aim III hypothesized that health literacy and transition readiness would be significantly related. Health literacy was not found to be significantly correlated with transition readiness. This finding suggests that although health literacy is considered low in the majority of SCD patients, it does not appear to be a significant predictor of transition readiness at this time. As such, there are many potential factors to consider such as the ability to measure the construct of health literacy. Given that health literacy is a developing construct (Nielsen-Bohlman, 2004), it is important to consider if current health literacy measures are accurately assessing the aspects of health literacy that are most relevant to successful transitions for SCD. Furthermore, future health literacy measures should consider disease-specific factors within the SCD population in order to assess the skills necessary and relevant to managing such a complex disease.

#### **Exploratory Analysis - Pediatric vs. Adult Care Performance**

Both transition readiness and health literacy scores were compared between patients receiving pediatric care and patients receiving adult care at the time of the study. In regards to transition readiness, patients receiving adult care displayed significantly higher transition readiness than patients still receiving pediatric care. Additionally, as mentioned previously, as patients get older they demonstrate higher transition readiness. Furthermore, results examining the relationship of these patient's transition readiness skills could be limited due to the small sample size examined and studies using assessing a larger SCD population is needed to fully understand these findings. However, the current findings did indicate that increased transition readiness in adult health care settings could likely be due to older age. Furthermore, the current SCD sample represents patients who sought and received health care services. Therefore, these

findings additionally support previous literature associated with improved disease management among both older patients and patients seeking adult care services (Annunziato et al., 2011; Wojciechowski et al., 2002). However, patients receiving pediatric health care services demonstrated similar health literacy compared to patients receiving adult health care services. This suggests that health literacy skills remain fairly consistent throughout health care transitions within the SCD population.

### **Future Directions**

The results from the current study indicate that among patients recruited from hospital settings, adolescents and emerging adults with SCD very much resemble general chronic illness populations on transition readiness. However, research on the relationship between transition readiness and clinical outcomes in SCD is limited. Therefore, future research examining the different levels of transition readiness among patients with SCD is needed to further understand the implications of transition barriers and deficits among this population. Furthermore, results found that older patients and patients receiving adult care services demonstrated significantly higher transition readiness overall and female patients demonstrated significantly higher self-advocacy than male patients. Therefore, future research should further examine potential factors and interventions targeted towards these variables influencing higher transition readiness (e.g., effects of age or gender).

The results from this study also suggest that health literacy is significantly higher in patients with SCD compared to healthy Black peers. Future research should examine the mechanisms through which experiences with chronic illness may impact health literacy, and how health literacy may affect functional outcomes. However, nearly half of

the adolescents/emerging adults with SCD demonstrated inadequate health literacy, which is further supported by similar results found in the healthy peer comparisons. Therefore, future research should examine the potential barriers that may be hindering health literacy.

Additionally, although health literacy was not significantly associated with transition readiness, there may be other aspects of health that health literacy could be affecting, such as general health care and physical well-being. Therefore, further understanding of various health factors that could be affected by health literacy among patients with SCD is needed and would benefit health care professionals in their knowledge and understanding for future work. Furthermore, higher health literacy was found among older patients and female patients. Therefore, future research should examine the potential factors attributing to decreased health literacy and effective interventions targeting those potential factors that place patients at risk for impaired health literacy.

Lastly, patients with SCD receiving adult care display significantly higher transition readiness than patients with SCD receiving pediatric care. Furthermore, there is minimal understanding on the transition readiness of individuals who do not continue SCD care into adulthood. Therefore, future studies should examine transition readiness differences across the entire populations of individuals with SCD such as different types of care (e.g., integrated or generalist), disease severity (e.g., minimal to complex medical complications), and individuals not receiving health care services. As such, further understanding of the differences will benefit clinicians in improving the understanding of factors related to disease management and transition to adult health care. Additionally,

the small sample size could be potentially contributing to limited results. Therefore, future research should examine factors within transition readiness skills and health literacy in a larger SCD population sample in order to attain the full potential of the results.

