

# Transition Needs of Adolescents With Sickle Cell Disease

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## MeSH TERMS

- activities of daily living
- adolescent development
- anemia, sickle cell
- self concept
- transition to adult care

**OBJECTIVE.** This article describes how adolescents with sickle cell disease (SCD) perceive their ability to perform everyday tasks required for transition to adult health care and independent living.

**METHOD.** The Adolescent Autonomy Checklist (AAC) was adapted to include skills associated with managing SCD (AAC-SCD) and was administered to adolescents during clinic visits. Participants indicated “can do already” or “needs practice” for 100 activities in 12 categories.

**RESULTS.** Of 122 patients, the percentage of adolescents who needed practice was greatest in living arrangements (38.7%), money management (35.8%), vocational skills (29.6%), and health care skills (25.5%). We found a significant effect of age and of cerebrovascular injury on the percentage of those who reported “needs practice” in multiple categories. We found no effect of gender and limited effect of hemoglobin phenotype on any skill category.

**CONCLUSION.** Findings support the need for educational intervention to improve transition skills in adolescents with SCD.

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Sickle cell disease (SCD) is a genetic disorder affecting approximately 100,000 Americans, the majority of whom are African-American (Hassell, 2010). Sickle cells in blood vessels lead to vaso-occlusion that can be painful and damaging to tissues and organs. Morbidities associated with SCD affect adolescents' participation in academic, extracurricular, and everyday activities. SCD negatively affects transition from pediatric to adult health care and independent living (Anie & Telfair, 2005).

## Negative Effects of Sickle Cell Disease on Function

At least 35% of patients with SCD have an overt or silent stroke, or cerebrovascular accident (CVA), by age 14 (Bernaudin et al., 2011; Ohene-Frempong et al., 1998). Adolescents with CVA have lower global IQ than age-, ethnicity-, and gender-matched controls (Hogan, Pit-ten Cate, Vargha-Khadem, Prengler, & Kirkham, 2006; Schatz, Brown, Pascual, Hsu, & DeBaun, 2001; Vichinsky et al., 2010). Children with sickle cell anemia

with or without CVA exhibit a gradual decrease in full-scale IQ (King et al., 2014). Pain episodes triggered by stress, anxiety, mood, sleep disturbances, weather, or physical activity may result in school absences and reduced extracurricular activities, producing decreased levels of participation in adolescent occupations (Herron, Bacak, King, & DeBaun, 2003; Jerrell, Tripathi, & McIntyre, 2011). Decreased cognitive functioning combined with reduced experience with activities of daily living (ADLs) can limit the ability of adolescents with SCD to transition to adult health care and independent living (Treadwell, Telfair, Gibson, Johnson, & Osunkwo, 2011).

## Identifying Perceived Health Care and Independent Living Task Needs in Adolescents With Sickle Cell Disease

The aim of this study was to describe specific tasks that adolescents with SCD need to practice in order to transition to adult health

care and independent living. To identify these tasks, members of our study team adapted the Adolescent Autonomy Checklist (AAC; Goodwyn, 1990) to include skills associated with managing SCD and thus developed the AAC–SCD. Team members included a board-certified pediatric hematologist, nurse practitioners, registered nurses, respiratory therapist, occupational therapist, psychologist, and social worker. The AAC–SCD is a self-report checklist. Self-report results for adolescents vary depending on the population (Huberty, Austin, Harezlak, Dunn, & Ambrosius, 2000; Mazefsky, Kao, & Oswald, 2011; Pinquart & Shen, 2011; Waters, Stewart-Brown, & Fitzpatrick, 2003). However, adolescents with chronic illness are more likely to indicate fewer needs than their parents (Cohen, Vowles, & Eccleston, 2010; Kalyva, Malakonaki, Eiser, & Mamoulakis, 2011; Vetter, Bridgewater, & McGwin, 2012; Wilson, Donders, & Nguyen, 2011). Despite the possible underestimation of needs, we sought adolescents’ perspective on their readiness to transition. Although psychometric properties of the AAC and AAC–SCD have not been determined, the AAC–SCD provides a tool to help adolescents with SCD identify tasks they need to practice and might be used for future intervention.

