



## Health Literacy in Adolescents With Sickle Cell Disease



Elizabeth L. Perry, PhD, RN<sup>a,\*</sup>, Patricia A. Carter, PhD, RN, CNS<sup>a</sup>, Heather A. Becker, PhD<sup>a</sup>,  
Alexandra A. Garcia, PhD, RN<sup>a</sup>, Michael Mackert, PhD<sup>b</sup>, Karen E. Johnson, PhD, RN<sup>a</sup>

<sup>a</sup> The University of Texas at Austin, School of Nursing, 1710 Red River Street, Austin, TX 78701, USA

<sup>b</sup> The University of Texas at Austin, Stan Richards School of Advertising and Public Relations, 300 West Dean Keeton, A1200, Austin, TX 78712, USA

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### ABSTRACT

**Purpose:** To evaluate health literacy in a cohort of 75 adolescents with sickle cell disease (SCD).

**Design and Methods:** This cross-sectional, descriptive correlational study included assessment of demographic measures and appraisal of data resulting from completion of the REALM-Teen and Newest Vital Sign (NVS) instruments by 75 Black, non-Hispanic adolescents with SCD. Convenience sampling was utilized. Inclusion criteria were a diagnosis of one of the four primary genotypes of SCD and age 10–19 years.

**Results:** Thirty-seven males and 38 females were recruited for the study. Their mean age was 14.7 years (SD = 2.2; range 8.1). Their grade level ranged from 4 to 12 (mean 8.7; SD = 2.2). Scores on the REALM-Teen ranged from 12 to 66 (mean 53.7; SD = 12.8). Scores on the NVS ranged from 0 to 6 (mean 2.37; SD = 1.33). These health literacy scores were lower using both the REALM-Teen and the NVS instruments when compared to scores in all healthy adolescents and adults. Current grade level and health literacy scores showed a moderately high positive correlation ( $r = 0.52, p < 0.01$ ). Health literacy scores were also significantly positively correlated with age ( $r = 0.49, p < 0.01$ ) and income ( $r = 0.37, p < 0.01$ ).

**Conclusions:** Health literacy in adolescents with SCD is suboptimal. Future research should include identifying facilitators and barriers to health literacy levels in a larger cohort of adolescents with SCD.

**Practice Implications:** Health literacy is a potential facilitator of successful health outcomes for all adolescents. This study lays a solid foundation for future adolescent health literacy initiatives.

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### Purpose

Approximately five and a half million children in the U.S. are living with a chronic illness, including HIV, sickle cell disease, asthma and diabetes (Centers for Disease Control and Prevention, 2011; National Center for Healthcare Statistics, 2011). It is estimated that 90% of these children will now live until at least the age of 20; thus, most of these children will be transferred from the care of a pediatrician to an adult health provider sometime during their late adolescent years (Blum, 1995). This transfer of care from pediatric services to adult services in patients with chronic illness is associated with increased morbidity and mortality for these patients (Brousseau, Owens, Mosso, Panepinto, & Steiner, 2010; Cadario et al., 2009; Debaun & Telfair, 2012).

The challenges of transitioning children with chronic illness from pediatric care to adult care are well described in patients with sickle

cell disease (SCD) (Debaun & Telfair, 2012; Hankins et al., 2012; Wills et al., 2010). Due to advancements in medicine, SCD is no longer only affecting children; but, instead, it is now also affecting a substantial number of adults. In fact, between 94% and 98% of children with all genotypes of SCD are now living to the age of 18 and beyond (Quinn, Rogers, McCavit, & Buchanan, 2010). However, the literature shows that after patients with SCD are transferred from pediatric care to adult care, significant morbidity and mortality occurs. For example, from 2005 to 2006, the highest rate of acute care encounters and rehospitalizations among patients with SCD occurred in patients between the ages of 18–30 years of age (Brousseau et al., 2010). In addition, recent analysis of The Dallas Newborn Cohort (a newborn inception cohort comprised of 940 participants followed for 8857 patient-years) showed that 94% of Cohort patients are now living to be 18 years of age or older (an increase from 85.6% in 2004). However, the only recent deaths in the cohort ( $N = 7$ ) occurred within 1.8 years after transfer of care from pediatric care to adult care (Median = 1.2 years; Range = 0.2–5.3 years) (Quinn et al., 2010).

Many factors may influence the success or failure of this transition, including: a) most patients are publically insured, leading to significant health disparities; b) patients with SCD have a high incidence of cognitive deficits; c) patients with SCD lack a medical home once

\* Corresponding author.

E-mail addresses: Elizabeth\_perry@baylor.edu (E.L. Perry),

pcarter@mail.nur.utexas.edu (P.A. Carter), hbecker@mail.nur.utexas.edu (H.A. Becker),

agarcia@mail.nur.utexas.edu (A.A. Garcia), mackert@utexas.edu (M. Mackert),

kjohnson@mail.nur.utexas.edu (K.E. Johnson).

<sup>1</sup> Baylor University, Louise Herrington School of Nursing, 3700 Worth Street, Dallas, TX 75246, USA.

transition is made (Debaun & Telfair, 2012; Hemker, Brousseau, Yan, Hoffmann, & Panepinto, 2011; Mvundura, Amendah, Kavanagh, Sprinz, & Grosse, 2009; Panepinto, Owens, Mosso, Steiner, & Brousseau, 2012). One proposed hypothesis is that health literacy plays a role in the outcomes related to transition of children from pediatric to adult health care. If patients with chronic illness have higher health literacy as adolescents, it is postulated that they are more likely to have better health outcomes during and after transition.

