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Associates of School Absenteeism in Adolescents With Sickle Cell Disease

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Abstract

Background—Despite high rates of school absenteeism in adolescents with sickle cell disease (SCD), the issue remains understudied. Potential associates of school absenteeism in adolescents with SCD include demographic (age, income), psychosocial (IQ, self-efficacy, competence, internalizing symptoms, negative thinking), and health-related (hemoglobin, health-care utilization, pain, disease knowledge).

Procedure—Forty participants ages 12–18 completed measures of psychosocial functioning, IQ, and pain. Medical chart reviews identified other health-related variables. A subsample also completed an assessment of goals. Using school records, absenteeism was the percent of school days missed in the previous year. Correlations tested associates of absenteeism and linear regression tested a model of absenteeism.

Results—Participants missed an average of 12% of the school year and more than 35% missed at least 1 month of school. Health-related and psychosocial variables, but not demographic variables, correlated with absenteeism. Attendance at clinic appointments and parent-reported teen pain frequency were significant associates of absenteeism in the regression model. For those who completed goal assessment, over 40% of goals identified were academically focused. Absenteeism was positively related to current academic goals and health-related hindrance of academic goals, and negatively related to future-oriented academic goals.

Conclusions—School absenteeism is a significant problem for adolescents with SCD despite the presence of academic goals. Collaboration between schools, parents, patients, and providers to understand and manage the impact of SCD on school attendance is recommended.

Keywords

absenteeism; adolescent; attendance; goals; pain; school; sickle cell disease

INTRODUCTION

Adolescents with sickle cell disease (SCD) have a high risk of school absenteeism, yet few studies have explored this problem in depth [1]. Youth with SCD have been found to miss an average of 20–40 school days in 1 year [2,3], and to have worse school attendance than controls

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[4] and siblings [5]. Additional findings include worse standardized test scores [11] and history of repeated grades and special services compared to controls [6]. Findings of lowered school attainment may be partially attributed to school absenteeism [7,8].

Because of the unique complications of SCD and its being a genetic disease mostly affecting individuals of African descent, the potential risk factors for school absenteeism in youth with SCD are a complex combination of disease, demographic, and socio-emotional variables [1, 9-11]. Disease factors (e.g., pain, cognitive impairment due to cerebral infarcts, hospitalizations), psychosocial variables (e.g., coping, self-efficacy), and poverty (experienced by many with SCD) may increase the likelihood of school absenteeism in youth with SCD, which may exacerbate problems with school achievement and socio-emotional functioning [3,12-14]. Associated with financially challenged school systems, ethnic minority students have demonstrated lower school achievement than Caucasian students [15], thus further increasing school-related risk among those with SCD [1,9,11].

Given disease [16] and socio-emotional problems increase with age, especially among those with low socio-economic and/or minority status [17], there is a particular need to study school absenteeism of adolescents with SCD. However, few studies have examined adolescents, associates of school absenteeism, or school records. Furthermore, most studies have not included parent report of the child's functioning, even though parent perspectives may influence decisions to stay home from school and/or access health care [3,18,19]. Finally, no research has assessed the academic goals of adolescents with SCD. Knowing if they are motivated to maintain academic goals, despite the impact of health on those goals, is potentially important for intervention planning and reducing the possibility that absenteeism is reinforced by secondary gain.

The present study aims to address limitations of previous research on school absenteeism in youth with SCD and to expand knowledge of the problem in a sample of only adolescents. The study describes rates of, and associates of, school absenteeism from school records. Similar to previous research, it is expected that at least 35% of the sample will have missed 20 or more days of school (1 month) [2]. It is also expected that the following demographic, health, and psychosocial variables will significantly relate to school absenteeism: (1) age and lower income [1,16], (2) number of days in the hospital for acute visits and for routine clinic appointments in the previous year, average hemoglobin level in the previous year, parent and teen-reported pain frequency and intensity, and parent and teen-reported disease knowledge [3,12,20], and (3) lower intelligence, self-efficacy, developmental competency, and more negative thinking and internalizing symptoms [13,14,20,21]. Pain frequency and intensity are expected to be the most significant predictors of school absenteeism [2,3,12,14]. In addition, for a subsample that completed a goal assessment measure, the following will be described: (1) number of academic goals identified in participant-generated lists of personal goals, (2) percentage of academic goals that are current versus long-term, and (3) health-related hindrance (i.e., impact of pain, other physical symptoms, and taking care of health) on the academic goals. It is expected that percent of academic goals identified will negatively relate, and health-related hindrance (HRH) of academic goals will positively relate, to school absenteeism.

