A Randomized, Controlled Pilot Trial of a School Intervention for Children with Sickle Cell Anemia

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Objective To investigate the feasibility and efficacy of a randomized clinical pilot trial comparing routine services (RS) with a school intervention program (SIP) for children with sickle cell anemia (SCA).

Method Twenty-four children (ages 8–12 years) with SCA were randomized to RS or SIP. General disease knowledge, consumer satisfaction, self-concept, and school absences were evaluated.

Results Compared with children receiving RS, children and teachers receiving SIP evidenced more accurate information about their disease, and children with SCA had significantly fewer absences. Teachers receiving SIP reported higher consumer satisfaction.

Conclusions A modest educational curriculum can increase knowledge of SCA, is associated with lower absentee rates, and yields high consumer satisfaction ratings.

Key words sickle cell anemia; school intervention; randomized controlled trial; consumer satisfaction.

Considerable data suggest that children with chronic illness are at risk for both academic and social difficulties at school (Sesson & Madan-Swain, 1993). Because of the importance of success in school for children, school intervention programs (SIPs) for chronically ill children have been developed (Katz, Rubinstein, Hubert, & Blew, 1988). The primary rationale for these programs is that a major developmental task of childhood is to function proficiently within the school environment, where academic achievement and positive social relationships with same-aged peers are major goals. These tasks may be especially difficult for a child with a chronic illness (Eiser, 1985).

One chronic illness that can be particularly challenging for children in school is sickle cell anemia (SCA). There are several features of SCA that may impact a child’s functioning in school. First, children with SCA are at risk for academic problems. They experience more school absences, which places them at risk for academic difficulties (Allen, 1983; Noll et al., 1996), and a significant minority of children with SCA also display subtle neurocognitive deficits associated with learning problems (Armstrong et al., 1996). Second, children with SCA often have numerous restrictions placed upon their activities and commonly experience chronic fatigue that can make it difficult physically to keep up with peers. School activities may be dramatically limited by hospitalizations, clinic visits, or physician’s restrictions (Charache, Lubin, & Reid, 1995). Third, SCA can have an adverse effect on a child’s appearance. Jaundice and small stature are typical visible effects of the disease, and it is not uncommon for children with SCA to appear different from other children, especially after the onset of puberty (Charache et al., 1995). Finally, children with SCA must deal with the illness with no hope of cure except bone marrow transplant. The unpredictable, episodic nature of the disease can be especially disruptive to maintaining a normal schedule. In some years, the disease will cause few difficulties, while other years may be marked by major disease-related disruptions.

The literature examining how children with SCA function in school suggests that these children have difficulties academically (Armstrong et al., 1996) and socially (Noll et al., 1996). Several studies conducted by our group have suggested that children with SCA are perceived as different from classmates by both teachers...
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Comparing routine services (RS) with SIPs for children with SCA.

The purpose of this study was to evaluate the feasibility and efficacy of a randomized clinical pilot trial comparing routine services (RS) with SIPs for children with SCA. Three hypotheses were tested. First, our previous experiences in the schools strongly suggested that our medical center's RS were not sufficiently intense, and the SIP condition was designed to provide critical, detailed information regarding SCA etiology and disease management. It was hypothesized that participants (children with SCA, teachers, and peers) in the SIP would exhibit more accurate disease knowledge than participants in the RS condition. Second, it was believed that participants in the SIP would report higher satisfaction with the medical center than participants in the RS condition, as the participants in SIP would not only appreciate the knowledge gained, but also recognize positive changes stemming from the intervention (e.g., changes in school management of disease-related issues for the child with SCA). Third, it was hypothesized that compared with children in the RS condition, children with SCA in the SIP would have fewer absences, as caregivers and the children themselves would feel more confident that the school had the information necessary for managing the disease and the children would have a greater self-concept (scholastic and social) given their improved adaptation within the school environment.

