

PREDICTORS OF GRADE RETENTION IN CHILDREN AND ADOLESCENTS WITH  
SICKLE CELL DISEASE

by

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This study examined the predictive value of sex, socioeconomic status (SES), disease severity, family achievement-orientation, and family relationship quality for predicting grade retention in children and adolescents with sickle cell disease (SCD). Additionally, this study investigated the extent to which family achievement-orientation and family relationship quality moderated relationships between the other predictor variables and grade retention. Data were extracted from a nationally representative database, the Cooperative Study of Sickle Cell Disease. Participants included 185 children and adolescents with SCD ranging in age from 7-16 years old. Older age and poorer reading achievement were significant predictors of grade retention. In addition, it was found that family achievement-orientation moderated the relationship between age and grade retention, such that high family achievement-orientation buffered against the negative effects of older age on grade retention. Additional research should study the influence of other dimensions of family functioning on grade retention and as a protective factor against other factors. Clinical implications include the identified need for

psychosocial interventions that promote achievement-orientation in family members of children and adolescents with SCD.



PREDICTORS OF GRADE RETENTION IN CHILDREN AND ADOLESCENTS WITH  
SICKLE CELL DISEASE

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## **CHAPTER I: INTRODUCTION**

Grade retention is defined as the requirement that a child repeat a grade in school due to a failure to make an adequate amount of academic progress (Schatz, Brown, Pascual, Hsu, & DeBaun, 2001). Grade retention is used throughout the United States as the primary remediation tool for grade failure, with 5-10% of children being retained in the United States each year (Jimerson, 2001). Researchers studying grade retention have noted a number of characteristics that are common among children who are retained at some point in their educational career. These characteristics include low socioeconomic status (SES), male sex, minority status, and being an adolescent. In addition to these characteristics, a risk factor that makes children particularly vulnerable to grade retention is the presence of a chronic illness, such as sickle cell disease (SCD; Barbarin, Whitten, & Bonds, 1994; Byrd & Weitzman, 1994; Guèvremont, Roos, & Brownwell, 2007; Jimerson, 2001; Pagani, Tremblay, Vitaro, Boulerice, & McDuff, 2001).

The purpose of the current study is to examine factors related to grade retention in children and adolescents with SCD. The following sections give an overview of sickle cell disease, grade retention, and grade retention in the SCD population.

### **Sickle Cell Disease**

SCD is a family of genetic blood disorders that predominantly affects African American populations, with approximately one in every 400-600 African Americans inheriting the disease ("Sickle Cell Disease," 2006). The term "sickle cell" in SCD refers to the malformation of affected individuals' red blood cells. These sickled cells sometimes get caught in tiny blood vessels and inhibit sufficient blood flow, leading to chronic anemia (Gustafson, Bonner, Hardy, & Thompson, Jr., 2006). Although sickled cells can be present in any part of the body, the most common areas are the spleen, bones, and joints (Swain, Mitchell, & Powers, 2006). When the

sickled cells get stuck in blood vessels, individuals may experience very painful episodes, the most common SCD-related complication (“Sickle Cell Disease,” 2006). The most common type of SCD is sickle cell anemia (HbSS), a homozygous genetic disease that results from two abnormal genes for hemoglobin S. HbSS is characterized as the most severe type of SCD because individuals with this type typically experience pain episodes earlier in life and more frequently than individuals with other types of the disease (Gustafson et al., 2006). Individuals with HbSS also experience more SCD-related complications overall. The other two common types of SCD are sickle cell hemoglobin C (HbSC) and sickle  $\beta$ -thalassemia (Hb S  $\beta$ -thalassemia). HbSC is, on average, associated with fewer disease-related complications and pain episodes than HbSS (Lutz, Barakat, Smith-Whitley, & Ohene-Frempong, 2004). There are two types of Hb S  $\beta$ -thalassemia, Hb S/ $\beta^0$  and Hb S/ $\beta^+$ . Hb S/ $\beta^+$  is mildly to moderately severe whereas Hb S/ $\beta^0$  is often as severe as HbSS (Stuart & Nagel, 2004).

SCD pain episodes are not typically triggered by any identifiable event and, therefore, are often unpredictable. Pain occurs in over 70% of patients with SCD and can last anywhere from a day to several weeks (Steinberg, 1999). In a daily survey study involving 20 children with SCD aged 8-12 years, Valrie, Gil, Redding-Lallinger, and Daeschner (2007) found that 16 of the 20 participants reported at least one episode of pain during the 2-month study. They also found that pain was reported on 22.24% of diary days and that the average severity of pain episodes was 48.73 on a 100-point scale. This is consistent with a daily survey study by Gil et al. (2003) of 37 adolescents with SCD, aged 13-17 years. Over a 6-month period, the average duration of pain episodes was 16.4 hours and the average pain severity rating was 40.8 on a 100-point scale.

Other complications associated with SCD are stroke and acute chest syndrome (ACS; Taras & Potts-Datema, 2005; Vickinsky et al., 1997). Strokes result from the narrowing of blood

cells in the brain and can be silent or overt. Silent strokes are often minor and may go undetected because they are not associated with overt symptoms, such as hemiparesis (muscle weakness) or seizure (Hillery & Panepinto, 2004). On the other hand, overt strokes may be extremely severe, resulting in sustained debilitation or even death (Taras & Potts-Datema, 2005). Both silent and overt strokes have been found to impair neurocognitive and academic abilities in children with SCD (Kral, Brown, & Hynd, 2001; White & DeBaun, 1998). In addition to neurological impairment, children who experience overt strokes typically miss several days of school as a result of hospitalization. A risk factor for having a stroke is a history of having ACS (Taras & Potts-Datema, 2005). ACS is a common complication of SCD and is the second most common cause of hospitalization for the SCD population, with 95% of patients with SCD being hospitalized for their first episode of ACS. The most common symptoms of ACS are fever, cough, and chest pain. The average length of hospitalization for ACS is 6.8 days, meaning that children and adolescents with SCD who experience ACS may miss a week or more of school as a result of the complication.