### **Limitations**

There are several limitations to this study that should be considered. First, the sample was very small which may have hindered potentially significant findings from being revealed within the current study. Secondly, the sample primarily included patients attending clinic visits and only included a small amount of individuals receiving inpatient care. In addition, among patients who were terminated from pediatric care, the sample only included individuals who had completed their transfer and were currently receiving adult care. Therefore, the study did not include individuals who did not complete their transfer to adult care, which may have limited the range and full understanding of the results. Furthermore, the current measure of transition readiness did not include standard interpretative scores of readiness to transition (e.g., severe, moderate, not severe). Therefore, the lack of significant differences found between the SCD population and the general chronic illness population may have been due to minimal understanding of the different levels of transition between chronic illness populations. Lastly, the measurement of health literacy is still a developing construct that has not established a strong reliable and valid measure to this date (Nielson-Bohlman et al., 2004). Therefore, the measurement chosen to assess health literacy in the current study has demonstrated inconsistencies in reliability that could have potentially limited the findings. However, compared to the available measurements of health literacy, the HLSI-SF appeared to

provide the most comprehensive assessment of skills handling health information beyond print literacy. Future research should examine and continue to develop a more reliable and valid measurement of health literacy. Furthermore, assessment of health literacy within the SCD population may benefit from a disease specific measure to ensure assessment of relevant and necessary skills within the domain of health literacy.

### **Implications for Practice**

The results from this study suggest that patients with SCD demonstrate similar transition readiness skills as other chronically-ill patients. Given the limited discrepancies, it is possible that transition readiness is not capturing disease specific difficulties. As such, health care professionals should continue to assess the specific needs and factors that attribute to their patients level of transition readiness. Furthermore, the results from this study suggest that although SCD patients demonstrate significantly higher health literacy than healthy Black peers, they may still be showing population-normative weaknesses in health literacy. The clinical relevance of this specific measure of health literacy, and particularly the specific cut-off scores for adequate knowledge are yet to be proven. Health literacy is still a developing construct that should be considered carefully. Therefore, as health care professionals continue to assess patient's health literacy skills, it is important they consider disease specific factors that could contribute to their limited health literacy and potentially provide a more accurate and comprehensive assessment

### **Conclusion**

This study demonstrated that patients recruited from hospital settings demonstrate similar transition readiness in both patients with SCD and across multiple chronic

illnesses. Additionally, SCD patients receiving adult care services demonstrate higher levels of transition readiness than patients receiving pediatric care. Therefore, future studies should examine both differences in alternative recruitment methods and specific factors associated to transition readiness skills among pediatric and adult care settings. Furthermore, adolescents/emerging adults with SCD demonstrate similar health literacy as overall healthy peers and significantly higher health literacy than healthy Black peers. It is, at one level, not surprising that exposure to medical care and the demands of SCD treatment over developmental time would lead to better skills in health literacy. However, we must keep in mind that this is a population with specific neurological and cognitive risks that might work against the development of these skills. Further work should be directed to this area, as the identification of specific strengths in this area may be an important finding for professionals to be aware of. Although health literacy did not demonstrate a direct relationship to transition readiness, there are several potential weaknesses of this study that should be addressed (e.g., inadequate power, measurement concerns including disease-specific relevance) before we dismiss this possible connection.

Overall, the current study found that patients with SCD demonstrate similar transition readiness as other chronic illness populations, health literacy skills similar to overall healthy peers and significantly higher than healthy black peers and that health literacy has not yet been found to demonstrate a direct influence on transition readiness. Additionally, older patients receiving adult health care services appear to demonstrate higher transition readiness. These findings suggest the need for future research examining specific factors and barriers within transition readiness and health literacy that are

attributing to decreased SCD management and ultimately affect a SCD patient's ability to transition to adult care.



Table 1  
*Demographic Characteristics of Participants (N=30)*

Characteristics	<i>n</i>	%
<b>Age</b>		
16	6	20
17	2	6.7
18	4	13.3
19	7	23.3
20	4	13.3
21	7	23.3
<b>Health Care Setting</b>		
Pediatric	18	60
Adult	12	40
<b>Gender</b>		
Male	15	50
Female	15	50
<b>Current Pain</b>		
Yes	14	46.7
No	16	53.3