Method

Participants

Potential participants with SCA were identified from the roster of all patients with SCA receiving care from a comprehensive sickle cell center. This was done by one of the authors, who had primary clinical responsibilities at the sickle cell clinic. Inclusion criteria were: (1) a diagnosis of hemoglobin SS (HbSS), (2) attendance at regular elementary school (ages 8–12 years), and (3) no full-time special education. Children in elementary school were the focus of this study because they attended school with one group of peers during most of the day. Children ages 5–7 years (kindergarten and first grade) and children in full-time special education were excluded due to concerns about their ability to complete outcome measures. Because this center is part of the only pediatric facility with board-certified pediatric subspecialists and is the only pediatric hospital in the region, the population of known patients with SCA represents nearly every case. Parents of the children were contacted and informed of the study's focus on helping children with SCA adjust in school by evaluating the efficacy of existing services from the comprehensive center to schools as well as a new SIP. Parents were told that...
children with cancer from this center were routinely provided these services but that they had not been tried for children with SCA. Finally, parents were informed that their child would be randomly placed into one of two intervention conditions, RS or SIP. This research was approved by the hospital’s institutional review board (IRB).

Parents with children meeting age and disease inclusion criteria were contacted during clinic visits or over the phone. Two families who were contacted did not agree to participate in the randomization. After consent was obtained, children were randomized into two groups. Although 28 parents reported that their children met inclusion criteria, it is of note that 4 children (all randomized into the SIP condition) were later excluded when it was learned that they were in full-time special education classes. The final groups consisted of 14 children randomized to the RS condition and 10 children to the SIP condition. A majority of the children attended public elementary schools that were large in size (500+ students), located in the inner city and serving predominantly African American students (approximately 80%). Twenty-two schools participated in this project. One school had 3 children who were participating. All schools contacted agreed to accept the intervention.

**Measures**

**General Knowledge Questionnaire (GKQ)**

Six medical professionals in pediatric hematology constructed a questionnaire assessing knowledge of SCA including etiology, disease management, and sequelae. An etiology/disease-management conceptual framework guided development of the GKQ. This 20-item multiple-choice measure was designed to determine how much the respondents (children, teachers, parents) knew about the cause and sequelae of SCA and disease management issues relevant to understanding the impact of SCA on a child in school. Initially, two versions were created, a “child version” utilizing basic questions and simple language, and an “adult version” which contained complex questions requiring more detailed knowledge about SCA. Both forms of the questionnaire used a multiple-choice format and contained distracters that reflected common misconceptions regarding SCA, its etiology, disease management, and various sequelae associated with the disease. We initially piloted the adult questionnaire on teacher friends and nurses who did not work in hematology. After discovering that these adults knew little about SCA, as they could not answer a majority of the questions on the adult version, we determined that the child version was sufficiently difficult and could be used for all participants.

Questions were designed to assess not only etiology and disease-management issues but also existing myths about the disease. A principal-components analysis was completed on the questionnaires completed by peers (n = 537) and a subsequent scree test identified factors that clustered into two domains. The first was represented by 13 items with an average factor loading of .63 (range, .35 to .72). A review of these items suggested that they measured disease etiology and physical sequelae, hence this domain was labeled the etiology domain. The second domain was represented by 7 items with an average loading of .59 (range, .46 to .68). These items seemed to reflect disease management within the school environment and were consequently labeled the disease management domain. Thus, the factorial composition of the GKQ suggests that participants responded to each domain as a whole and that the defined domains were specific to etiology and disease management within the school environment. Cronbach’s α was computed as a measure of overall internal consistency for the GKQ. For this sample, the resulting coefficients were: overall = .89; etiology = .85; disease management = .77.

**Satisfaction Questionnaires**

Traditionally, many investigations of the outcome or effectiveness of services have included client ratings of their functioning and/or changes in functioning, but have lacked direct evaluation by the clients of the program from which they receive services (Young, Nicholson, & Davis, 1995). Three separate satisfaction questionnaires were developed for this study. The child satisfaction questionnaire was a 9-item visual Likert scale (frowning, neutral, smiling face) designed to evaluate the subjective experience of a child with SCA before, during, and after the intervention (factor loading average = .71 [range, .57 to .93]; Cronbach’s α = .71). The parent satisfaction questionnaire consisted of 20 items using a Likert scale to assess parents’ interest in the school intervention, perception of the quality of the intervention, and perception of intervention efficacy (factor loading average = .77 [range, .50 to .91]; Cronbach’s α = .88). Finally, the teacher satisfaction questionnaire (TSQ) had 27 items on a Likert scale to assess satisfaction with the provision of information about SCA, its management, and the availability and delivery of services. It contained two factors: satisfaction
with information received (factor loading average = .83 [range, .63 to .94]; Cronbach’s \( \alpha = .95 \)) and quality of services (factor loading average = .76 [range, .51 to .95]; Cronbach’s \( \alpha = .92 \)).