The course of SCD varies between individuals and also varies across the lifespan of an individual. For example, some individuals with SCD may never experience a pain episode, while others may have frequent and increasing pain episodes throughout their entire lives (Swain et al., 2006). Another trend that exists in the course of SCD is that children and adolescents who experience complications tend to have increasingly more complications as they get older. However, after adolescence, complications do not tend to significantly change over time (Platt et al., 1991). Due to the variation among individuals with SCD, a great deal of research has been conducted regarding the relationship between disease factors and outcome variables, such as academic, psychological, social, and family functioning (Swain et al., 2006). One such outcome

variable that has long-term implications for children and adolescents with SCD is grade retention.

### **Grade Retention**

The purpose of grade retention is to give students a second chance to master the curriculum of the grade in which they were retained. In line with its purpose, the idyllic view of grade retention is that it is a successful tool for preventing future academic failure. However, in contrast to its purpose, the majority of research on grade retention has yielded a common conclusion: it is not an effective tool for remediating academically delayed children. In 2001, Jimerson found that retaining a child did not have long-term positive effects on socioemotional or achievement outcomes. Pagani et al. (2001) also reported that grade retention fails to remediate students' academic deficits, and additionally found that it intensifies some negative outcomes, such as inattentiveness and anxiety. Furthermore, both Guèvremont et al. (2007) and Pagani et al. (2001) found a strong significant association between grade retention and withdrawal from high school. Perhaps most important, Pagani et al. (2001) also determined that negative outcomes, such as high school withdrawal, inattentiveness, and anxiety, that follow grade retention are not simply a continuation of poor academic and behavioral patterns, but are a new sequencing of events that commence as a result of retention. This finding is extremely important, because it indicates that grade retention is a faulty practice that sets off a unique chain of events resulting in negative outcomes for retained children.

Guèvremont et al. (2007) conducted a study to examine the predictors of grade retention in a sample of 128,557 children ranging from kindergarten to eighth grade. They examined data from the 2001-2002 school year and identified a profile of characteristics that increase the risk of grade retention. The profile included male sex, young age compared to grade peers, low or mid-

low SES, high number of school moves, having a mother who was young at the child's birth, and receiving income assistance. They also found that first, second, seventh, and eighth grade are high-risk grades for retention. In addition to these characteristics, a study by Barbarin et al. (1994), found that older age was significantly associated with a measure of academic adjustment, which included grade retention. In another study, McCoy & Reynolds (1999) studied a population of 1,164 low-income, mostly African American 14-year old children. The participants were part of the Chicago Longitudinal Study, so the researchers were able to retroactively identify early factors that predicted grade retention by age 14. Of the 1,164 participants, 296 had been retained once and 19 had been retained more than once. The study revealed six significant predictors of grade retention. Boys were at a greater risk than girls, increased number of school moves was associated with an increased probability of retention, and increased parental participation in the child's school was associated with a decreased chance of the child being retained. The other predictors were three measures of academic performance that were measured when the child was in first grade. Low reading achievement and low math achievement, as measured by the Iowa Test of Basic Skills (ITBS), were related to a high probability of grade retention. Lastly, a 1-point difference in reading grade, as reported by teachers on a scale from 1-5 with a "5" representing an "A" and a "1" representing "F", was associated with an increased probability of retention (McCoy & Reynolds, 1999). Thus, this study found that a mix of social and academic factors serve as risk factors for grade retention in a general population of children and adolescents.

Taken together, these studies highlight factors that put students at higher risk for grade retention. Risk factors found in both studies include male sex and indicators of low SES. It is important to note that while Barbarin et al. (1994) found older age to be a predictor of grade

retention, all other studies controlled for age. As children get older, the likelihood of grade retention naturally increases because with each year that passes, there are more opportunities for grade retention to occur. The following sections will review grade retention in the SCD population and the influence of these identified risk factors and other possible risk factors (e.g., disease severity and family functioning) that may lead to grade retention in children and adolescents with SCD.

### **Grade Retention in the SCD Population**

It is estimated that about 50% of children and adolescents with SCD will be retained at least one grade level during their educational career (Javid, 1999). This figure is quite larger than the 5-10% of all children who are retained annually in the US (Jimerson, 2001). Fowler et al. (1988) examined 28 children with SCD aged 6-17 years and 28 of their healthy peers matched on sex and SES. They found that 54% of the children in the sickle cell group had repeated a grade in school whereas only 43% of the children in the healthy group had repeated a grade at the time of the study; however, the difference was not significant (Fowler, et al., 1988). On the other hand, Schatz (2004) investigated grade retention in a group of 50 children with SCD aged 7-17 years and 36 healthy children. Results indicated a significant difference between the two groups, with 30% of children with SCD reporting grade retention and only 8.3% of children in the control group reporting grade retention (Schatz, 2004). From these studies, it is evident that children with SCD are consistently retained at a much higher rate than their healthy peers. These studies do an excellent job of describing the pattern of grade retention in the SCD population; however, they fail to explain what factors may contribute to these patterns.

## **Factors that May Affect Grade Retention in Children and Adolescents with SCD**

**Sex.** Although sex has been found to be a predictor of grade retention in the general population (Pagani et al., 2001; Byrd & Weitzman, 1994), research concerning sex and grade retention has not been conducted within the SCD population. There is, however, reason to believe that this pattern may exist in the SCD population as indicated by studies that have found sex to be predictive of academic functioning in this population. Specifically, there is evidence that within the SCD population, boys exhibit poorer cognitive and academic functioning than girls. Fowler et al. (1988) found that male sex was a significant risk factor for poor cognitive functioning in children with SCD. Also, in a meta-analysis of studies of adjustment for children and adolescents with SCD, White and DeBaun (1998) found that boys typically exhibit poorer overall adjustment than girls, including academic functioning.

**SES.** Much like sex, SES has been found to be a predictor of grade retention in the general population (Guèvremont et al., 2007; McCoy & Reynolds, 1999), but it has not been researched in relation to grade retention in the SCD population. However, research has found an association between SES and academic achievement in children and adolescents with SCD. Schatz (2004) examined the relationship between SES and academic achievement in a sample of children and adolescents with SCD. The study measured academic achievement using the Wide Range Achievement Test, third edition (WRAT-3) and measured SES using yearly household income and years of parental education. Results indicated that low family income was significantly correlated with poor academic achievement. There was also a correlation found between low parental education and poor academic achievement, although this correlation fell short of statistical significance. Similarly, Devine, Brown, Lambert, Donegan, and Eckman (1998) found significant correlations between low maternal education level and poor reading and

math achievement, as measured by the Woodcock-Johnson Psychoeducational Battery-Revised (WJ-R), in a sample of children with SCD.