Table 2  
*Mean, Standard Deviation, and One Sample T-Test Comparisons*

	<u>SCD Sample</u>		<u>Normative Sample</u>		t	df	p
	M	SD	M	SD			
Transition Readiness (TRAQ) ( <i>n</i> = 30)							
Self-Management	3.28	.938	3.51	1.01	1.360	29	.184
Self-Advocacy	3.80	.592	3.86	0.74	.571	29	.573
Health Literacy (HLSI-SF) ( <i>n</i> = 30)							
Overall Comparison	--	--	66.30	N/A	.263	29	.794
Race-Based Comparison	--	--	53.00	N/A	4.114	29	.000*

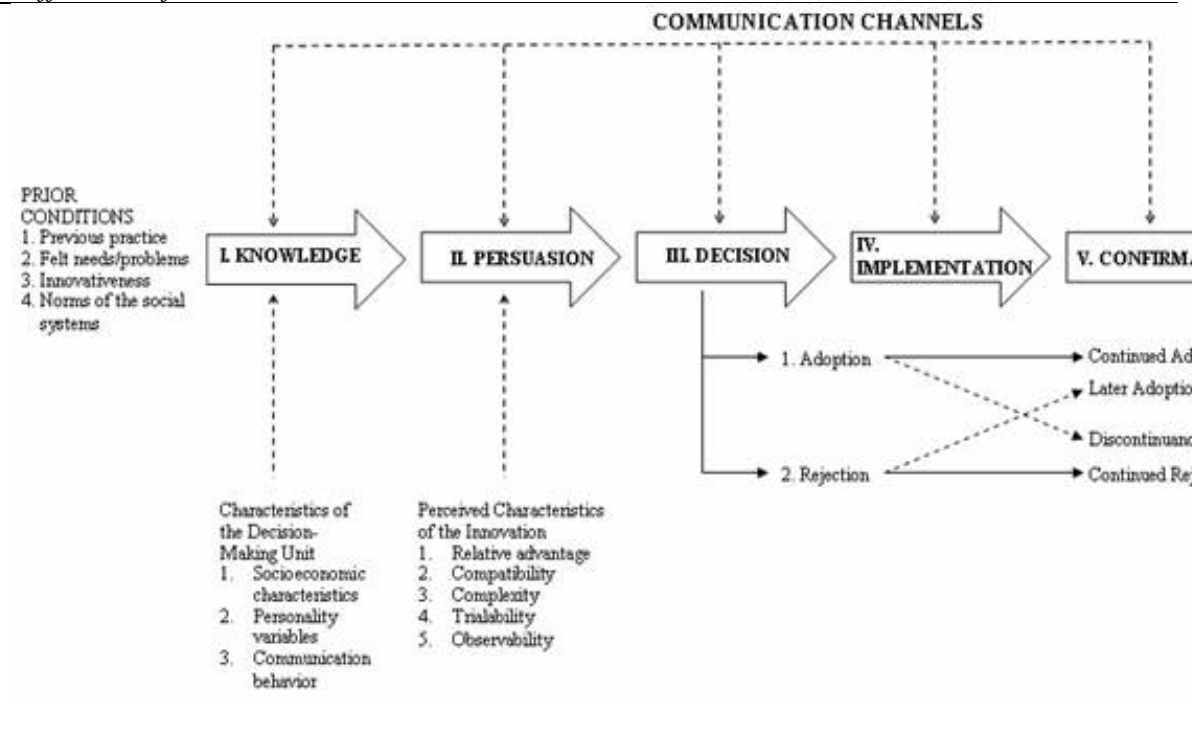
*Note:* TRAQ Scores range from 1-5, HLSI-SF scores range from 0-100, and \* =  $p < .05$

Table 3  
*Independent Sample T-Test Comparisons in Health Care Settings*

	<u>Pediatric Care (n=18)</u>		<u>Adult Care (n=12)</u>		t	df	p
	M	SD	M	SD			
Transition Readiness (TRAQ)							
Self-Management	2.93	.984	3.79	.585	2.708	28	.011*
Self-Advocacy	3.61	.617	4.08	.442	2.247	28	.033*
Health Literacy (HLSI-SF)	65.91	21.16	69.17	15.64	.456	28	.652

*Note:* TRAQ Scores range from 1-5, HLSI-SF scores range from 0-100, and \* =  $p < .05$

Figure 1  
*Diffusions of Innovation Model*



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