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Risk and Resilience Factors for Grade Retention in Youth with Sickle Cell Disease

Rebecca J. Ladd, M.A.,
East Carolina University

Cecelia R. Valrie, Ph.D., and
East Carolina University

Christy M. Walcott, Ph.D.
East Carolina University

Abstract

Background—Youth with sickle cell disease (SCD) are at higher risk for grade retention than healthy peers. This is salient because research suggests grade retention is ineffective and places youth at additional risk for negative outcomes. The aims of the present study were to identify possible risk factors for grade retention in youth with SCD and to examine positive family functioning as a possible resilience factor.

Procedure—Data were extracted from phase 3 of the Cooperative Study of Sickle Cell Disease, a multisite, longitudinal study of individuals with SCD. Participants were 370 youth, aged 6–16 years, with complete data on history of grade retention. Collected data included demographics, history of grade retention, disease severity factors, evidence of stroke, family functioning, and academic achievement. A logistic regression model predicting grade retention risk was calculated.

Results—Increasing age, lower reading achievement, and lower family cohesion were predictive of higher likelihood of grade retention. Also, high family achievement-orientation moderated the negative effects of increasing age on likelihood of grade retention, such that at increasing levels of family achievement-orientation, the relationship between age and grade retention decreased.

Conclusions—These findings suggest the need for interventions that promote connectedness and achievement-orientation in families of youth with SCD. Research is also needed to further explore other possible risk or resilience factors for grade retention in this population, such as school absenteeism.

Keywords

sickle cell disease; grade retention; family functioning

It is estimated that 23–54% of youth with sickle cell disease (SCD) will be retained at least one grade level during their educational career [1–5], which is much larger than the 5–10% of all children who are retained annually in the U.S. [6]. Researchers have failed to identify

what factors would be useful to target to reduce the likelihood of grade retention for this population. Notably, the majority of research on grade retention indicates that it is not an effective strategy for remediating academically delayed children [7–9]. Negative outcomes of grade retention include higher school dropout rates, inattentiveness, and anxiety, and are not a continuation of poor academic and behavioral patterns, but a new sequencing of events resulting from retention [9]. Research indicates the negative effects of grade retention are not dependent on the grade in which the child is retained, and retention offers no measurable benefits, regardless of timing [10]. Thus, youth with SCD who are retained at any grade are placed at higher risk of academic failure.

The primary driver of grade retention in youth is poor academic performance. Youth with SCD are at risk of poor academic performance due to the neurocognitive effects of their disease, specifically stroke. Overt and silent strokes in youth with SCD can result in problems with attention, memory, and executive functioning [11]. In addition to academic performance, demographic characteristics associated with grade retention in healthy children are low socioeconomic status (SES), male sex, minority status, and increasing age, as there are more opportunities for grade retention as children age [7, 9, 12]. SCD disease-related factors, such as SCD genotype, hemoglobin level, and SCD-related pain, have been linked to cognitive and academic functioning [13–16], and may be potential risk factors for grade retention for youth with SCD.

Positive family functioning may be a resilience factor against grade retention in youth with SCD. In families of youth with SCD, higher family cohesion has been associated with higher IQ scores and an optimistic family attitude and lower levels of family conflict predicted better academic adjustment [1]. Familial overprotection and problems in family relations have predicted poorer academic adjustment in youth with SCD [18]. Thus, positive family functioning may directly reduce the likelihood of academic difficulties and provide an atmosphere that promotes the development of more effective coping strategies for dealing with adversity. This may create a situation where positive family functioning buffers against the negative effects of risk factors for grade retention in youth with SCD.

The present study aims to address limitations of previous research on grade retention in youth with SCD and inform prevention efforts to reduce grade retention in this population. The study used a nationally representative sample of youth with SCD, participants from the Cooperative Study of Sickle Cell Disease (CSSCD), to identify risk and resilience factors for grade retention in youth with SCD. It was hypothesized that lower reading and math achievement, evidence of stroke, and the following demographic and disease-related factors would be associated with a higher likelihood of grade retention: lower income, male sex, older age, severe genotype (HbSS and HBS β 0), low hemoglobin level, and SCD-related pain in the past 1–2 years. The study also investigated whether positive family functioning acts as a resilience factor. It was hypothesized that indicators of positive family functioning (e.g., low conflict, high expressiveness, high cohesion, and high achievement-orientation) would be directly associated with a lower likelihood of grade retention and would buffer against the impact of poor academic performance, evidence of stroke, demographic and disease-related risk factors on grade retention.