For each questionnaire, five experts in pediatric hematology, representing a variety of professional disciplines (e.g., psychology, medicine, education) rated each item on every questionnaire in terms of relevance (degree to which an item was germane in assessing participant satisfaction with the intervention) and item construction (degree to which an item was thought to be understandable and clear to potential participants). Each generated item was reviewed during weekly research staff meetings, and appropriate revisions were made until all experts agreed that the item was clear and relevant.

Because of the small sample size, the following precautions were taken to ensure the verity of results. We utilized stringent criteria to counteract spurious findings stemming from the small sample size; specifically, those criteria included high factor loadings, factor saturation, and face validity (Guadagnoli & Velicer, 1988). Items not meeting the above criteria were excluded from factors to ensure high \( \alpha \) for each factor.

**Absentee Data**
At the end of the school year, the school provided attendance data for each child with SCA by quarter or marking period. Thus, attendance was assessed by comparing attendance rates for the marking periods pre- and postintervention.

**Self-Perception Profile for Children**
(SPPC; Harter, 1985)
The SPPC consists of subscales designed to measure children’s self-competencies in the areas of (a) scholastic work, (b) social acceptance, (c) athletic ability, (d) physical appearance, (e) behavioral conduct, and (f) global self-worth. The reliability and validity of these scales are acceptable (Cole et al., 2001; Harter, 1985). In addition, the SPPC is reported to be appropriate for use with African American children (Alderman & Dover-spike, 1988) and has been used with children who have SCA (Noll et al., 1996).

**Block Design and Vocabulary Subtests of WISC-III**
These subtests of the Wechsler Intelligence Scale for Children, Third Edition (WISC-III) were administered in order to obtain an estimated measure of intellectual functioning. They were used because they have displayed the highest correlations with Full Scale IQ scores for children aged 8–12 years, with correlations ranging from .70 to .79 for Block Design and .77 to .84 for Vocabulary (Wechsler, 1991). This information was obtained for descriptive purposes.

**Procedures**
The majority of children with SCA attended school in the local urban school district, and this school system had an IRB. Hence, after this research was approved by the hospital’s IRB, a protocol document was submitted to the school’s IRB. This also was approved.

For both conditions, the initial contact was made with each child’s school principal. We made an initial phone call and then sent a package of information describing the study (available from R.B.N). With the principal’s permission, subsequent contacts were made with teachers in both conditions. No consent was required for the GKQ from peers or teachers. These data did not contain any identifying information except a school identifier number, and both the hospital and school IRBs agreed with our contention that completion of this measure anonymously created minimal risk.

**RS Condition**
Teachers were contacted and informed of our interest in having the class participate in a survey about SCA. A “survey time” was scheduled, during which the teacher and all children in the classroom of the child with SCA were asked to complete the GKQ. No additional services were provided unless specifically requested by the school or parents. This RS condition reflects the current “as needed” provision of services by the comprehensive sickle cell center, which occurs only when a family or teacher of a child with SCA makes a request. Of note, no liaison services were requested by any of the schools or families in this condition.

**SIP Condition**
Many months were spent developing the materials we wanted to use in the schools. This process included sickle cell clinic staff and members of the school intervention team from the oncology service. In addition to the time spent developing materials, we practiced teacher and peer presentations prior to making school visits. This permitted greater standardization and allowed us to develop specific strategies for presentations to teachers and peers. SIP consisted of five steps. First, the family was contacted to let them know we would be contacting their child’s school. We asked
parent(s) about specific concerns they currently might have regarding their child in school. Second, the child’s teacher was called and informed of our interest in providing better coordination of care between the hospital, family, and school. A packet of information (available from R.B.N) was sent and a teacher in-service was scheduled with the member of our SIP team. The information packet covered basic facts about SCA, addressing such questions as, what is SCA? what are the effects of SCA? what is sickle cell trait, as distinct from SCA? what is the history of SCA and sickle cell trait? how is SCA diagnosed? and, what is the treatment for SCA? Additionally the packet contained specific information for teachers regarding management of observable complications of SCA, including pain, chronic fatigue, hyperhemolytic episodes, strokes, infection, dehydration, absenteeism, small stature, and academic difficulties. For each of these problems, specific action steps were recommended subsequent to describing the problem.

