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Assessment of Transition Readiness in Adolescents with Sickle Cell Disease and their Caretakers, A single institution experience

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Abstract

AIM—Sickle Cell Disease (SCD) is associated with high child mortality and birth incidence in sub-Saharan Africa. Improved SCD medical services in Ghana aims to enhance survival into adulthood, creating emerging need for transition from pediatric to adult care. Anticipating transition for adolescents with SCD, we sought to understand patient and caretaker perspectives on transition to adult care within Ghana.

MATERIALS AND METHODS—Structured interviews were conducted with a sample of patients ages 12–15 years and accompanying adults at Ghana's Komfo Anokye Teaching Hospital Sickle Cell Clinic (KATH SCC) covering four areas: SCD medical knowledge, symptom self-management, psychosocial impact, and transition preparation.

RESULTS—In total, 46 children (mean age 13 years) paired with 46 adults were interviewed. Most children and caretakers had some knowledge about SCD and disease management. At least one-third lacked knowledge about SCD as an inherited condition. Youth were significantly more

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concerned about family burden and social stigmatization than adults. Most were unaware that patients are expected to switch care to adult medical providers by age 15 years, but were willing to transfer if needed.

CONCLUSIONS—Our clinic-based assessment at KATH SCC identified needs of adolescents and caretakers for education and counseling about disease, self-management, transition, family burden, and stigmatization. These findings provide insights into perspectives and educational gaps of families treated for SCD. Results suggest consideration of transition planning for adolescents with SCD and their caretakers in Ghana. Generalizability of our findings and practical methods to address needs for transition within Africa remain to be tested.

Keywords

Sickle cell; Transition; Adolescents; Ghana

INTRODUCTION

Sickle Cell Disease (SCD) is an inherited blood disorder[1] that has been identified by the World Health Organization (WHO) as a significant public health problem worldwide[2]. Africa bears the highest burden of the disease[3]. The incidence of SCD in screened Ghanaian newborns is approximately 2%[4], with SCD types SS (HbSS) and SC (HbSC) being the predominant sub-types[1]. In communities within Sub-Saharan Africa without newborn hemoglobinopathy screening and access to standardized health services for SCD, an estimated 50–90% of affected children die during early childhood[5].

In countries with well-resourced health services, newborn screening, and other interventions implemented over the past several decades, more than 95% of affected children survive into adulthood. Prolonged survival created need for transition services to adult care[6,7]. Challenges to successful longitudinal SCD care include successful transition from pediatric to adult care and addressing life-skill challenges and psychosocial concerns to support the shifting of responsibility from family and medical staff to patients[8–13]. Transition to adult care in the U.S. usually takes place between ages 18–21 years. The process requires pediatric patients to adopt skills and take responsibility to minimize adverse disease-associated complications, attend medical visits, and engage in other aspects of disease self-management[14,15].

Among low income countries in Sub-Saharan Africa such as Ghana, early screening for SCD and improving services are expected to enhance disease survival[16,17]. As elsewhere, challenges associated with transition from pediatric to adult care, including anxiety[11,18,19], may be magnified by the African practices of early transition to adult care during mid-teen years[20,21]. Traditionally high childhood mortality had minimized need for adult-directed medical care. A study of autopsy data in Ghana's capital city of Accra demonstrated SCD to be one of top three causes of death in adolescents 10–19 years of age[22]. Improved patient survival in Ghana and elsewhere in the region is predicted to expand, as are the needs for providers and health systems suited to adult patients. Based on these trends, understanding the needs of adolescent patients in Ghana in order to provide information, resources, and support may enhance the effectiveness of transition to adult care.

The Komfo Anokye Teaching Hospital (KATH) is a major academic medical center and the second-largest tertiary referral hospital in Ghana. The KATH Sickle Cell Clinic (KATH SCC) is one of two large, established specialized pediatric SCD centers in Ghana. A team of pediatric hematology providers, residents and nurses provides the clinic's large number of patients with standardized SCD care[3]. SCD patients are routinely referred to the KATH general adult clinic by age 15 years.

Using a structured interview at a single SCD clinic in Ghana, the aim of this study was to assess the knowledge and perspectives of older pediatric patients with SCD and their caretakers prior to transition, focusing on the four domains that have been relevant for assessing transition readiness in the U.S and U.K.: SCD medical knowledge, independent management of SCD symptoms, psychosocial impact of SCD and transition preparation[13,23]. KATH SCC patients ages 12–15 years and adult caretakers accompanying these children were interviewed to compare their perceptions about the child's perspectives on these topics.