Methods

Study Population and Procedures

The CSSCD data set was obtained from the National Heart Lung and Blood Institute (NHLBI) Biologic Specimen and Data Repository Information Coordinating Center (BioLINCC [19]). The CSSCD was a national, longitudinal study of the course of SCD from birth to death with the purpose of identifying contributing factors to the morbidity and mortality of individuals with SCD. It began in 1977 and was composed of three phases with bi-annual interviews and evaluations. For the current study, we chose to extract data from the first data collection period of Phase 3 because it included the largest number of participants aged 6 to 16 years. Phase 3 was conducted from 1994–1998, and was a follow-up of 378 participants from the Phase 1 infant and pediatric cohorts. It included neuropsychological and brain magnetic resonance imaging (MRI).

Measures

Demographic characteristics—The child's age and sex were collected from participants at the beginning of Phase 1. Age was reported in years. Socioeconomic status, as measured by annual household income, was collected upon entry into Phase 3 and was reported as brackets ranging from < \$5,000 to > \$100,000. Given that income is recorded as an ordered list with a wide range of categories that are mostly evenly spaced, it is treated like a continuous variable in the subsequent analyses ranging from 1 to 8.

Disease Severity Factors and Evidence of Stroke—SCD genotype, hemoglobin level, and SCD-related pain were used as indicators of SCD disease severity. SCD genotype was determined during the Phase 1 physical exam. Hemoglobin level and SCD-related pain information were collected upon entry into Phase 3. For SCD-related pain, the parent/guardian of the youth was asked, "since the patient's last routine CSSCD visit, has the patient experienced a sickle cell pain crisis?" Using these variables as measures of disease severity is common in studies of individuals with SCD (e.g., [20–23]). Evidence of stroke was determined using results from an MRI taken within 6 weeks of Phase 3 neuropsychological assessments. Participants with MRIs that indicated infarct or silent stroke were classified as having evidence of a stroke.

Family functioning—The *Family Environment Scale* (FES [24]) 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 and three composite scales. T-scores were calculated for each of the subscales (mean=50; SD=10). The current study only used the cohesion, expressiveness, conflict, and achievement-orientation subscales, as these scales have been associated with academic and cognitive functioning in previous research [1, 18]. The measure was administered by interview to each participant's parent/guardian upon entry into Phase 3. Previous research finds internal consistencies within appropriate ranges for the scales (Cronbach's $\alpha = 0.61$ – 0.78). The FES has been validated as a measure of family adjustment in diverse families of healthy children, including African American families [25], and is classified as approaching "well-established" status for measuring family functioning for pediatric populations, including children with SCD [26].

Academic achievement—Academic achievement was measured using the *Woodcock-Johnson Revised, Tests of Achievement* (WJ-R [27]) upon each participant's entry into Phase 3. The WJ-R is a standardized measure of achievement for individuals aged 2 and up (mean=100, SD=15). For the current study, the two broad scales of the WJ-R were reported, Broad Reading and Broad Mathematics, using scores standardized by age [19]. These broad scales are commonly used in clinical practice and research as primary indicators of academic achievement for this measure. Cronbach's alphas for the achievement cluster scores of the WJ-R are in the mid-0.90s. The WJ-R correlates well with other achievement tests, falling in the 0.60–0.70 range [28].

Grade retention—History of grade retention was collected via the history form, which was completed by the participants' parents/guardians at the beginning of Phase 3. Parents/guardians were asked, "Has the patient ever repeated a grade?" Parent-report measures of grade retention using similar questions have been used in previous research [4]. Parent-report of a similar variable, academic achievement, has been found to have adequate validity [29].