Third, a one-hour in-service session for the primary teacher and relevant school faculty was scheduled. During this meeting, the information about SCA in the packet was reviewed and questions were answered. Specific problems identified by the parent(s) or school staff were also discussed. Fourth, a one-hour peer in-service was held in the classroom. Prior to going to the school, the family was contacted a second time to let them know that we had scheduled the classroom visit. Children were given the option to stay in their class, leave during the in-service, or cancel the in-service. All remained in the class and none requested that we cancel. The children were not given any additional preparation. We developed specific guidelines (available from R.B.N) for this class discussion. This presentation addressed such questions as, what is SCA? what do sickled cells look like? what causes SCA? is it contagious? what are some of the physical problems caused by SCA (pain, tiredness, stroke, jaundice)? what activities are restricted for children with SCA? and, how can you be a good friend to a child with SCA? The language and examples used in each class varied depending on the judgment of our staff member. We utilized three intervention staff, all of whom had college degrees. Two of these staff members administered the SIP for children with cancer at the medical center and one staff member was an educator from the sickle cell center. A supervisor with a Ph.D. in clinical child psychology and considerable clinical experience working with children with SCA and their families monitored these staff on a weekly basis. At the beginning of the peer in-service, the child with SCA was identified. Staff were encouraged to add information regarding the disease and its management in order to facilitate discussion and positive peer communications. Immediately following the peer in-service, teachers and all students completed the GKQ.

Fifth, the family of the child with SCA was contacted shortly after the peer session to evaluate the immediate impact of the intervention. We wanted to ensure that the child with SCA was comfortable with the peer in-service, and we specifically asked whether any teasing or ostracism occurred. A similar call was made to the teacher after the peer in-service. Continual liaison follow-up (minimum one contact per month) through phone contact with the teacher and the family assessed the need for additional services (e.g., individualized disease-management information for the school, pain medications in the office, extra school books at home, modification of physical education requirements, etc.). These follow-up services were provided on an as-needed basis so that the intervention could be custom tailored to the needs of the child, school, and family. Finally, during the summer immediately following the academic year of the intervention, data investigating program satisfaction and child self-concept were obtained from participating teachers, parents, and children with SCA. In general, teacher satisfaction data were collected during the first two weeks of summer break, while data on child and caregiver satisfaction and on child self-concept were collected during a home visit scheduled at the family’s convenience during June or July.

**Results**

**General Knowledge of SCA**

Group differences in general knowledge were investigated by tabulating frequencies for items answered correctly on the GKQ. $t$ tests were used to examine differences in number of correct questions provided by teachers, children with SCA, and classmates. Significant differences were found between the SIP and RS intervention groups for teachers, children with SCA, and peers. No significant differences were found for parent knowledge (Table I).

**Peers**

Examination of peer responses to individual GKQ items provided information about specific deficits in knowledge of SCA. The lack of knowledge and misconceptions
Table I.  General Knowledge of Sickle Cell Anemia (SCA) as a Function of Intervention Group

<table>
<thead>
<tr>
<th>Condition</th>
<th>Participant</th>
<th>RS Mean (SD)</th>
<th>SIP Mean (SD)</th>
<th>t Value</th>
<th>Effect Size Cohen’s d</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Teachers</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Overall knowledge</td>
<td>13.6 (2.1)</td>
<td>17.9 (1.6)</td>
<td>5.32**</td>
<td>2.25</td>
</tr>
<tr>
<td></td>
<td>Etiology</td>
<td>10.5 (1.7)</td>
<td>12.5 (1.4)</td>
<td>3.03**</td>
<td>1.27</td>
</tr>
<tr>
<td></td>
<td>Disease management</td>
<td>4.1 (1.4)</td>
<td>6.4 (0.7)</td>
<td>4.82**</td>
<td>1.97</td>
</tr>
<tr>
<td></td>
<td>Classmates</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Overall knowledge</td>
<td>6.3 (2.9)</td>
<td>15.1 (4.3)</td>
<td>24.69**</td>
<td>2.49</td>
</tr>
<tr>
<td></td>
<td>Etiology</td>
<td>4.4 (2.2)</td>
<td>10.6 (3.1)</td>
<td>24.46**</td>
<td>2.38</td>
</tr>
<tr>
<td></td>
<td>Disease management</td>
<td>2.1 (1.4)</td>
<td>5.5 (1.6)</td>
<td>17.69**</td>
<td>2.28</td>
</tr>
<tr>
<td></td>
<td>Children with SCA</td>
<td>10.9 (2.6)</td>
<td>16.3 (3.4)</td>
<td>4.08**</td>
<td>1.83</td>
</tr>
<tr>
<td></td>
<td>Etiology</td>
<td>7.6 (2.0)</td>
<td>11.7 (2.3)</td>
<td>4.42**</td>
<td>1.92</td>
</tr>
<tr>
<td></td>
<td>Disease management</td>
<td>4.2 (1.0)</td>
<td>5.6 (1.4)</td>
<td>2.19*</td>
<td>1.19</td>
</tr>
<tr>
<td></td>
<td>Parents</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Overall knowledge</td>
<td>13.4 (2.2)</td>
<td>14.9 (2.1)</td>
<td>1.65</td>
<td>0.69</td>
</tr>
<tr>
<td></td>
<td>Etiology</td>
<td>9.7 (1.6)</td>
<td>10.8 (1.3)</td>
<td>1.75</td>
<td>0.74</td>
</tr>
<tr>
<td></td>
<td>Disease management</td>
<td>4.9 (0.8)</td>
<td>5.5 (1.2)</td>
<td>1.62</td>
<td>0.61</td>
</tr>
</tbody>
</table>