METHODS

The study was approved by the Institutional Review Board at Columbia University, Kwame Nkrumah University of Science and Technology and KATH.

Study inclusion criteria were: KATH SCC patients with SCD ages 12–15 years attending the clinic between June – August 2016 and the accompanying adult. Potential participants were approached in the KATH SCC clinic by two research staff members, both Ghanaian-born native speakers of English and Twi (MKS and CKT). Families were approached to offer study participation if the child was not having pain or other acute symptoms. Oral consent and assent were obtained from adult and pediatric subjects, respectively, following the reading of an IRB-approved script by one of these two study staff. Structured interviews using a guide questionnaire were conducted following enrollment. Both the consent/assent script and the guided interview were offered in English or in Twi (a predominant language spoken by most of the clinic attendees), and selected per subject preference.

Interview questions had been adapted from two surveys that previously had been used to assess transition readiness and transition related concerns of adolescents in the U.S.: Sickle Cell Transfer Questionnaire (SCTQ)[13] and Transition Intervention Program Readiness for Transition (TIP-RFT)[23]. Those studies had identified four major domains that were relevant to SCD transition from pediatric to adult care cited above. Our interview consisted of 31 questions to touch on all four domains, affording structured and narrative responses. Questions on demographics and clinic utilization were also included in the interview. Responses from pediatric or adult participants were recorded on paper by the interviewer and later analyzed. For each question, the adults were asked for their perceptions of how the child would respond to or think about each question.

Interview questions were first piloted with a small number of patients and their accompanying adults. To ensure fidelity of the interview process, the lead interviewer (MKS) demonstrated obtaining consent/assent and interviewing to the secondary interviewer

(CKT). Subsequently, interviews by the latter were observed by the former. Periodic discussions on adherence to consistent methodology continued during the course of study period to ensure continued fidelity.

In almost all cases, interviews with patients and the accompanying adult were conducted separately to minimize response bias. Notes from the interviews were taken in the interview language, then translated into English by MKS. Following the interview, the child's clinic-based medical record was reviewed to confirm the child's sickle cell type (HbSS, HbSC, other).

Descriptive statistics and qualitative analysis were used for data analysis. P-values were calculated using Chi-square test. Quotes from subjects were transcribed and translated by MKS, and used to illustrate specific points.

RESULTS

Piloting

Four children and four accompanying adults were interviewed. Subsequently, minor language changes were made to the guide to improve clarity and two follow-up questions were added on clinic utilization.

Recruitment

A total of 53 children and 49 adults attending the KATH SCC were invited to participate in the study. Five children were ineligible, one declined and one did not complete an interview. One adult declined to participate and two did not complete interviews. In all, 46 children and 46 accompanying adults met eligibility criteria, consented and completed interviews. None of the enrolled pediatric patients were siblings. Most subjects chose to speak Twi for interviews.

Sample Demographics

Demographics of the sample are shown in Table 1. Mean age of pediatric participants was 13.0 years (range 12–15) and 61% were female. The majority of children (61%) had partial or complete junior high school education (7^{th}–9^{th} grades). For SCD type, 59% had HbSS, 35% HbSC, and 6% did not have an SCD type located in their paper-based medical record. Adult participants were grouped as parents (70%) or non-parents (30%). All adults were family members, either parents, grandparents, uncles, aunts, siblings or cousins. Mean age of all participating adults was 39.8 years (range 18–70), mean age of parents was 42.7 (range 31–55), and mean age of other family members was 33.1 (range 18–70). Level of their education ranged from no formal education to university or vocational school.

SCD Medical Knowledge

Responses of children and adult groups are compared in Table 2 which shows the proportion in each group agreeing with questionnaire statements.

In general, the majority of pediatric subjects had some knowledge about SCD. Most children (61%) agreed that SCD is a blood disorder and more (74%) agreed that SCD is an inherited disease. Survey responses for adults reflect the proportion who reported that their children would agree to the statements listed. A similar number of adults correctly reported that their child knew both facts: 70% and 72% respectively. Half (52%) of the children knew that SCD is a familial disease, while two thirds (63%) knew about SCD's heterogeneous clinical manifestations. Nearly half of adults (46%) reported that their child knew these two facts. On knowing the child's sickle type, significantly fewer children (39%) knew compared to the adults (63%) ($p = 0.02$). Two children volunteered that "my mother hasn't told me [my sickle type]."