## Method

### Research Design

The institutional review board of St. Louis Children’s Hospital approved this single-arm, retrospective study.

### Participants

All participants were patients at the hematology clinic. Patients were included if they were between ages 13 and 21 yr and completed the AAC–SCD. Non-English-speaking patients were excluded.

### Instrument

Both the AAC and the AAC–SCD contain 12 categories listing a total of 100 common tasks with columns to indicate “can do already,” “needs practice,” “plans to start,” and “accomplished.” Many of the tasks involve multiple skills. For the health care skills

category, the number of items on the AAC–SCD increased from 16 to 32 statements to include skills necessary for SCD self-management. Three categories were added because of their importance to the population: nutrition, sexual development, and money management. To maintain 100 items, some categories and items on the AAC were removed or consolidated for the AAC–SCD. Individual items less relevant to this population were removed. For instance, many families did not have stable homes; thus, we removed the categories including the family, gardening, and community.

Categories in the AAC–SCD include kitchen, nutrition, laundry, housekeeping, emergency, personal skills, health care skills, sexual development, money management, leisure skills, vocational skills, and living arrangements; it takes approximately 15 min to complete. The AAC–SCD was incorporated into standard care for adolescents treated in the Sickie Cell Clinic beginning at age 13. Psychometric properties for the AAC–SCD have not been assessed; however, the tasks are consistent with needs addressed in life and health skills programs for at-risk adolescents, including foster youth (e.g., health, financial, employment; Courtney, Lee, & Perez, 2011), students with special health care needs (e.g., health care management, self-advocacy; Hess & Straub, 2011), and adolescents with SCD (e.g., health literacy, disease self-management skills, interaction and communication with providers, life planning; Treadwell et al., 2011).

### Procedure

Participants completed the AAC–SCD in clinic during regular appointments. A staff member asked participants to place a mark in either the “can do already” or the “needs practice” column. In this article, we are reporting the needs-practice data.

### Data Analysis

Data were analyzed with IBM SPSS Statistics Version 19.0 (IBM Corporation, Armonk, NY). Descriptive statistics were used to determine the percentage of adolescents who checked the needs-practice column for each AAC–SCD item and category among all participants and among three age groups: 13–15 yr, 16–18 yr, and 19–21 yr. The mean

number of responses indicating needs practice for each item was averaged to create a category score. Nonparametric tests were used to analyze the categorical data. The Kruskal–Wallace test for independent samples was used to determine the effect of gender, age category, SCD phenotype, or brain injury status on the mean percentage who indicated “needs practice” for each category. Post hoc analyses were performed using Mann–Whitney *U* with a Bonferroni  $\alpha$  level adjustment of  $p = .05/\text{number of comparisons}$  (Pallant, 2010).

## Results

### Demographics

The AAC–SCD was administered to 122 adolescents ages 13–21 yr (Table 1). Sixty-one (50%) were male. The mean age was 16.1 yr (standard deviation = 2.5). Hemoglobin analysis confirmed SCD. Twelve (9.8%) adolescents were diagnosed with overt stroke confirmed by MRI, 30 (24.6%) were diagnosed with silent stroke, and 80 (65.6%) had no confirmed CVA.

### Needs Assessed by Category

Descriptive means and standard deviations for “needs practice” for the 12 categories are shown in Table 2. The category of greatest need was living arrangements; 38.5% ( $n = 42$ ) of participants checked “needs practice” for at least one item in that category. For health care skills, 25.4% ( $n = 30$ ) reported “needs practice.” We found no effect of gender for any category.

### Individual Items

At least 25% of adolescents in both the 13–15 and 19–21 age groups checked “needs practice” to know hemoglobin type. All age groups needed practice with understanding individualized education programs (IEPs; 38%), transition plan of the IEP (42%), and 504 educational plans (41%).