RS = routine services; SIP = school intervention program.
Overall knowledge = 20 items; etiology = 13 items; disease management = 7 items.

a N, RS = 14; N, SIP = 10
b N, RS = 312; N, SIP = 225
*p < .05, two-tailed, between groups.
**p < .01, two-tailed, between groups.

exhibited by peers in the RS condition as compared with peers in the SIP are striking. For example, 21% of children in the RS condition believed that dirty needles caused SCA, and 56% believed that the disease was a result of a bad blood transfusion. In contrast, 93% of the children who participated in SIP could correctly identify that the disease was genetically transmitted. In addition, children in the RS condition also reported that pain related to SCA was caused by “bad blood” (66%), infection (14%), or falling down (6%). In contrast, 85% of the children in the SIP condition correctly reported that SCA pain was caused by the red blood cells. Finally, only 26% of the children in the RS condition knew that SCA affected primarily African Americans in the United States (92% in the SIP); instead, 62% of these children believed that the disease was most prevalent in individuals of Asian descent.

Peers in the RS condition endorsed items indicating that children with SCA had numerous physical restrictions, including the belief that children with SCA were not allowed to run (22%), take long walks (19%), or play tackle football (32%). The majority of peers in the RS condition (90%) believed that SCA was a communicable disease. That is, they believed that SCA could be “caught” from a classmate by: sitting together in class (31%), sharing a drink (33%), or receiving a blood transfusion (26%). In contrast, 92% of the children in the SIP condition were aware that SCA was not communicable and that they could not “catch” SCA from a classmate. Finally, very few peers in the RS condition were aware that strokes could occur with SCA (4%) or were aware of what might happen if a child were having a stroke (21%), while many children in the SIP condition knew about strokes (83%) and their warning signs (86%).

Teachers
Examination of responses by teachers in the two conditions also showed the major impact of the intervention. For example, only 21% of the teachers in the RS condition (compared with 100% of teachers in the SIP condition) were aware that SCA could cause strokes. Only 64% of these same teachers knew that a sign of stroke was an inability to move. In regard to daily disease management, 29% of teachers in the RS condition (0% in the SIP) endorsed items stating that SCA was communicable through transfusion of blood products. Seventy-eight percent of these same teachers (0% in the SIP) did not know that increased hydration is an important component of disease management and that this intake often necessitates an exception to school rules regarding drinks within the classroom. This same percentage of teachers in the RS condition also did not know that children with SCA do not concentrate urine as efficiently as children without the disease and therefore need to use the bathroom more frequently.

Children with SCA
Although all of the children with SCA received medical care in a comprehensive center routinely providing education (typically since birth), those receiving the SIP displayed significantly greater overall knowledge than those in the RS condition. For example, children with SCA who did not receive the SIP endorsed items reflecting misconceptions about the disease, including the erroneous beliefs that: their disease was caused by “bad blood” (36%); SCA could be cured through blood transfusions (21%); and SCA required a dramatic restriction of physical activities (71%). These findings suggest that the SIP was also informative for children with SCA, providing them with disease information they were lacking, or correcting misconceptions they had about their disease.
Parents
Caregiver general knowledge of SCA was not expected to differ across groups, since the intervention did not directly include caregivers. Nonetheless, these data were analyzed to explore caregivers’ current knowledge level so that deficit areas could be targeted in future interventions. Although caregivers displayed more knowledge about etiology and disease management than did their children, they evidenced some surprising knowledge deficits. Some caregivers did not know that SCA pain was caused by sickled red blood cells and attributed their child’s pain to bad blood (8%) or infection (29%). Only 29% of caregivers knew that SCA could impact a child’s growth. Finally, alarmingly, only 37% of caregivers knew the most common indicator of a stroke (inability to move or speak).