**Disease severity.** Though SCD disease severity has not been examined as it relates to grade retention, disease severity has been shown to impact cognitive and academic functioning in children and adolescents with SCD. For example, Hurtig, Koepke & Park (1989) conducted a study that examined the associations between disease severity, as measured by SCD genotype, and several types of adjustment in children and adolescents with SCD. The study included 70 sickle cell patients aged 8-16 years old. They found that genotype significantly predicted IQ when sex and age were controlled, with individuals with HbSS having poorer IQ scores than individuals with HbSC. Similarly, a study by Steen, Xiong, Mulhern, Langston, and Wang (1999) that included 50 children and adolescents with SCD aged 4-17 years found a significant difference between the full scale IQ of participants with HbSS and HbSC. Patients with HbSS had an average full scale IQ of 71.9 whereas patients with HbSC had an average full scale IQ of 87.4. Hijmans et al. (2011) examined neurocognitive deficits in 37 children with SCD aged 6-18 years old. Hemoglobin level was used as a measure of disease severity with the understanding that lower hemoglobin indicates higher disease severity. Results indicated that lower hemoglobin predicted poorer verbal short-term memory in participants. These results indicate that children and adolescents with SCD who have lower levels of hemoglobin and thus, higher disease severity, experience more neurocognitive deficits, particularly with verbal short-term memory.

**Family functioning.** Another factor that has not been examined as it relates to grade retention in children and adolescents with SCD, but that has been shown to affect academic performance in children with SCD is family functioning. Family functioning is defined as “the social and structural properties of the global family environment” (Lewandowski, Palermo,



Stinson, Handley, & Chambers, 2010). There are several domains of family functioning, such as family conflict, cohesion, expressiveness, and achievement-orientation. Family conflict is the amount of hostility that is felt and expressed among family members. Family expressiveness is the extent to which family members express their feelings with each other in a constructive way (Gold, Treadwell, Weissman, & Vichinsky, 2011). Family cohesion is the amount of emotional bonding among family members. Lastly, family achievement-orientation is the extent to which the family orients its' activities in the pursuit of success (Moos & Moos, 1986).

Current research suggests that when compared to families with healthy children, families of preschool children with SCD experience a greater amount of conflict and negative interactions (Burlew, Evans, & Oler, 1989; Evans, Burlew, & Oler, 1988). However, research on families with school age children and adolescents with SCD has found that these families do not have poorer family functioning when compared to families of healthy children. Once children reach school age, the differences between family functioning in families of children with SCD and families of healthy children seem to disappear or reverse. For example, Noll et al. (1994) found no significant differences in family conflict between 32 families of children with SCD and 32 families of healthy children aged 8-15 years. Another study by Midence, McManus, Fuggle, and Davies (1996) examined family cohesion and family conflict with a sample of 39 children with SCD and 24 healthy control children aged 6-16 years. Results indicated that families of children with SCD exhibited a significantly higher level of family cohesion and a significantly lower level of family conflict than the families of healthy control children.

Of note, there appears to be a difference in the functioning of families of children and adolescents with SCD as a result of the sex of the child with SCD. Hurtig (1994) measured family functioning in 70 families of children and adolescents with SCD aged 8-16 years. The

study found that family functioning was significantly better in families of girls with SCD than families of boys with SCD.

Although there is a dearth of research looking at the influence of family functioning on grade retention in children with SCD, there has been research indicating that family functioning impacts cognitive and academic performance in children with SCD. Fowler et al. (1988) found that for families of children with SCD, high family cohesion was correlated with high intelligence scores. Barbarin, Whitten, Bond, and Conner-Warren (1999) conducted a study to determine associations between family functioning and measures of adjustment in children with SCD. The study found that high demands to participate in expected behaviors (i.e., household chores), familial overprotection, and problems in family relations predicted total adjustment (inclusive of academic functioning). Barbarin et al. (1999) also found that an optimistic family attitude significantly predicted successful academic adjustment and that high-conflict family relationships predicted poorer academic adjustment. Additionally, children whose parents had high anxiety and poor coping skills had significantly more negative academic outcomes.

### **The Current Study**

The ineffectiveness and possible harm of grade retention combined with the high rate of grade retention in the pediatric SCD population supports the need for research on factors uniquely related to grade retention within this population. Associations have been found between sex, SES, and grade retention in healthy populations, but sex and SES have not been examined in relation to grade retention in children and adolescents with SCD. In addition, disease severity and family functioning have been related to poorer cognitive and academic functioning in the SCD population, but have not been examined in relation to grade retention in the population. Thus, the current study aimed to examine how sex, SES, disease severity, and family functioning

may impact grade retention in children and adolescents with SCD. It was hypothesized that male sex, low SES, high disease severity, and poor family functioning (e.g., high family conflict, low family cohesion, low family expressiveness, and low family achievement-orientation) would be significantly associated with grade retention. The secondary aim of the study is to examine whether the associations between (1) age and grade retention, (2) sex and grade retention, and (3) SES and grade retention, and (4) disease severity and grade retention are moderated by family functioning. Specifically, it was hypothesized that favorable family functioning would serve as a protective factor against the influence of age, sex, SES, and disease severity on grade retention in children and adolescents with SCD.

## **CHAPTER II: METHOD AND DATA ANALYSIS PLAN**

### **Participants**

All of the data for the current study came from the Cooperative Study of Sickle Cell Disease (CSSCD; National Heart, Lung, and Blood Institute, 2008). The purpose of the CSSCD was to study the course of SCD from birth to death and to determine the factors that contribute to the morbidity and mortality of individuals with SCD. The CSSCD began in 1977 and was composed of three phases. Phase 1 of the study included 4,085 participants ranging from newborns to adults. Phase 2 was conducted from 1989-1994 and included 450 participants. Phase 3 was a follow up phase of the infant and pediatric cohorts and was conducted from 1994-1998 and included 378 participants. The current study used data collected at the beginning of Phase 3, because this point in the study included the greatest number of participants between the ages of 7 and 16 years and because it was the most recent data available from the CSSCD.