Although we found a significant decrease in health care skill needs between the 13–15 and 19–21 age groups,  $\chi^2(2, N = 118) = 10.19, p < .017$ , at least 20% of 19- to 21-yr-old adolescents expressed a need for practice for many individual items. These tasks included “Make own

**Table 1. Demographics (N = 122)**

Variable	n (%)
Age, yr	
Mean (standard deviation)	16.1 (2.5)
Range	13–21
Gender	
Male	61 (50.0)
Female	61 (50.0)
SS status	
SS	70 (57.4)
SC	31 (25.4)
SBT	18 (14.8)
Other	3 (2.5)
Infarct	
None	80 (65.6)
Silent	30 (24.6)
Overt	12 (9.8)

Note. SBT =  $\beta$  thalassemia disease; SC = sickle cell disease; SS = sickle cell anemia.

doctor's appointments" (22%), "Know when to get a complete blood count (CBC) and other tests" (39%), "Have genetic counseling if appropriate" (45%), "Considered finding a doctor I will use for my adult hematologist" (43%), and "Know the difference between primary care and specialists, and what each provides" (22%). Although vocational skills needs decreased significantly from 41.7% in the 13–15 age group to 22.7% in the 16–18 age group ( $Z = -2.6$ ,  $p < .01$ ) and 15.22% in the 19–21 age group ( $Z = -3.15$ ,  $p < .01$ ), an individual item of concern was "How to prepare a résumé"; 50% of the 13–15 age group, 24% of the 16–18 age group, and 26% of the 19–21 age group checked "needs practice."

### Cerebrovascular Accident (Stroke)

We found a significant effect of CVA on housekeeping,  $\chi^2(2, N = 116) = 7.04$ ,  $p < .05$ ; personal skills,  $\chi^2(2, N = 118) = 6.49$ ,  $p < .04$ ; and health care skills,  $\chi^2(2, N = 118) = 6.43$ ,  $p < .05$ . Significantly more adolescents with overt stroke than adolescents with normal magnetic resonance images needed practice in housekeeping (18.3% and 5.4%, respectively;  $Z = -2.63$ ,  $p < .01$ ); personal skills (17.0% and 7.6%, respectively;  $Z = -2.54$ ,  $p < .015$ ), and health care skills (41.4% and 23.5%, respectively;  $Z = -2.54$ ,  $p < .015$ ). Differences between normal and silent stroke were not significant for any category.

### Age Category

Category means and standard deviations for the three age groups are presented in Table 2. Needs in most categories tended to decrease with increased age. For three categories—emergency (e.g., using fire extinguisher), money management, and living arrangements (e.g., understanding leases)—there was no significant change over time, and more than 20% of adolescents in all age groups checked "needs practice."

### Discussion

Despite the possible underestimation of needs on a self-report tool, adolescents with SCD identified a significant number of deficits in transition skills. Adolescents with

CVA had significantly more needs in the personal skills, housekeeping, and health care skills categories than adolescents with silent stroke or no brain injury. Categories in which more adolescents in all age groups needed practice were emergency, money management, and living arrangements. In addition, all age groups indicated needs of 20% or more for several individual items in the health care and vocational categories. These findings likely underestimate the true needs of this population.

Given the prevalence of cognitive challenges among this population, educational supports are commonly needed (King et al., 2006, 2014). Kindergarten through 12th-grade educational programming often does not include life skills training for the types of tasks for which these adolescents indicated needing more practice. Transition programs for ages 19–21 may have that type of training but are not available in every school district. Our data indicate that about 50% of 13- to 15-yr-olds, 40% of 16- to 18-yr-olds, and 22% of 19- to 21-yr-olds did not understand IEP and 504 programs. Better understanding of and self-advocacy to obtain support and resources might promote academic attainment.

The AAC–SCD provided insight into tasks for which adolescents with SCD reported they need practice. Educational programs that address SCD-specific health care needs might improve overall health and decrease emergency department use.