Data Analysis Plan

All analyses were conducted using SPSS statistical software. Missing data were handled using pairwise deletion. Descriptive statistics of each variable were calculated. Correlations and chi-squares were calculated to examine the relations between history of grade retention and potential risk and resilience factors. Next, a hierarchical logistic regression was calculated predicting grade retention using the potential risk and resilience factors to examine the unique contributions of each factor. The first block entered were potential risk factors significantly ($p < 0.05$) related to grade retention based on the previous analyses. The second block entered were the family functioning variables, which allowed for the examination of the direct effects of family functioning on risk of grade retention, and controlled for the main effects of the variables in subsequent analyses. To examine the possible moderating effects of positive family functioning on risk factors, a third block of variables was entered consisting of the interactions between the family functioning variables and significant risk factors from the first block of variables entered. Prior to analyses, all continuous predictor variables were standardized with a mean of 0 and a standard deviation of 1 to eliminate unnecessary collinearity between the predictors and the interaction terms. A moderation effect was indicated if the interaction was significant while controlling for the main effects of each variable [30]. Each significant interaction term was probed by evaluating the relationship between the predictor variable and history of grade retention at low, medium, and high levels of family functioning.

Results

Descriptive Statistics

The sample extracted from the CSSCD dataset included 370 youth with SCD who had complete data on history of grade retention. Descriptive information on the sample is provided in Tables I and II. Parents of 71 participants (19.2%) reported that their child or adolescent had been retained at least one grade. The average age of the participants was 10.6

years (range = 6–16 years), the majority of the participants were male (54.3%), and the median household income of the sample was between \$10,000 and \$14,999. Most of the participants had a severe genotype (63%), had not experienced SCD-related pain in the past year (72.7%), and have no evidence of a stroke (76.1%). The average Hb level was 9.17 (range = 5.6 to 14.5). The academic achievement and family functioning subscale scores were in the average range (see Table I). Due to missing data, only 204 of the 370 overall participants were used in the subsequent logistic regression analyses. Participants not used in the analyses did not significantly differ on academic functioning, evidence of stroke, demographic, disease severity, and family functioning factors from participants used in the analyses.

Risk Factors for Grade Retention

Correlations indicated that older age ($r = 0.28, p < 0.01$), lower income ($r = -0.15, p = 0.01$), lower reading achievement ($r = -0.32, p < 0.01$), and lower math achievement ($r = -0.31, p < 0.01$) were related to higher likelihood of grade retention (see Table I). In contrast, correlations and chi-squares indicated that sex, disease severity factors (e.g., SCD genotype, Hb level, and pain in the past year), and evidence of stroke were not related to grade retention. Thus, age, income, reading achievement, and math achievement were entered as the first block of factors in the logistic regression predicting history of grade retention (see table III). As a block, the risk factors significantly predicted grade retention risk ($\chi^2(4) = 42.13, p < 0.01$). Older age ($OR=2.98, CI_{95} = 1.76, 5.04$) and lower reading achievement ($OR=0.31, CI_{95} = 0.15, 0.62$) uniquely predicted a higher likelihood of grade retention.

Family Functioning as a Resilience Factor

Correlations indicated that higher family cohesion ($r = -0.20, p < 0.01$) was related to lower likelihood of grade retention (See Table I), while family conflict, expressiveness, and achievement-orientation were not related to grade retention. To control for the main effects of the family functioning variables during the subsequent analyses, they were all entered as the second block in the logistic regression. Adding the variables to the model did not significantly increase the fit of the model; however, lower family cohesion ($OR=0.52, CI_{95} = 0.31, 0.87$) uniquely predicted a higher likelihood of grade retention; thus indicating that higher family cohesion is directly associated with lower likelihood of grade retention.

To examine the possible protective effects of positive family functioning on the effects of risk factors, the interactions between the significant risk factors (age and reading achievement) and the family functioning variables were entered as the third block in the logistic regression. Adding the interactions to the model significantly improved the fit of the model ($\chi^2(8) = 22.01, p < 0.01$). The interaction between age and family achievement-orientation ($OR=0.39, CI_{95} = .22, 0.71$) significantly predicted likelihood of grade retention. The interaction was further investigated by evaluating the relationship between age and grade retention at low, medium, and high levels of family achievement-orientation as outlined by Baron and Kenny (1986) [30]. Age uniquely predicted a higher likelihood of grade retention at low ($OR=18.67, p<0.01$), medium ($OR=7.73, p<0.01$), and high family achievement levels ($OR=2.88, p = 0.01$). However, the pattern of findings indicate that at increasing levels of family achievement-orientation, the relationship between age and grade

retention decreases. This suggests that higher family achievement-orientation buffers against the negative effects of increasing age on likelihood of grade retention.