Satisfaction with the Program
Teacher Satisfaction
A multivariate analysis of variance was used to analyze differences across treatment groups on the two factors comprising the TSQ, satisfaction with information and satisfaction with service. A main effect was observed for group, with teachers in the SIP exhibiting greater overall satisfaction, $F(2,21) = 10.24$, $p < .001$. Inspection of univariate $F$s showed that teachers receiving the SIP reported greater satisfaction with information, $F(1,22) = 6.38$, $p < .05$, and overall service, $F(1,22) = 17.61$, $p < .001$.

Child Satisfaction
The child satisfaction data were analyzed with an analysis of variance (ANOVA). No main effects were observed, $F(1,22) = 0.46$, ns.

Caregiver Satisfaction
Data examining caregiver satisfaction were initially analyzed with an ANOVA. No main effects were observed, $F(1,21) = 2.48$, ns.

Absences and Self-Concept
We had anticipated that children in the SIP condition would have fewer absences and more positive self-concept than children receiving the RS intervention. There were no differences observed between groups on self-concept, or school absences occurring prior to the intervention (Table II). Differences were observed between groups for the number of absences after the intervention was conducted. Specifically, children who had received the SIP had significantly fewer school absences than children receiving RS. No differences were found subsequent to the intervention for self-concept.

Discussion
The first hypothesis examined knowledge about SCA and was supported. All groups of participants who received the SIP had greater knowledge about transmission, communicability, and clinical symptoms. Teachers receiving SIP displayed greater knowledge of the special needs of children with SCA within the school environment. This awareness has the potential to attenuate problems experienced by children with SCA that may stem from a previous lack of information regarding the special needs of children with SCA within the school environment.

Regardless of intervention condition, all children with SCA responded correctly to questions about transmission of the disease, its noninfectious nature, and lack of a cure. These findings suggest that children with SCA who are followed by a comprehensive center understand these rudimentary facts about the etiology of their disease. However, these same children differed in their breadth of knowledge. In contrast to children receiving RS, children with SCA receiving SIP could also correctly identify the physical sequelae associated with the disease (e.g., strokes, anemia), warning signs of a stroke, what

<table>
<thead>
<tr>
<th>Table II. Outcome Measures as a Function of Treatment Condition: Children with Sickle Cell Anemia</th>
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<tbody>
<tr>
<td>Outcome Measure</td>
</tr>
<tr>
<td>IQ (estimates)</td>
</tr>
<tr>
<td>Self-concept (Harter)</td>
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<tr>
<td>Scholastic competence</td>
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<tr>
<td>Social acceptance</td>
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<tr>
<td>Athletic competence</td>
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<tr>
<td>Physical appearance</td>
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<tr>
<td>Behavioral conduct</td>
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<tr>
<td>Global self-worth</td>
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<tr>
<td>Absences</td>
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<tr>
<td>Preintervention</td>
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<tr>
<td>Postintervention</td>
</tr>
</tbody>
</table>

RS = routine services; SIP = school intervention program.
* $N = 14$.
* $N = 10$.
\[ d \]
Within-group $t$-tests for correlated measures.
\[ d \]
Average absences prior to the peer in-service.
\[ d \]
Average absences after the peer in-service.
* $p < .01$, two-tailed tests, between groups.
causes SCA pain, and their special needs within the school.

The most striking differences in knowledge level were evidenced between groups of classroom peers. Peers receiving RS had many misconceptions and negative stereotypes associated with SCA. For example, many peers believed that SCA occurred primarily in Asian individuals, was communicable through touch or a blood transfusion, was caused by bad blood, and necessitated drastic restrictions of physical activities. Given that a majority (over 75%) of the peer participants in this study were African American, the finding that many peers (48.5%) did not know that SCA is a genetically inherited disease that predominantly affects African Americans was disconcerting. Furthermore, although many peers recognized that SCA is a blood disorder, they reported many misconceptions about the disease, endorsing responses that described SCA as bad blood. It is of note that the term bad blood has been used by the African American community to describe syphilis, and also has been used to describe HIV and AIDS (Masera, Monguzzi, & Tornotti, 1990). Such a negative label may result in the desire for children with SCA to conceal the presence of their disease in the absence of professional encouragement and support. Waiting for a request for services will result in suboptimal care.