**Table 2. Mean Percentage of Skill Categories Marked "Needs Practice," by Age Group**

AAC–SCD Categories (No. of Items)	% of Participants, All Age Groups, $M(SD), n$	% of Age Group 13–15 yr, $M(SD), n$	% of Age Group 16–18 yr, $M(SD), n$	% of Age Group 19–21 yr, $M(SD), n$
Kitchen (4)	2.9 (0.12), 119	4.6 (2.2), 55	1.8 (1.4), 41	1.1 (1.1), 23
Nutrition (6)	15.8 (0.22), 119	19.7 (3.1), 55	10.6 (2.9), 41	15.9 (5.2), 23
Laundry (6)	11.7 (0.20), 120	15.0 (2.8), 56	7.9 (2.5), 41	10.1 (4.3), 23
Housekeeping (6)	7.4 (0.16), 116	10.8 (2.6), 54 <sup>a</sup>	3.2 (1.5), 39	6.5 (3.6), 23 <sup>b</sup>
<b>Emergency (4)</b>	<b>25.4</b> (0.30), 117	<b>27.3</b> (4.0), 54	<b>21.3</b> (3.8), 40	<b>28.3</b> (8.2), 23
Personal skills (6)	8.7 (0.12), 118	12.2 (1.9), 54	6.9 (1.4), 41	3.6 (1.5), 23
<b>Health care skills (32)</b>	<b>25.4</b> (0.22), 118	<b>32.5</b> (3.3), 54	<b>20.9</b> (2.6), 41	17.1 (4.6), 23 <sup>b</sup>
Sexual development (6)	12.7 (0.25), 114	<b>23.6</b> (4.5), 52 <sup>a</sup>	4.3 (2.3), 39	2.2 (1.6), 23 <sup>b</sup>
<b>Money management (6)</b>	<b>35.8</b> (0.39), 113	<b>46.1</b> (5.7), 51	<b>29.2</b> (5.9), 39	<b>24.4</b> (6.4), 23
Leisure skills (13)	0.11 (0.15), 115	12.6 (2.1), 52	9.2 (1.9), 40	9.7 (3.7), 23
<b>Vocational skills (6)</b>	<b>29.6</b> (0.33), 112	<b>41.7</b> (4.9), 50 <sup>a</sup>	<b>22.7</b> (4.5), 39	15.2 (5.9), 23 <sup>b</sup>
<b>Living arrangements (5)</b>	<b>38.5</b> (0.40), 109	<b>46.4</b> (5.8), 48	<b>32.6</b> (6.1), 38	<b>32.8</b> (8.4), 23

Note.  $n$  = number who completed survey. **Bold** indicates that more than 20% of participants who completed the survey indicated "needs practice" in that category. The 16–18 age group did not differ from the 19–21 age group. AAC–SCD = Adolescent Autonomy Checklist–Sickle Cell Disease;  $M$  = mean;  $SD$  = standard deviation.

<sup>a</sup>A significantly greater proportion of the 13–15 age group than the 16–18 age group marked this item,  $p < .017$ . <sup>b</sup>A significantly lower proportion of the 19–21 age group than the 13–15 age group marked this item,  $p < .017$ .

Programming is also needed to help adolescents with SCD develop independent living skills and the ability to self-advocate for academic support programs in secondary and higher education. Training for résumé writing and job interview skills is also needed.

## Implications for Occupational Therapy Practice

Occupational therapy practitioners can assist adolescents with SCD in the transition to adult health care and independent living in the following ways:

- Health care: Teach adolescents to schedule appointments, manage medication, and request medical tests
- Money management: Help adolescents open a bank account and create a budget
- Vocational skills: Teach résumé preparation and interview skills
- Education: Assist adolescents in learning to self-advocate.

## Limitations and Future Directions

This study was retrospective; participants were not randomized. Data were from a single center. However, this urban clinic likely captures patients similar to those in other hematology clinics.

Because the AAC-SCD is a self-report checklist, needs are based on self-perception. Participants may possibly have underestimated needs and overestimated abilities. Future studies might include parent report of abilities and the Assessment of Motor and Process Skills (Fisher & Jones, 1999). ▲

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