Discussion

The aims of the present study were to identify possible risk and resilience factors for grade retention in youth with SCD. In the sample, 19.2% of youth had been retained at least one grade. Although somewhat lower than previous estimates, this figure is still much higher than the estimated 5–10% of children who are retained annually in the U.S. [6]. As we hypothesized, older age and lower reading achievement predicted higher likelihood of grade retention. Inconsistent with our hypotheses, evidence of stroke, sex, disease severity factors, SES, and math achievement were not found to be predictive of likelihood of grade retention. Older children with SCD may have a greater probability of grade retention because they have been in school longer and SCD symptoms tend to get worse with age [31]. Although disease severity factors examined in this study were not related to likelihood of grade retention, other disease factors may be related to grade retention. Studies have reported higher rates of school absenteeism among youth with SCD compared to healthy peers, with estimates indicating 35% of youth with SCD miss about a month of school per year [32, 33]. Some students with SCD are possibly being retained due to school absences instead of achievement-related reasons. Also, though pain crises frequency was not related to grade retention, frequency and severity of lower level pain experienced at home may influence a child's academic progress by affecting their ability to focus in the classroom or leading to school absences. Lastly, reasons evidence of stroke was possibly not related to grade retention in the current study was because the location, severity, and timing of each stroke as well as the number of strokes experienced were not taken into account. Also, children who experience a stroke may be more likely to have an individualized education plan, thus decreasing their risk of grade retention due to special education services. This may explain why children with SCD with and without stroke had a similar likelihood of being retained. In conclusion, research is needed to examine the possible influence of these factors on grade retention.

Consistent with our hypotheses, the results indicated that higher family cohesion was predictive of lower likelihood of grade retention. Additionally, the results indicated that high family achievement-orientation buffered against the negative impact of increasing age on likelihood of grade retention. It is possible that youth with SCD in families with high achievement-orientation have more home-based academic supports or develop additional coping mechanisms to overcome academic obstacles. Thus, when they age and experience more disease-related complications, they are better equipped to handle academic demands. Overall, these results support the need to incorporate families into interventions focused on preventing grade retention in youth with SCD.

A limitation of this study was that 45% of the sample was missing data related to at least one of the predictor variables. The reduced sample size used in the logistic regression may have limited the power of the analyses to identify risk and resilience factors. In addition, there are different ways that researchers measure SES, disease severity, and family functioning. It is possible that the measures selected for this study did not capture all aspects of the

underlying constructs, and thus, additional research is still needed related to these factors. Lastly, the grade retention rate from the current study (19.2%) is lower than the grade retention rates of 23–54% reported in other studies of youth with SCD [2–5]. This difference may be because this study used a nationally representative sample that is much larger than other study samples. Thus, estimates concerning grade retention from previous studies may not be representative of the national pediatric SCD population. The current study also used parent-report of grade retention, which may be subject to social-desirability or recall bias. Future research should use direct review of school records to confirm grade retention. It is also possible that school reform legislation that has occurred in the past 10–15 years has altered the rates of grade retention. With the advent of the No Child Left Behind Act in 2001, which uses grade-level tests as the determining factor for grade promotion, the U.S. has seen a significant increase in grade retention [36]. Additionally, due to the advancements in treatment of SCD since the 1980–90s, including the advent of hydroxyurea, more children who might not have been able to attend school due to the severity of their complications may now be in school, and facing the possibility of grade retention. Taken together, there is a need for research to clarify current national estimates of grade retention in youth with SCD.