### **Procedure**

Data were extracted from the CSSCD data set for each of the participants during the first data collection period of Phase 3. Inclusion criteria consisted of being aged 7-16 years and exclusion criteria consisted of not having a complete dataset for the variables of interest. Age, sex, and SCD genotype of the child came from information compiled in the CSSCD's patient roster. Scores of family conflict, family cohesion, family expressiveness, and family achievement-orientation came from the Family Environment Scale, which was administered to each participant's biological mother (or guardian) at the beginning of entry into Phase 3. History of grade retention of the participants came from the history form completed by the participants' guardians at the beginning of Phase 3. SES, as measured by annual household income, was collected during a baseline interview with the participants upon their entry into the study. Lastly,

academic achievement, as measured by the Woodcock-Johnson Revised, Tests of Achievement, was measured upon each participant's entry into Phase 3 of the study.

## **Measures**

**Demographic information.** Basic demographic information was collected from participants at the beginning of the CSSCD via a baseline interview. Demographic information used in the current study includes the child's age and sex, and the annual household income. Sex was coded as "1" for female and "2" for male. Since Phase 3 was a follow up of the infant and pediatric cohorts, this information was collected when participants initially entered the study in either Phase 1 or Phase 2. This means that annual household income reflects the participant's SES sometime during the 1980s.

**Disease severity.** SCD genotype was used as a measure of SCD disease severity. This information was collected during a baseline exam that was conducted with each participant. For the current study, severe genotypes (HbSS and Hb S/ $\beta^0$ ) were coded as "1" and mild genotypes (HbSC and Hb S/ $\beta^+$ ) were coded as "0". Using genotype as a measure of disease severity has been used in many studies examining individuals with SCD (Ashley-Koch, Yang, & Olney, 2000; Barakat, Smith-Whitley, & Ohene-Frempong, 2002; Brown et al., 2000).

**Family functioning.** The Family Environment Scale (FES; Moos & Moos, 1986) was used to assess family functioning. The FES includes 90 true/false items, assesses social and environmental aspects of family functioning and is composed of ten subscales. The specific subscales used in the current study included conflict, cohesion, expressiveness, and achievement-orientation. Conflict, cohesion, and expressiveness make up the Family Relationship Index (FRI). Therefore, for the current study, family functioning included two scores, family achievement-orientation and FRI. Sample questions from the FES can be found in Appendix A.

The FES was normed on a diverse sample of 1,432 normal families and 788 distressed families. For the current study, the scale was orally administered to each participant's biological mother (or guardian). All items on the FES are true/false and responses were coded as follows: "1" = "true," "2" = "false." T-scores were then calculated for each of the subscales. The FES averages .71 for internal consistency of subscales and .70 for test-retest reliability in a normative sample (Moos & Moos, 1994). It has been validated as a measure of family adjustment by empirical evidence that found that distressed families exhibit lower cohesion, expressiveness, independence, intellectual-cultural orientation, and active-recreational orientation and higher conflict and control than nondistressed families (Moos & Moos, 1986). The FES has also been validated in families of children with a chronic illness. Children with a chronic illness whose mother reported behavior problems had family functioning profiles consisting of high conflict and low supportiveness (Kronenberger & Thompson, 1990). Additionally, the FES has been validated in African American families (Tolson & Wilson, 1990). The FES was normed such that the mean score on each subscale is 50 with a standard deviation of 10.

**Academic achievement.** Academic achievement was measured using the Woodcock-Johnson Revised, Tests of Achievement (WJ-R; Woodcock & Johnson, 1989). The WJ-R is a standardized measure of achievement for individuals aged 2 and up. The WJ-R was normed on a sample of 6,359 participants in over 100 geographically diverse communities in the United States. For the current study, two subscales of the WJ-R were reported, Broad Reading and Broad Mathematics. The WJR-Compuscore Program was used to score and convert the raw scores to scores standardized by age (National Heart, Lung, and Blood Institute, 2008). Those standard scores were used for the current study. The internal consistency coefficients for the achievement cluster scores of the WJ-R are in the mid-.90s and are above .90 for the individual

subtests. The WJ-R correlates well with other achievement tests, with correlations falling in the .60-.70 range (McGrew, Werder, & Woodcock, 1991). The WJ-R is normed such that the mean score is 100 with a standard deviation of 15.

**Grade retention.** History of grade retention was collected via the history form, which was completed at the beginning of Phase 3. This form was completed by the participant's parent/guardian. For the current study, answers to "Has the patient ever repeated a grade?" were coded as "1" for "yes" and "0" for "no". Self-report measures of grade retention using similar questions have been used in previous research studies (Griffith, Lloyd, Lane, & Tankersley, 2010; Martin, 2011; Schatz, 2004).

### **Data Analysis Plan**

Descriptive statistics of each variable were reported. To investigate the primary hypothesis, a logistic regression was calculated to determine the predictive value of sex, SES, disease severity, family relationship quality, and family achievement-orientation for predicting grade retention in children and adolescents with SCD. Academic achievement and age were controlled for in the analysis. The secondary hypothesis was tested by including the interactions between family relationship quality and family achievement-orientation scores and age, sex, SES, and disease severity in the previously described logistic regression model predicting grade retention. A moderation effect was indicated if the interaction was significant while the main effects were controlled for (Baron & Kenny, 1986). Each significant interaction term was probed by evaluating the relationship between the predictor variable and grade retention at low, medium, and high levels of family functioning. This was done by standardizing the family functioning variable so that it had a mean of 0 and a standard deviation of 1. To create high levels of family functioning, 1 was subtracted from the standardized scores, to create low levels of family

functioning, 1 was added to the standardized scores, and to create medium levels of family functioning, the standard scores were kept at a mean of 0.



## CHAPTER III: RESULTS

All analyses were conducted using SAS and SPSS statistical software.

### **Descriptive Statistics**

The data sample extracted from the CSSCD dataset included 185 children and adolescents with SCD ranging in age from 7-16 years old with an average age of 10.69 ( $SD = 2.52$ ). Eighty eight participants were female (47.6%) and 97 (52.4%) were male (see Table 1). Also, 116 had HbSS (62.7%), 59 had HbSC (31.9%), 7 had Hb S/ $\beta^+$  (3.8%) and 3 had Hb S/ $\beta^0$  (1.6%). The median household income bracket was \$10,000-\$14,999 and income brackets ranged from less than \$5,000 to \$70,000-\$99,999. In regards to grade retention, 29 participants (15.7%) reported being retained a grade and 156 (84.3%) did not report being retained a grade (see Figure 1).