In contrast, peers receiving SIP endorsed items that reflected accurate information of disease etiology, transmission, sequelae, and management within the school environment. Extant research more than two decades old (Feldman, 1980) has noted the importance of positive peer involvement to chronically ill children’s ability to manage their disease in a school environment. It can be speculated that peers who understand the needs of a child with SCA may be in a better position to serve a protective function. Specifically, they may be more accepting of common, daily problems associated with SCA. Moreover, when classmates (or teachers) know the signs of a stroke or other indications that a child with SCA is experiencing physical distress, they may recognize that their classmate needs help and take action. Greater knowledge could be life saving.

The second hypothesis examined satisfaction with the intervention and was partially supported. Across both intervention conditions, all participants reported high satisfaction ratings, with the only significant difference between group findings observed with teachers in the SIP condition reporting higher satisfaction than teachers in the RS condition. Differences in satisfaction were not observed between any other groups. The finding of high satisfaction with SIP teachers is especially important, as the onus of monitoring and implementing disease-management strategies within the school setting will often rest on the child’s teacher. It appears that once educated about SCA and their pupil’s specific disease-related needs, teachers recognize the severity of the illness and its sequelae and acknowledge the benefits of taking action despite perceived costs and/or barriers (e.g., additional time and energy required to establish exceptions to school rules, monitoring the child, etc).

Finally, to address the importance of the effects of the intervention and consumer satisfaction, it is vital to look to the responses of consumers and caregivers. Of note, the classroom in-service did not cause classmates’ ostracism of the child with SCA, but instead increased their knowledge of the disease. Careful follow-up with caregivers, teachers, and the children with SCA detected no instances of teasing, although this was a major concern for the staff of the comprehensive center and for some of the parents. Parents voiced some concerns when the study was described, but only two families declined to participate. Thus, it appears that prior to participating, each family was sufficiently motivated or concerned about the threat to their child’s health given the existing care structure and recognized the value of taking action despite perceived costs and/or barriers (e.g., concerns that their child would be stigmatized, possibilities that disease-management strategies within the school would not change). Future research in this area might cite our experience when parents and children are approached to conduct SIP.

It was also hypothesized that children receiving SIP would have fewer absences. Lower rates of absenteeism were found for children with SCA in the SIP. It could be speculated that the comprehensive follow-up services reassured parents that their child’s needs could be effectively addressed at school. Knowing that teachers and school professionals could effectively manage the child’s illness at school, parents may have been less likely to keep their child home for minor physical complaints.

The finding of significantly fewer absences for children receiving SIP is quite impressive and encouraging. Children with SCA have been identified as having school performance problems stemming in part from frequent absences (Briscoe, 1987). Given that children with SCA are already at risk for learning problems because of potential neurocognitive deficits, any intervention that can increase instructional time and exposure to academic material by decreasing absences
is likely to maximize a child’s ability to reach her academic potential. Ultimately, increasing a child’s school attendance and opportunities for learning and academic proficiency is likely to facilitate future job opportunities and maximize social integration and quality of life.

Finally, we had anticipated that children with SCA who received SIP would have a higher self-concept. This prediction was based on our expectation that sharing information with peers and teachers at school would boost the self-concept of children with SCA. Our data did not support this prediction. In the context of recent work examining self-concept and its meaning for children (Baumeister, Campbell, Krueger, & Vohs, 2003), we believe that this focus on self-concept may not be a desirable or anticipated effect. Future work might benefit from an examination of the impact of SIP on the actual behavior of children with SCA (and their peers) or the self-efficacy of youth with SCA.

**Additional Observations**

Although most parents responded correctly to questions tapping transmission of the disease, its noninfectious nature, and lack of an available cure, they displayed knowledge deficits regarding physical sequelae associated with the disease (e.g., strokes, anemia), warning signs of a stroke, and the special needs that children with SCA have within the school environment. Given the observed knowledge deficits, it is of particular concern that only one parent attended the intervention, although all were encouraged to attend. We do not believe that this behavior reflects parental indifference. Although many medical professionals recognize that education leads to empowerment and can provide a link to more effective advocacy, it is possible that the importance of this process has not been effectively conveyed to parents. Moreover, poor parental participation may reflect the status of single-parent, low-income families who are unable to attend many school-related functions because of other demands (Noll et al., 1996).