Due to the negative effects of grade retention on youth and the higher rate at which youth with SCD are retained than healthy children, more focus is needed on this issue. Lower reading achievement and older age were found to be risk factors, while high family achievement-orientation and high family cohesion were found to be resilience factors. Other possible risk or resilience factors for grade retention in this population, such as SCD-related school absences, lower level pain frequency and severity, and the development of adaptive coping strategies, should be investigated. One clinical implication of these results is that family functioning may influence the academic progress of youth with SCD. In conclusion, these findings suggest the need for interventions that promote connectedness and achievement-orientation in families of youth with SCD and future research to explore other possible risk and resilience factors for grade retention in this population.

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Table I

Descriptives of Continuous Variables and Correlations with Grade Retention

	M	SD	Range	r
Age (years)	10.6	2.7	6–16	0.28**
Income ^a	\$10,000–\$14,000		< \$5,000 to \$70,000–\$99,999	–0.15*
Hb level	9.2	1.8	5.6–14.5	–0.04
Broad Reading	89.1	18.3	19–136	–0.32**
Broad Math	88.8	15.5	25–131	–0.31**
Family Conflict	46.5	10.3	32–75	0.03
Family Expressiveness	48.4	9.5	15–66	–0.06
Family Cohesion	53.8	11.8	9–68	–0.20**
Family Achievement-Orientation	54.9	7.2	35–72	–0.00

^aIncome was a categorical variable. The median category and range is presented.

* $p < 0.05$.

** $p < 0.01$.

Table II

Descriptives of Categorical Variables and Chi-square Tests Based on Risk of Grade Retention

	Percent	χ^2	p
Grade Retention			
Yes	19.2%		
No	80.8%		
Sex			
Female	45.7%	2.1	0.15
Male	54.3%		
Sickle cell type			
HbSS or HbS/ β^0	63.0%	0.6	0.42
HbSC or HbS/ β^+	37.0%		
SCD Pain			
Yes	26.9%	2.1	0.14
No	73.1%		
Stroke			
Yes	23.9%	0.1	0.76
No	76.1%		

Note: Degrees of freedom for all chi-squares were 1.

* $p < 0.05$.

** $p < 0.01$.

Table IIIHierarchical Logistic Regression to Predicting Grade Retention (N = 204^a)

	OR	95% CI	χ^2
Block 1 Overall Model			42.13**
Age	2.98**	1.76–5.04	
Income	1.00	0.60–1.65	
BR	0.31**	0.15–0.62	
BM	1.24	0.60–2.55	
Block 2 Overall Model			49.135**
Block 2 Statistics			7.01
Age	3.17**	1.80–5.59	
Income	0.94	0.56–1.60	
BR	0.32**	0.15–0.67	
BM	1.12	0.51–2.44	
Family Cohesion	0.52*	0.31–0.87	
Family Expressiveness	1.15	0.71–1.85	
Family Conflict	0.61	0.35–1.05	
FAO	1.15	0.70–1.90	
Block 3 Overall Model			71.15**
Block 3 Statistics			22.01**
Age	7.33**	3.01–17.85	
Income	0.86	0.48–1.55	
BR	0.24**	0.10–0.61	
BM	0.94	0.39–2.30	
Family Cohesion	0.46*	0.22–0.98	
Family Expressiveness	1.23	0.55–2.76	
Family Conflict	0.58	0.25–1.33	
FAO	1.62	0.82–3.20	
Age*Family Cohesion	1.60	0.72–3.54	
Age*Family Expressiveness	0.57	0.29–1.14	
Age*Family Conflict	1.65	0.84–3.23	
Age*FAO	0.39**	0.22–0.71	
BR*Family Cohesion	0.91	0.53–1.56	
BR*Family Expressiveness	0.75	0.46–1.21	
BR*Family Conflict	1.81	0.92–3.57	
BR*FAO	1.25	0.68–2.28	

Note. OR=Odds Ratio; CI=Confidence Interval; BR=Broad Reading; BM=Broad Math; FAO=Family Achievement-Oriented. All variables in the logistic regression were continuous, and thus, were standardized prior to these analyses.

^a Only 204 of the 380 overall participants were used for these analyses due to missing data. Participants not used in the analyses did not significantly differ on academic functioning, evidence of stroke, demographic, disease severity, and family functioning factors from participants used in the analyses.

* $p < 0.05$.

** $p < 0.01$.