Independence in Managing Disease Symptoms

During a pain crisis, at least 61% of the children knew how different activities affect their symptoms, what to do to ease pain, where to go for care, what care is helpful, what to say to the health care provider at the hospital, and could engage with the hospital healthcare team. Each of these same responses were corroborated by at least 63% of adults (Table 2). Of children who reported knowing how to handle a pain crisis, some (50%) took analgesics including ibuprofen and paracetamol, as well as maintenance medications such as folic acid and penicillin. Others (28%) reported that they "massage [their] body with hot water and apply *kojooto dompedompe,*" (a locally used topical ointment). A few (11%) did both. Half of children (48%) and adults (46%) reported that the child had already taken some initiative to learn about SCD. Many of these children (86%) reported watching topical television programs, asking family members about the disease or both.

Psychosocial Impact of SCD

Children generally were more concerned about their current health and other people discovering that they had SCD than about future health-related challenges. Most of the children (76%) worried about having SCD. Of these, eleven mentioned that they worry about missing school days, not being able to participate in activities when in pain or being "the only one with [SCD]" in their families.

Significantly fewer adults than children (48% versus 76%, $p = 0.01$) reported that the child worried about their health. One parent did not believe that the child worried about his health because "if [the child] did, he wouldn't be doing some of the things he does now." Nonetheless, some adults expressed concerns. One adult stated "Now that he will be going to [a senior high boarding school], he worries about it. Because of that, we can't even take him [to that school]." Another adult stated that "It bothers her but I distract her from it. We don't allow her to read papers or watch TV programs about the sickness. Sometimes I tell her they are lying so don't worry."

More children than adults (28% versus 6%, $p = 0.01$) stated that they felt having SCD was a burden to their family. Reasons given by children for their concerns were the cost of care and time spent by their parents taking care of them. One parent said about the child, "Since she is still young, I don't see her thinking that way." Another parent said, "As for me, she is not a burden to me." Almost all children (96%) and adults (93%) agreed that the children

had considered plans for their future. Few children (< 26%) and fewer adults (< 17%) reported that the children were worried about impediments to accomplish future plans or not having control of their lives because of SCD. One child who did not worry about the future said, “I see it as it can’t do anything to me.”

A majority of children (70%) and adults (72%) had revealed the child’s illness to the teachers at school. In some cases, they stated disclosure of the child’s diagnosis was revealed to explain a school absence or avoid being beaten as school punishment. In other cases, disclosure to the child’s teacher was intended to access help if a pain crisis were to arise in school. One parent stated, “As for the teachers, when they see her eyes, they will ask me if my child has sickle cell and they will advise me to go to the clinic.” Fewer than half of children (37%) told their friends about their condition. Some children feared being teased. One child stated that “For some people, if you tell them and you are playing, they will tease you.” In some cases, parents discouraged the child from telling friends, for example, because “I don’t want her friends to know or else they will laugh at her; I don’t tell people so they don’t call [her a] *sickler.*”

Transition Preparation

A minority of children (35%) and adults (37%) were aware of the need for transfer to adult care by age 15 years. However, a majority of both groups (72 and 74% respectively) were confident that the child would be ready to transfer by the requisite age. Several subjects stated their acceptance of transfer based on its being required by the healthcare team. One child stated, “If they say we should go, we can’t say we won’t go, we have to go.” Another said, “Because whatever the doctors say, I listen.” Some children were concerned they did not have enough information about adult care, SCD or what to expect and almost all (97%) desired more information in those areas.

DISCUSSION

Until recently, high childhood mortality from SCD in Ghana and elsewhere in Africa obviated the need to plan for adult care[5]. With the advent of newborn screening programs for hemoglobinopathy and subsequent special disease care, survival of SCD patients is expected to increase beyond their childhood years for many patients[16,17]. Consequently, some areas in the region are expanding the need for medical services beyond pediatrics[24,25,26].

At the KATH SCC, adolescents and their accompanying adult family members were asked about a range of topics that have previously been identified as important for successful transition to adult SCD care in the U.S and U.K[13,23]. To our knowledge, this is the first patient survey about SCD transition in Ghana or elsewhere in Africa.