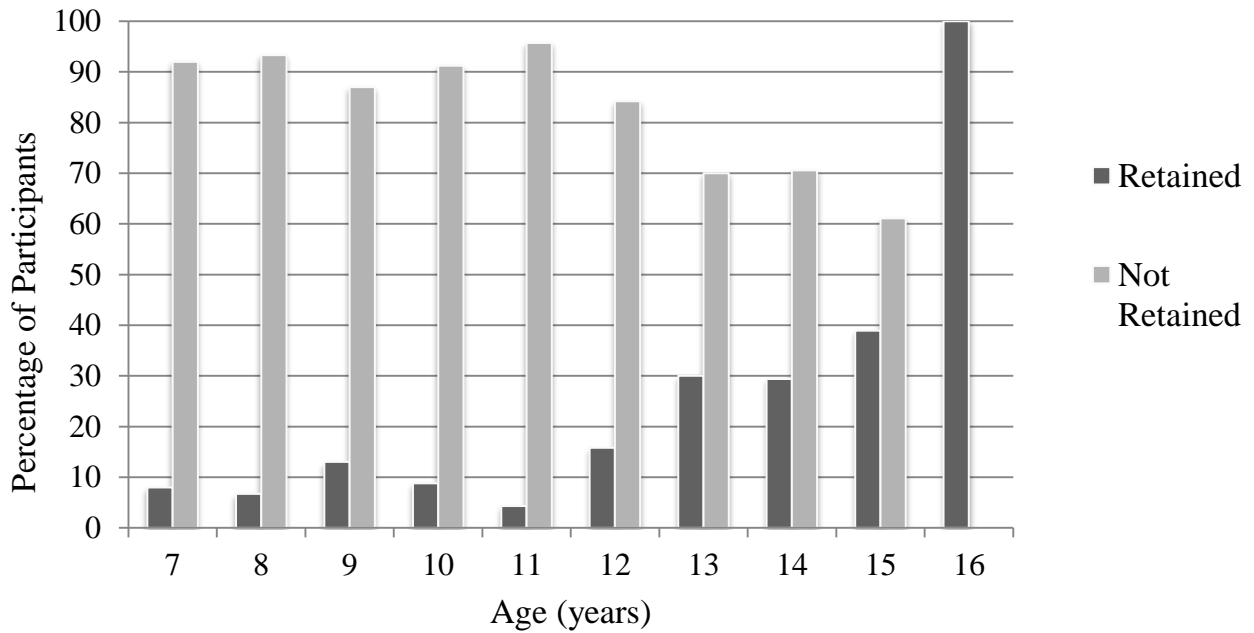
Table 1

*Sample Demographics*

|                           | <i>N</i>   | <i>Percent</i> |
|---------------------------|------------|----------------|
| <b>Sex</b>                |            |                |
| <b>Female</b>             | 88         | 47.6%          |
| <b>Male</b>               | 97         | 52.4%          |
| <b>Sickle cell type</b>   |            |                |
| <b>Severe</b>             | <b>119</b> | <b>64.3%</b>   |
| <b>HbSS</b>               | 116        | 62.7%          |
| <b>Hb S/β<sup>0</sup></b> | 3          | 1.6%           |
| <b>Mild</b>               | <b>66</b>  | <b>35.7%</b>   |
| <b>HbSC</b>               | 59         | 31.9%          |
| <b>Hb S/β<sup>+</sup></b> | 7          | 3.8%           |
| <b>Household income</b>   |            |                |
| <b>&lt; \$5,000</b>       | 15         | 8.1%           |
| <b>\$5,000-\$9,999</b>    | 46         | 24.9%          |
| <b>\$10,000-\$14,999</b>  | 33         | 17.8%          |
| <b>\$15,000-\$19,999</b>  | 28         | 15.1%          |
| <b>\$20,000-\$29,999</b>  | 25         | 13.6%          |
| <b>\$30,000-\$49,999</b>  | 27         | 15.0%          |
| <b>\$50,000-\$69,999</b>  | 9          | 4.9%           |
| <b>\$70,000-\$99,999</b>  | 2          | 1.1%           |
| <b>Grade Retention</b>    |            |                |
| <b>Yes</b>                | 29         | 15.7%          |
| <b>No</b>                 | 156        | 84.3%          |

Figure 1

*Percentage of Participants Retained by Age*



Descriptive information on family functioning and academic achievement measures is in Table 2. The reading achievement scores ( $M = 89.02$ ,  $SD = 19.39$ , range = 19-136) and math achievement scores ( $M = 88.03$ ,  $SD = 15.37$ , range = 25-131) fell within the low average range relative to national norms. The mean score on the family achievement-orientation subscale fell within the average range ( $M = 54.85$   $SD = 7.19$ , range = 35-72). The family relationships index is made up of three subscales (family conflict, family cohesion, and family expressiveness) and the mean scores of all the scales fell in the average range: family conflict ( $M = 45.97$ ,  $SD = 10.25$ , range = 32-75), family cohesion ( $M = 54.19$ ,  $SD = 11.54$ , range = 9-68), and family expressiveness ( $M = 48.15$ ,  $SD = 9.37$ , range = 21-66).

Table 2

*Descriptive Statistics of Academic Achievement and Family Functioning*

|                                       | <i>M</i> | <i>SD</i> | <i>Range</i> |
|---------------------------------------|----------|-----------|--------------|
| <b>Reading Achievement</b>            | 89.02    | 19.39     | 19-136       |
| <b>Math Achievement</b>               | 88.03    | 15.37     | 25-131       |
| <b>Family Achievement-Orientation</b> | 54.85    | 7.19      | 35-72        |
| <b>Family Conflict</b>                | 45.97    | 10.25     | 32-75        |
| <b>Family Cohesion</b>                | 54.19    | 11.54     | 9-68         |
| <b>Family Expressiveness</b>          | 48.15    | 9.37      | 21-66        |

Correlations were calculated for all variables in the analysis (see Table 3). Pearson product correlations were used with two continuous variables, point biserial correlations were used with one dichotomous and one continuous variable, and phi coefficients were used with two dichotomous variables (see Table 3). A high likelihood of grade retention was significantly associated with older age ( $r = .27, p < .01$ ), low reading achievement ( $r = -.34, p < .01$ ), and low math achievement ( $r = -.26, p < .01$ ). Low reading achievement was significantly associated with male sex ( $r = -.15, p < .05$ ), low scores on the family relationships index ( $r = .24, p < .01$ ), low math achievement ( $r = .73, p < .01$ ), and low annual household income ( $r = .35, p < .01$ ). Low math achievement was significantly associated with more severe sickle cell types ( $r = -.15, p < .05$ ), low scores on the family relationships index ( $r = .20, p < .01$ ), and low annual household income ( $r = .33, p < .01$ ). Finally, high annual household income was significantly associated with high scores on the family relationships index ( $r = .20, p < .01$ ).