The above findings are especially noteworthy given that the parents and children with SCA in this study have been followed by a comprehensive sickle cell center. This center has been in existence for several decades and provides medical and educational services about SCA for parents and individuals in the community. Phone contact is routinely made with schools in the fall of each school year, but this clearly is not sufficient. Written materials, school visits (one for staff and one for the peers), and regular follow-up (at least monthly) with families and schools are essential. It is disconcerting that some parents who receive services from this center did not know rudimentary facts about their child’s disease. Only one parent responded correctly to all of the questions, and this parent was the only one who had attended the intervention in-service. Of great concern, 63% of the parents did not know the warning sign of a stroke. This lack of knowledge is particularly problematic given that all of the children in this study had HgbSS.

Finally, we speculate that society would value increasing the knowledge base of individuals who have a chronic disease. An increase in knowledge could positively impact the health of individuals with SCA by empowering them to effectively manage the day-to-day demands of their illness. Such education may also facilitate increased individual and group advocacy, resulting in greater access of services for afflicted individuals. Increasing knowledge can also impact the community. Considering the concomitant lack of accurate information and the existing misinformation and stigma associated with the disease, the African American community could be well served by additional educational services targeting the transmission and management of SCA.

This study had several limitations. First, although significant gains in knowledge were evidenced immediately following the in-service, there was no long-term follow-up, and an assessment of knowledge at baseline pre- and postintervention would have been a stronger design. Second, the impact that the intervention had on actual social relationships of children with SCA is an important issue that was not addressed by this study. Given that children with SCA are perceived as different from classmates by both teachers (Noll et al., 1992) and peers (Noll et al., 1996), it would be important to assess changes in peer relationships stemming from this type of intervention. Third, we did not keep track of specific additional services required for children in the SIP group. Fourth, while a framework was developed regarding school contact, teacher education, peer in-services, and follow-up care, we have not developed integrated materials necessary for dissemination of the effort. Fifth, this work occurred for only one year. Additional work is needed using SIP for multiple years to assess its impact. Sixth, this work was completed in only an elementary school. We speculate that children with SCA in middle and high school would benefit from SIP. Finally, these results are limited by our small sample size and the application of this intervention at only one comprehensive center.
To our knowledge, the present study represents the first empirical research that attempted to evaluate the efficacy of an SIP for children with SCA. Numerous papers have suggested the need for these types of services for children with cancer, but this has not been the case for SCA. We are disturbed by the lack of attention to this issue, despite an obvious need, and certainly such an effort has the potential to make these children's daily routines in school more supportive. These findings must be tested further to determine whether the results can be generalized to the total population of children with SCA, as well as children with other chronic illnesses. Future research efforts should consist of interventions conducted at multiple sites utilizing a multiyear, developmentally tailored curriculum that can systematically glean outcome information regarding peer relationships and self-concept, as well as academic achievement of the children with SCA. Long-term follow-up should evaluate retention of information about SCA and details of what is provided for each child/school and examine changes in the above variables across time.

We acknowledge that these types of projects are very difficult to implement. Senior staff with strong clinical and empirical skills working with children with SCA and schools are needed. They must develop strategies for intervention, but more importantly they must lead these efforts. For example, the senior investigator who had worked in the sickle cell clinic for over 5 years when this work began completed all recruitment for the current project. Numerous meetings with families of children with sickle cell occurred, and the local community sickle cell awareness group actively supported this effort after the senior investigator made a formal presentation to their board. Senior investigators must take additional time to develop a clear understanding of issues for schools regarding research. Schools are extremely open to collaborating with scientists, but only when they are assured that the research can be helpful and has minimal potential to harm participating children. Materials that are provided to schools must be meticulously developed. Even the phone calls for this work were scripted in writing.

Finally, given the central role that caregivers play in the lives of their children, all interventions should target both children with SCA and their parents. Our work failed in this effort. It will be essential to secure greater parental involvement in future interventions. Initial efforts should focus on educating parents about SCA and teaching them to work in tandem with medical professionals to best determine their child's needs within the school environment. With accurate knowledge of their child's disease and assistance at obtaining educational services, parents will have greater potential to effectively advocate for the special needs of their children. In conclusion, a focused, multisystem (e.g., family/school), multiyear effort using a health education curriculum in the school and continued research directed at the stigma associated with this illness appear to have the potential to improve the health and welfare of children with SCA.

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References