MATERIALS AND METHODS

This study includes baseline data from a cognitive-behavioral pain management intervention for teens with SCD. Approval was received from the appropriate Institutional Review Boards.

Potential participants were contacted via phone or approached in clinic. Baseline data collection took place in families' homes or other community location.

Measures

Demographic assessment—Caregivers answered questions about caregiver and adolescent education, age, and ethnicity; caregiver's job and relationship status; family socioeconomic status; and whether or not their child repeated a grade, had a learning problem, or ever received special education services.

Health-related variables—Medical chart review determined average hemoglobin level, number of sickle cell clinic appointments attended and number of days in the hospital for acute care (including emergency department and in-patient days) in the previous year.

Pain—The Varni/Thompson Pediatric Pain Questionnaire (PPQ) provided self- and caregiver-report of perceived pain in the previous week [22]. Subscale score of pain frequency (three items with a range of 0–3) was utilized. The internal consistency (Cronbach's α) of adolescents = 0.65; α of caregivers = 0.92. Rating of intensity (1 item with range of 1–10) was also used. Higher scores indicate greater intensity and frequency.

Disease knowledge—The Sickle Cell Knowledge Questionnaire is a reliable and valid 20-item true/false measure completed by caregivers and adolescents [23]. Total score of number of items correct was used.

General self-efficacy—The Perceived Self-Efficacy scale includes 20-items assessing youth self-report of perceived self-efficacy to handle potentially stressful events on a 5-point scale (1 = not at all sure, 5 = very sure) [24]. Validity of this measure is supported by associations with teacher ratings of school behavior and self-ratings of locus of control and anxiety [24]. For this sample, Cronbach's α is 0.89.

Coping—The Coping Strategies Questionnaire assessed strategies employed during SCD-related pain and consists of 80 items rated on a 7-point Likert-type scale from never (0) to always (6) [25]. The Negative Thinking subscale was used. Cronbach's α is 0.85 in the sample.

Developmental competence—The Child Behavior Checklist (CBCL; caregiver report) and the Youth Self-Report Form (YSR; youth report) are psychometrically sound and widely used general behavioral screening measures with multiple subscales [26,27]. The Total Competence subscale, which assesses competence with regards to school, social, and extra-curricular activities, was used.

Internalizing symptoms—The Internalizing Problems sub-scale of the CBCL and YSR were also used. Items are rated on a three-point scale ranging from 0 ("Not True") to 2 ("Very True or Often True").

Cognitive ability—The Test of Nonverbal Intelligence, 3rd Edition, Form A is a nonverbal measure of cognitive ability [28]. Total IQ scores were used.

Goals and health-related hindrance—The Health-Related Hindrance Inventory (HRHI)–SCD Version assesses goals and HRH [29]. Participants rate the extent to which pain, other symptoms, and doing things to take care of health interferes with their ability to work on 6 personal self-identified goals on a 7-point scale. Academic goals were coded by two independent raters and included any goals related to school/college. HRH ratings were averaged for all academic goals. Higher scores indicate worse HRH. Goals were also coded as current or future-oriented academic goals (anything that would take place more than one year in the future). Initial reliability and validity has been reported [29] and the α in the sample is 0.86.

School attendance—Parental consent was provided to request school attendance records in the previous year. Absenteeism was calculated as the number of days absent out of the total number of possible school days in the previous year per district calendars.

Data Analysis

Descriptive statistics were computed for all variables. Correlations were used to demonstrate relationships between percent of school days missed and potential correlates. A linear regression tested a model of potential predictors (i.e., significant correlates of school absenteeism).