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” (Ratzan & Parker, 2000). Numeracy is an associated concept and is defined as “the ability to use numbers and mathematical concepts” (Weiss et al., 2005, p. 515). Higher health literacy and numeracy are associated with higher levels of health knowledge, more positive health behaviors, and improved clinical outcomes in adults; whereas low adult health literacy contributes to between \$106 and \$236 billion in U.S. health expenditures annually (Kutner, Greenberg, Jin, Paulsen, & White, 2006). The relationships between improved health outcomes related to high health literacy in pediatric populations is beginning to surface, however, significant gaps still remain (Cheng, Dreyer, & Jenkins, 2009; Driessnack, Chung, Perkhounkova, & Hein, 2014; Jang & Kim, 2015; Manganello, DeVellis, Davis, & Schottler-Thal, 2015; Patel, Ferris, & Rak, 2016; Sanders, Federico, Klass, Abrams, & Dreyer, 2009; Warsh, Chari, Badaczewski, Hossain, & Sharif, 2014).

The purpose of this study was to describe the factors influencing facilitators and barriers of health literacy levels in adolescents with SCD. Specifically, the research question was “what is the relationship among age, gender, current grade level, annual household income, parental education level, number of annual healthcare encounters and differing levels of health literacy in adolescents with SCD?”

## Design and Methods

This study used a descriptive, correlational cross-sectional design to explore the facilitators and barriers to health literacy levels in adolescents with sickle cell disease (SCD). A framework for studying adolescent health literacy was developed by Manganello and is named the Adolescent Health Literacy Model (Manganello, 2008). This model was used for this project to help conceptually and operationally define variables. Please see Fig. 1 for a graphic of the original model by Manganello (2008). The section of the model that was used for this study has been outlined below.

Because this was an exploratory study, only “Individual Traits” and their relationships to health literacy were evaluated; thus, the model

was adapted for this study (please see Fig. 2 for the adapted model). Therefore, based on the “Individual Traits” construct, age, gender, current grade level, annual household income, parental education level and number of annual healthcare encounters were correlated with health literacy scores in order to determine relationships among variables (Manganello, 2008).

## Instruments

The REALM-Teen is currently the only validated health literacy instrument for adolescents (Davis et al., 2006). Several studies have evaluated the use of the Newest Vital Sign (NVS) health literacy instrument for use in adolescents; however, the data is limited and more data is needed to fully validate this instrument for use in adolescents (Driessnack et al., 2014; Jang & Kim, 2015; Patel et al., 2016; Warsh et al., 2014). Therefore, a secondary aim of this study was to gather validation data for the Newest Vital Sign (NVS) health literacy instrument for use in adolescents. Thus, both instruments were administered to each participant.

## REALM-Teen

The REALM-Teen shows strong internal consistency (Cronbach's  $\alpha$ : 0.94) and strong test-retest reliability ( $r = 0.98$ ) (Davis et al., 2006). The REALM-Teen also has high criterion validity for reading ability when correlated with two other literacy tests, the Wide Range Achievement Test-3 (WRAT-3) ( $r = 0.83$ ) and Slosson Oral Reading Test-Revised (SORT-R) ( $r = 0.93$ ) (Davis et al., 2006). The REALM-Teen is the only one, however, that measures literacy in the context of health.

The REALM-Teen is a one page instrument with three widely spaced columns, consisting of 66 total health words arranged in increasing order of difficulty for pronunciation. The test is scored according to correct pronunciation. Correct pronunciation is based on dictionary pronunciation, which is considered the standard when conducting research regarding correct pronunciation (Davis et al., 2006). The raw test score is obtained by counting the number of incorrect pronunciations and skipped words and subtracting them from the total number of words. Therefore, the raw score is the total number of correctly pronounced words; and, the final score is the conversion of the raw score to a grade-level score. For the purposes of this study, raw REALM-Teen scores were used for analysis.

## Newest Vital Sign (NVS)

The NVS evaluates both literacy and numeracy (the ability to understand and work with numbers) as well as the ability to locate and apply information (Weiss et al., 2005). It is important to validate the NVS for

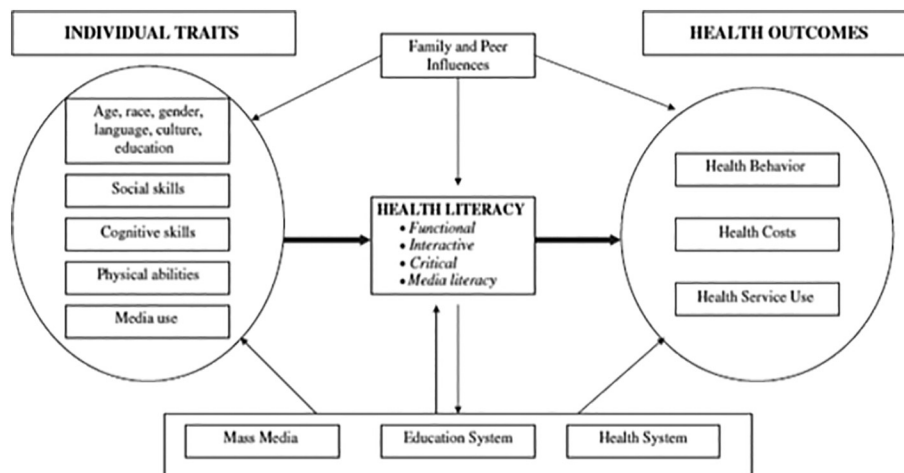


Fig. 1. Adolescent health literacy framework (Manganello, 2008).

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