Table 3

*Correlations Between Variables*

|                                          | 1     | 2     | 3      | 4     | 5    | 6     | 7      | 8      | 9  |
|------------------------------------------|-------|-------|--------|-------|------|-------|--------|--------|----|
| <b>1. Age</b>                            | --    |       |        |       |      |       |        |        |    |
| <b>2. Sex</b>                            | -.05  | --    |        |       |      |       |        |        |    |
| <b>3. Annual Household Income</b>        | .04   | -.05  | --     |       |      |       |        |        |    |
| <b>4. Sickle Cell Type</b>               | .03   | .01   | .05    | --    |      |       |        |        |    |
| <b>5. Family Achievement-Orientation</b> | .09   | .02   | .04    | .01   | --   |       |        |        |    |
| <b>6. Family Relationships Index</b>     | -.01  | -.04  | -.20** | .11   | .08  | --    |        |        |    |
| <b>7. Reading Achievement</b>            | .02   | -.15* | .35**  | -.09  | -.02 | .24** | --     |        |    |
| <b>8. Math Achievement</b>               | -.12  | -.13  | .33**  | -.15* | -.05 | .20** | .73**  | --     |    |
| <b>9. Grade Retention</b>                | .27** | .08   | -.09   | .10   | .05  | -.14  | -.34** | -.26** | -- |

\* $p < .05$ . \*\* $p < .01$ .

### Logistic Regression Model Predicting Grade Retention

To test the primary aim, a logistic regression model predicting grade retention as the outcome variable was calculated and age, sex, annual household income, disease severity, family achievement-orientation, family relationships index, reading achievement, and math achievement were used in the model as predictor variables (see Table 4). The overall model was found to be significant ( $-2LL = 99.36$ ,  $p < .01$ ). Age ( $OR = 3.36$ ,  $CI_{95} = 1.80, 6.29$ ) was found to be significantly predictive of grade retention. For each one year increase in age, individuals were 336% more likely to be retained. Reading achievement ( $OR = 0.95$ ,  $CI_{95} = 0.91, 0.99$ ) was also

found to significantly predict grade retention. For each one point decrease in reading achievement, individuals were 5.82% more likely to be retained.

To test the secondary aim, the interactions between family functioning and age, disease severity, income, and sex were also included in the logistic regression model predicting grade retention (see Table 4). The interaction between age and family achievement-orientation ( $OR = 0.46$ ,  $CI_{95} = 0.23, 0.89$ ) was found to be significantly predictive of grade retention. The interaction of age and family achievement-orientation was further investigated as outlined in the data analysis plan. The model for low levels of family achievement-orientation showed that age uniquely predicted grade retention ( $OR = 7.38$ ,  $p < 0.01$ ), meaning that for each one year increase in age, individuals were 738% more likely to be retained. The model for medium levels of family achievement-orientation also showed that age uniquely predicted grade retention ( $OR = 3.36$ ,  $p < 0.01$ ), meaning that for each one year increase in age, individuals were 336% more likely to be retained. In contrast, the model for high levels of family achievement-orientation showed that age did not uniquely predict grade retention ( $OR = 1.53$ ,  $p = 0.25$ ). These findings indicate that as levels of family achievement-orientation increase, the relationship between age and grade retention decreases. Therefore, family achievement-orientation moderated the relationship between age and grade retention in children and adolescents with SCD.

Table 4

*Logistic Regression to Predict Grade Retention (N = 185)*

|                                             | <b>-2LL</b> | <b><math>\beta</math></b> | <b>OR (95% CI)</b> |
|---------------------------------------------|-------------|---------------------------|--------------------|
|                                             | 99.36       |                           |                    |
| <b>Age</b>                                  |             | 1.21**                    | 3.36 (1.80-6.29)   |
| <b>Sex</b>                                  |             | 0.26                      | 1.30 (0.39-4.23)   |
| <b>Annual Household Income (SES)</b>        |             | 0.07                      | 1.08 (0.56-2.08)   |
| <b>Disease Severity (sickle cell type)</b>  |             | 0.68                      | 0.51 (0.15-1.72)   |
| <b>Family Achievement-Orientation (FAO)</b> |             | 0.13                      | 1.13 (0.11-11.89)  |
| <b>Family Relationships Index (FRI)</b>     |             | -1.88                     | 0.15 (.02-1.52)    |
| <b>Reading Achievement</b>                  |             | -0.06**                   | 0.95 (0.91-0.99)   |
| <b>Math Achievement</b>                     |             | 0.00                      | 1.00 (0.95-1.06)   |
| <b>Age*FAO</b>                              |             | -0.79*                    | 0.46 (0.23-0.89)   |
| <b>Age*FRI</b>                              |             | -0.55                     | 0.58 (0.31-1.09)   |
| <b>Disease Severity*FAO</b>                 |             | 0.65                      | 0.52 ( 0.15-1.81)  |
| <b>Disease Severity*FRI</b>                 |             | -0.18                     | 1.20 (0.46-3.15)   |
| <b>Income*FAO</b>                           |             | -0.41                     | 0.67 (0.34-1.29)   |
| <b>Income*FRI</b>                           |             | -0.38                     | 0.68 (0.38-1.23)   |
| <b>Sex*FAO</b>                              |             | 0.20                      | 1.22 ( 0.30-4.98)  |
| <b>Sex*FRI</b>                              |             | 1.14                      | 3.12 (0.89-10.90)  |

\* $p < .05$ . \*\* $p < .01$ .