RESULTS

Participants

Fifty-three patients at a sickle cell center completed baseline data. Of those, 40 adolescents had complete school attendance data and are included in this study. A subsample (n = 16) completed assessment of goals. (This measure was under development until half-way through recruitment.) Eligibility criteria were: (1) ages 12–18, (2) not receiving transfusion or hydroxyurea therapy (pain reduction medical treatments), and (3) having SCD types SCD-SS or SCD S beta-thalassemia (types associated with more pain and complications) [30]. Participants had an average age of 14 (SD = 1.58), were in 5th–11th grade (M = 7.65, SD = 1.66), 25 were female (62.5%) and 39 were African-American (97.5%). Most (n = 30, 75%) had SS type of SCD, while 25% had S Beta-thalassemia type. Forty-one percent (n = 18) had a family income less than $35,000 per year. Parents reported that 22.5% (n = 9) repeated a grade and 20.0% (n = 8) received special education services. A more detailed description of the sample and procedures is described elsewhere [21]. When comparing demographics of nonparticipants with participants, non-participants were significantly older (M = 15.74) than the participants (M = 14.11; $P < 0.001$).

Associates of School Absenteeism

As anticipated, more than 35% of the sample (37.5%, 15 of 40) missed 20 or more days of school. The mean percentage of missed school days was 11.67% (SD = 1.09; range = 0–55.40). As shown in the Table I, adolescents experienced mild to moderate pain, disease knowledge and self-efficacy were moderate, developmental competence and IQ were low average, and internalizing symptoms were average. School absenteeism was significantly associated with health-related and psychosocial variables, but not with the demographic variables (see Table I). The significant correlates ($P < 0.01$) were entered into a linear regression to test a model of absenteeism. The model accounted for 67% of the variance of absenteeism [F (5, 40) = 16.12, $P < 0.001$]. As shown in the Table I, beta coefficients are presented for the variables entered into the regression equation. Number of attended clinic appointments and more parent-reported pain frequency related to absenteeism in the model.

For those who completed the goal assessment measure (HRHI), the average number of academic goals identified was 2.88 (range = 0–6; 41%) out of an average of 6.88 goals identified per adolescent. An average of 52% were current and 48% were future-oriented academic goals. Almost every adolescent in the subsample (15/16) identified at least one academic goal. Current goals included, “get better grades,” “be in school more,” “keep up with my school work,” and “understand math.” Future-oriented goals included, “graduate high school,” “go to college,” and “get into a good college.” Contrary to prediction, percent of academic goals identified was not related to absenteeism. However, as shown in the Table I, correlations were found between absenteeism and percent of academic goals that were present-and future-oriented. Participants endorsed a modest amount of HRH and it was positively associated with absenteeism.

DISCUSSION

This study examined the relationship between a comprehensive set of variables and school absenteeism in adolescents with SCD. Other strengths include the focus on adolescents, inclusion of parent-report and medical and school record data, and assessment of goals to identify academic priorities. Similar to previous research [2], over 35% of adolescents with SCD had missed 4 or more weeks of school in the previous year with an average of 12% missed days. Such absenteeism may prevent adolescents with SCD from receiving necessary specialized educational services and may result in lowered academic achievement [4,9].

As hypothesized, health-related and psychosocial variables related to absenteeism, but demographic variables did not. Fortunately, most of the variables found to relate to absenteeism (e.g., disease knowledge, self-efficacy, and developmental competence) are ones that are potentially modifiable and amenable to intervention. Collectively, these variables suggest the need for teens with SCD to gain more skills, knowledge, and confidence to manage their disease and normative adolescent challenges.

That parent reporting of teen pain significantly correlated with absenteeism reflects the potential role of parents' in decision-making about school attendance [3,19]. That parent report of pain frequency, not pain intensity, was the most significant pain-related associate of absenteeism in regression analyses suggests that when teens reported pain to parents, regardless of intensity, they were more likely to miss school. Perhaps parents fear that pain will worsen and not be adequately managed in school, regardless of intensity. It is also possible that school absences may impact parental perception of teen pain frequency. Furthermore, the association of clinic appointment attendance to school absences is not surprising and indicates that compliance with medical recommendations may undermine school attendance. These findings emphasize the need for collaboration between parents, medical providers, and school systems [4,31].

Despite the significant problem of school absenteeism, data from a subsample showed that those adolescents with SCD are identifying academic goals. The relationship between percent of current academic goals and absenteeism may reflect an increase in goals related to "catching up" in school. The negative relationship between percent of future-oriented academic goals and school absenteeism may illustrate the potential for long-term goals to be a protective factor against missing school or that school attendance may facilitate formation of more long-term goals. Although further investigation is warranted to understand these goal processes, goal motivation is important for well-being and teens with SCD may benefit from help identifying achievable long-term goals [32,33].