## CHAPTER IV: DISCUSSION

The primary purpose of the present study was to investigate the predictive value of sex, SES, disease severity, family achievement-orientation, and family relationship quality for predicting grade retention in children and adolescents with SCD. Contrary to the primary hypothesis, these factors were not significant predictors of grade retention. There are a few possibilities for why these results were not found to be significant. First, it is possible that each of these variables do not play a direct role in contributing to an individual's likelihood of being retained, but that they are each a part of a larger pool of risk factors that all come together to increase the risk of retention. Also, the rationale for including sex, SES, disease severity and family functioning in the model was because there is literature linking these variables to academic functioning in the SCD population. However, it is possible that the mechanisms by which these factors impact academic functioning do not contribute to the occurrence of grade retention. Additionally, though research has linked sex and SES to grade retention in healthy children, it may be that the characteristics that often lead to grade retention are different for children with and without SCD. An implication of this explanation is that to reduce grade retention in the pediatric SCD population, targeted interventions focused on disease-related consequences that might lead to grade retention, such as school absenteeism, pain crises, and neurological impairment need to be adopted.

In regards to the secondary aim, results were consistent with the hypothesis that family functioning would moderate the relationship between age and grade retention. Specifically, results indicated that high family achievement-orientation served as a protective factor buffering against the impact of older age on grade retention. Children who are older have a greater probability of being retained simply because they have been in school longer and, therefore, have had more opportunities to be retained. Also, previous research has shown that SCD tends to get



worse with age, particularly between the ages of 0 and 20 (Platt et al., 1991). This means that as children age, they are experiencing more disease-related complications that may lead to neurological impairment, an increased number of school absences, and decreased time and energy to complete school assignments. However, it is possible that children and adolescents with SCD who are in a family with high achievement-orientation have more home-based academic supports and have learned coping mechanisms to overcome obstacles that interfere with achievement. Thus, as these individuals face increasingly more disease-related complications, they are more equipped to keep up with academic demands. This finding supports the idea of including a family component that promotes achievement-orientation both within the family unit and within individual family members in interventions focused on preventing grade retention in children and adolescents with SCD.

Inconsistent with the secondary hypothesis, family relationship quality did not moderate the relationship between predictor variables and grade retention. In the current study, family relationship quality was treated as one variable; however, it is actually composed of three separate factors: family conflict, cohesion, and expressiveness. Although family relationship quality as a whole was not a moderator, it is possible that one of the three components may influence the impact of risk factors on grade retention. Therefore, future investigations on grade retention in pediatric SCD populations should examine these aspects of family functioning separately.

### **Limitations**

A limitation of this study is that the data were collected in the mid-1990s. Due to the advancements in treatment of SCD since the 1990s, these results may not be representative of today's pediatric SCD population. For example, certain disease-related factors may not interfere

with grade promotion as much as they did 15-20 years ago due to medical developments that make SCD symptoms easier to manage. Also, annual household income was collected upon each participant's entry into phase 1 of the study. This means that this data were collected anywhere from 10-15 years prior to their entry into phase 3, which is when the other data used in this study were collected. Therefore, it is possible that participants' SES could have changed and possibly impacted other outcome variables measured in this study. Secondly, there are a few different ways that researchers measure SES, disease severity, and family functioning. Alternative measures of SES include maternal education (Byrd & Weitzman, 1994) and reliance upon income assistance (Guèvremont et al., 2007); alternative measures of disease severity include number of pain crises (Barbarin et al., 1994), number of disease-related complications, and number of SCD-related hospitalizations (Gold et al., 2011); alternative measures of family functioning include other self-report measures that use parents, children, or both as respondents, as well as observational methods (Lewandowski et al., 2010). It is possible that the measures selected for this study did not capture all aspects of the predictor variables and, therefore, fell short of statistical significance. Also, this study did not directly account for the influence of stroke. Controlling for academic achievement indirectly accounted for the impact of stroke on academic performance; however, there may be other effects of stroke that impact grade retention that were not accounted for by controlling for academic achievement.

Another element of this study that may be a limitation is that only 15.7% of the sample reported grade retention. This figure is considerably smaller than the estimate of grade retention reported in other studies involving the pediatric SCD population (Javid, 1999; Schatz, 2004). The small sample of retained children may have made it difficult to identify factors that predict grade retention in this population. However, it should be noted that this study used a nationally

representative sample that is much larger than the other study samples of the articles reviewed earlier. Thus, estimates concerning grade retention from previous studies may not have been representative of the national pediatric SCD population. It is, however, possible that school reform legislation that has occurred in the past 10-15 years has altered the rates of grade retention. For example, with the advent of the No Child Left Behind Act in 2001, which uses grade-level tests as the determining factor for grade promotion and de-emphasizes the traditional view of promoting students with same-age peers, the United States has seen a significant increase in grade retention (Jimerson, Woehr, Kaufman & Anderson, 2004). In other words, there seems to be a general uptrend of grade retention rates in the general school population that may be reflected in the discrepancy between retention rates reported in this study and retention rates reported in studies using more recent data. In sum, it seems that there is a need for further research in order to clarify national estimates of grade retention in the SCD population.

### **Future Directions and Clinical Implications**

The findings from this study suggest possible areas for future research concerning grade retention in children and adolescents with SCD. In relation to family functioning, future research may examine areas of family functioning that were not assessed in this study. Intellectual and cultural aspects of family functioning are areas that were not examined in this study that may be interesting areas for future research. Additionally, other models of family functioning may produce new insights into the relationship between family functioning and grade retention in children and adolescents with SCD. For example, in contrast to the FES, The McMaster Model of Family Functioning (Epstein, 1978) is a problem-oriented model of family functioning that proposes seven dimensions of family functioning, including problem solving, communication, roles, affective responsiveness, affective involvement, behavioral control, and general

functioning. Scores on a measure based on the McMaster Model, the McMaster Family Assessment Device (FAD; Epstein, Baldwin, & Bishop, 1983), have been related to pain and functional limitations in pediatric pain populations (Lewandowski et al., 2010). This implies that the family functioning aspects promoted by the McMaster Model would be worthwhile to explore in future research in the area of grade retention in children and adolescents with SCD and other chronic pain illnesses.

Another avenue for future research might look at grade retention in relation to the number of SCD-related school absences. It may be that some students with SCD are being retained simply because of a high number of absences, and not because of academic or achievement-related factors. For example, in a sample of 72 children and adolescents with SCD ranging in grade from kindergarten to 11<sup>th</sup> grade, 25 participants (35%) reported having missed more than 20 school days per year (Peterson, Palermo, Swift, Beebe, & Drotar, 2005). Similarly, a study by Nettles (1994) found that a sample of 32 children with SCD missed anywhere from 20-33 days of school in an academic year, whereas 34 healthy control children missed an average of 8 days in an academic year. Public school systems have attendance policies mandating that students attend a pre-determined number of school days (regardless of if absences are excused or unexcused) in order to be eligible for grade promotion. The pre-determined number of days is determined by individual school districts; however, the number is usually around 20 days (Pitt County Board of Education, 2011; Wake County Public School System, 2011; Wilson County Board of Education, 2011). Putting the two studies mentioned above in the context of these attendance policies, it is easy to see how some students with SCD may be retained simply based upon attendance and not because of performance-related factors.

More broadly, similar research should be conducted in other pediatric pain populations to examine if pain patterns affect patterns of school absences and thus, patterns of grade retention in these chronically ill children. Additional research may also benefit from looking at the relationship between grade retention and per capita income by region or urban versus rural locations. These variables would take into account aspects of students' environments that may influence school districts' distribution of funds to identify students who may need special educational services, such as tutoring outside of school or disability-related services. This research would be interesting both for children with SCD as well as children with other chronic illnesses that have neurological implications, because of the potential remedial effects that such services could have on academic deficits caused by neurological impairment. It may be that school districts with more resources are better able to remediate at-risk students and, ultimately, prevent grade retention in these students.

The results of this study also have clinical implications. The most notable clinical implication is derived from the finding that family achievement-orientation can buffer against the effects of age on grade retention. This finding implies that the attitude of the family towards achievement is just as important as the attitude of the child with SCD towards achievement. Therefore, it seems important that families be included in psychosocial interventions aimed at helping these children remain engaged and successful in school, regardless of disease-related distractors. For example, services that may be offered to chronically ill children in the school system include at-home or in-hospital tutoring (Sexson & Madan-Swain, 1995) and psychoeducational assessment (Sexson & Madan-Swain, 1993). The results of this study suggest that the more involved a parent is in obtaining and utilizing these services, the more likely a child is to benefit from them and thus, prevent grade retention. An important caveat of the above

clinical implication is that we know that the probability of grade retention increases with age. Therefore, it is important that parents of chronically ill children remain engaged and involved in their child's academic career throughout development.

Another clinical implication deals with assessment of children with SCD. The results of this study support the idea of including a measure of family functioning in assessing the needs of a child with SCD struggling in school. If it is found that these students have little family achievement-orientation, services and interventions can be tailored to include the family as needed in order to potentially prevent grade retention. An example of a family-focused intervention is the Triple P- Positive Parenting Program (Sanders, 1999; Sanders, Turner & Markie-Dadds, 2002). Triple P is a parenting program that is designed to teach parents and families effective methods of interaction and communication with the ultimate goal of decreasing problematic behavior and conflict within the family. A strength of this approach is that the intervention can be implemented at several levels depending on the needs and feasibility of the population. For example, the program can be implemented at the community level or the individual family level and can be lead by the family alone or can be guided by a trained practitioner. The same researchers who developed Triple P are currently developing and researching a new program called Positive Parenting for Healthy Living, which is a version of Triple P that has been adapted for families of children with chronic illness. The aim of this program is to help parents assist their children in better managing their illness, learning and using coping skills, managing emotions, and dealing with behavior problems (The University of Queensland, 2012).

## **Conclusion**

The present study found that older age and low reading achievement were predictive of grade retention in the SCD pediatric population. Additionally, it was found that the negative impact of age on grade retention was buffered by high levels of family achievement-orientation. These findings suggest that more research should be conducted to determine the ways in which predictors of grade retention differ between healthy children and children with SCD or other chronic health conditions. Clinically, these findings suggest the need for psychosocial interventions that promote achievement-orientation in parents and caregivers of children and adolescents with SCD and other chronic illnesses.

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## Appendix A

### Family Environment Scale Sample Items

#### *Family Cohesion:*

1. Family members really help and support one another.

#### *Family Expressiveness:*

2. Family members often keep their feelings to themselves.

#### *Family Conflict:*

3. We fight a lot in our family.

#### *Family Achievement-Oriented:*

4. We feel it is important to be the best at whatever you do.



Appendix B

IRB Approval



**EAST CAROLINA UNIVERSITY**  
**University & Medical Center Institutional Review Board Office**  
4N-70 Brody Medical Sciences Building- Mail Stop 682  
600 Moye Boulevard · Greenville, NC 27834  
Office 252-744-2914 · Fax 252-744-2284 · [www.ecu.edu/irb](http://www.ecu.edu/irb)

**Notification of Continuing Review Approval: Expedited**

From: Biomedical IRB  
To: [Cecelia Valrie](#)  
CC:

Date: 8/21/2012

Re: [CR00000524](#)  
[UMCIRB 08-0660](#)

[IMPORTED] The Influence of Neuropsychological Functioning on Adjustment in Children and Adolescents with Sickle Cell Disease

The continuing review of your expedited study was approved. Approval of the study and any consent form(s) is for the period of 8/21/2012 to 8/20/2013. This research study is eligible for review under expedited category #7. The Chairperson (or designee) deemed this study no more than minimal risk. Changes to this approved research may not be initiated without UMCIRB review except when necessary to eliminate an apparent immediate hazard to the participant. All unanticipated problems involving risks to participants and others must be promptly reported to the UMCIRB. The investigator must submit a continuing review/closure application to the UMCIRB prior to the date of study expiration. The Investigator must adhere to all reporting requirements for this study.

The approval includes the following items:

| Name                                                                        | Description                         | Modified          | Version |
|-----------------------------------------------------------------------------|-------------------------------------|-------------------|---------|
| <a href="#">Consent</a>   <a href="#">History</a>                           | Consent Forms                       | 8/30/2011 8:58 PM | 0.01    |
| <a href="#">Memo from NHLBI</a>   <a href="#">History</a>                   | Additional Items                    | 8/30/2011 9:05 PM | 0.01    |
| <a href="#">NHLBI Data Distribution Agreement</a>   <a href="#">History</a> | Additional Items                    | 8/30/2011 9:05 PM | 0.01    |
| <a href="#">Protocol</a>   <a href="#">History</a>                          | Study Protocol or Grant Application | 8/30/2011 7:31 PM | 0.01    |

The Chairperson (or designee) does not have a potential for conflict of interest on this study.