Several limitations should be noted. For one, participants consented to a behavioral pain management intervention and were not receiving preventative medical therapy to manage pain. Thus, the current sample may be more affected by or motivated to deal with pain or they may experience more school absenteeism given the absence of prophylactic medical treatment for pain. The sample size is also small and power is limited, yet size is comparable to other similar studies [3,12]. The sample size was even smaller for those completing the goal assessment measure, thus further research is needed with a larger sample. Also, the cross-sectional design limits the ability to determine temporal relationships between risk factors and absenteeism. Finally, it is unknown if instruction took place outside the school at home or hospital for those who were counted as absent from school.

Because adolescents with SCD report having important academic goals, yet school absenteeism is a significant problem, more attention to this issue is warranted. School engagement is a critical protective factor for many adverse outcomes among adolescents [8] and may be a distractor from pain and other complications. Thus, attendance should be assessed at clinic

visits for youth with chronic illness as interventions in the medical setting or facilitated by the medical team may help promote school attendance. For example, adolescents and their caregivers may benefit from: (1) change in treatment regimen (e.g., addition of hydroxyurea) to reduce pain and improve functional outcomes, (2) education to the schools about warning signs of pain and ways teens can manage it in the school, (3) development of specialized education plans (e.g., 504 plan, IEP) to deal with high rates of health-related absenteeism, or (4) learning cognitive-behavioral strategies to deal with schools and manage and/or reduce pain (e.g., communication skills to deal with school; problem-solving techniques to deal with school and pain; relaxation, guided imagery, and distraction techniques to manage pain). Overall, results support the need for a combined treatment approach of psychological, medical, and school-based interventions. Future research should explore parent perceptions of the school and school-related variables that may affect attendance among adolescents with SCD. These include availability of analgesic medication, school attitudes and knowledge about SCD, allowance of precautions to minimize the risk of pain (e.g., wearing a coat in cold classrooms, keeping water bottles at desks), and availability of a school nurse or other on-site health services [9].

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TABLE I

Descriptives and Correlations With Absenteeism

	Mean (SD, range)	Correlation	β[b]
Demographic			
Age of teen	13.95 (1.58, 12–18)	17	
Income[a]	$35,000–$49,999 (<$10,000 to over $125,000)	−0.28†	
Health-related			
No. of days at hospital for emergent care in previous year	4.41 (6.8, 0–24.00)	0.52**	0.19
No. of routine sickle cell clinic appointments attended in previous year	4.51 (5.35, 0–32.00)	0.47**	0.76**
Average hemoglobin in previous year	9.12 (1.85, 6.33–15.30)	−0.22	
Pain frequency—Teen report	0.55 (0.73, 0–2.67)	0.20	
Pain frequency—Parent report of teen	0.43 (0.77, 0–2.67)	.64***	7.34***
Pain intensity—Teen report	3.05 (3.04, 1–10)	0.14	
Pain intensity—Parent report of teen	3.18 (3.37, 1–10)	0.29†	
Disease knowledge—Teen	15.88 (2.30, 11–20)	−0.41**	−0.62
Disease knowledge—Parent	17.05 (1.88, 11–19)	−0.03	
Psychosocial			
IQ	89.35 (11.93, 67–120)	−0.12	
Self-efficacy	66.67 (13.70, 41–98)	−0.32*	
Negative thinking	46.56 (29.70, 0–114)	0.06	
Developmental competence—Teen report	43.76 (10.98, 24–72)	−0.38*	
Developmental competence—Parent report of teen	40.87 (9.75, 26–63)	−0.46***	−0.18
Internalizing symptoms—Teen report	55.51 (10.68, 36–78)	−0.02	
Internalizing symptoms—Parent report of teen	52.34 (7.62, 37–71)	−0.01	
Goals[c]			
HRH of academic goals	1.55 (1.20, 0–3.57)	0.55*	
% Academic goals out of total goals	41 (19, 0–67)	−0.06	
% Academic goals: Current	48 (27, 0–75)	0.59*	
% Academic goals: Future	52 (27, 25–1)	−0.59*	

[a] Income was a categorical variable. The median category and range is presented;

[b] Significant ($P < 0.01$) correlates with absenteeism variables were entered into the regression predicting absenteeism; corresponding beta coefficients are shown.

[c] Goal-related variables were not entered into the regression because they were not assessed in the total sample;

† $P < 0.10$;

* $P < 0.05$;

** $P < 0.01$;

*** $P < 0.001$.