Gaps in knowledge about SCD transition and self-management have been identified in adolescents and young adults and their caregivers in the U.S, U.K, and Nigeria[12,13,19,27,28,29]. Similarly, child participants in our study lacked some knowledge about SCD and disease management. Compared to the findings from a U.S study by Sobota et al assessing transition readiness of adolescents[28], SCD knowledge was generally lower

amongst the KATH SCC child participants in our study. Another study by Sobota et al of adolescents with SCD reported lack of disease medical knowledge as a barrier to successful transition[29]. Additional knowledge gaps identified in our study included basic knowledge about type of SCD and which medications to use for a painful crisis. Inadequate knowledge about appropriate analgesia used by adolescent patients has also been reported in Nigeria by John-Olabode et al[19]. Additional factors for knowledge gaps among our sample may include younger age of child participants and cultural norms norms that place primary responsibility for educating children about SCD on family members rather than on health care providers. A few adults expressed concern that clinic staff did not speak directly to the children during visits.

Our results suggest that parents and other adult caregivers may intentionally limit the child's knowledge about SCD. Some parents intentionally withheld the diagnosis from their child to delay anxiety about the illness. As SCD is often deadly among children in Africa, some adults may prefer to shield children from the diagnosis.

Challenges to understanding SCD as an inherited disorder may be related to the low English literacy rates of study participants. Most subjects spoke only Twi, the local language. This language does not include terms for "inherited" or "genetic," a gap that may challenge teaching about SCD. In Ghana, family roles for protecting children from harm may also take into account traditional beliefs about loss of power through supernatural forces[30].

Previous studies from the U.S, U.K, and Nigeria have also reported psychosocial issues faced by adolescent and young adult patients with SCD related to transition[11,19,31]. In contrast to findings by other studies[12,28], few patients in our survey were concerned about future health-related challenges to employment or financial support of their medical care. Overall less concern about the future among our surveyed patients may be attributable to their younger age, the relative paucity of individuals with SCD living into adulthood and some misconceptions about SCD. One child mentioned being told that "If you pass 28 years, you won't die."

Our participants suggest that social stigmatization of SCD exists in schools and among peers. Stigmatization for SCD has been reported in studies conducted in the U.S.[28], Ghana[32], and Nigeria[18]. In contrast, many parents and children had informed teachers about having SCD. This perspective suggests that teachers may be entrusted to assist young adolescent patients in negotiating their schooling despite serious health needs.

While transfer from the KATH SCC to a general medical clinic is required by age 15, no expectation of transition planning was detected among our sample. While most participants were unaware of transfer to adult care, they reported feeling ready to do so when required. This perspective was contrary to other studies from the U.S and U.K, where adolescent participants expressed reluctance to transfer to adult care for several reasons, including familiarity with the pediatric clinic and medical team and fear of the unknown on the adult side[12,13,19,33]. Our study participants expressed concerns about not being familiar with adult care systems, but were determined to follow the healthcare team's established rules

and recommendations about transfer. This perspective is consistent with local cultural norms for patients to trust and accept recommendations by healthcare providers.

Adolescent patients interviewed in this survey were younger than those from studies performed in the U.S. and elsewhere. Transition to adult SCD care typically occurs later in high-income countries than in this sample from Ghana[10]. Younger age of transfer to adult care in Ghana and elsewhere in Africa may raise different developmentally driven issues than those reported elsewhere[12,28,34].

Limitations of our study include its modest sample size at a single SCD clinic. Hence, our results may not be representative of transition at other SCD clinics in Ghana or elsewhere in the region. Most, but not all of the children were paired with their parent. The roles of these other family members in providing overall and medical care to the children interviewed were unclear. Young adults with SCD who have already transitioned were not interviewed about their experiences with transition.

Our study at a major pediatric SCD clinic in Ghana suggest that these youth commonly lack key basic information about SCD, have concerns about peer stigmatization and are unaware of the need to transition to general medical care and the implications for their own care. As suggested in other studies[10,13,19,28,29], future efforts to improve transition to adult SCD care may need to include education of young adolescents and their adult caregivers about the disease and self-management. Additional features related to transition raised here include addressing sense of self-burden to families and stigmatization in school and among peers. As successful screening and implementation of other measures for SCD medical care expand in Ghana and elsewhere in Africa, these issues may need to be addressed in surviving adolescent patients.

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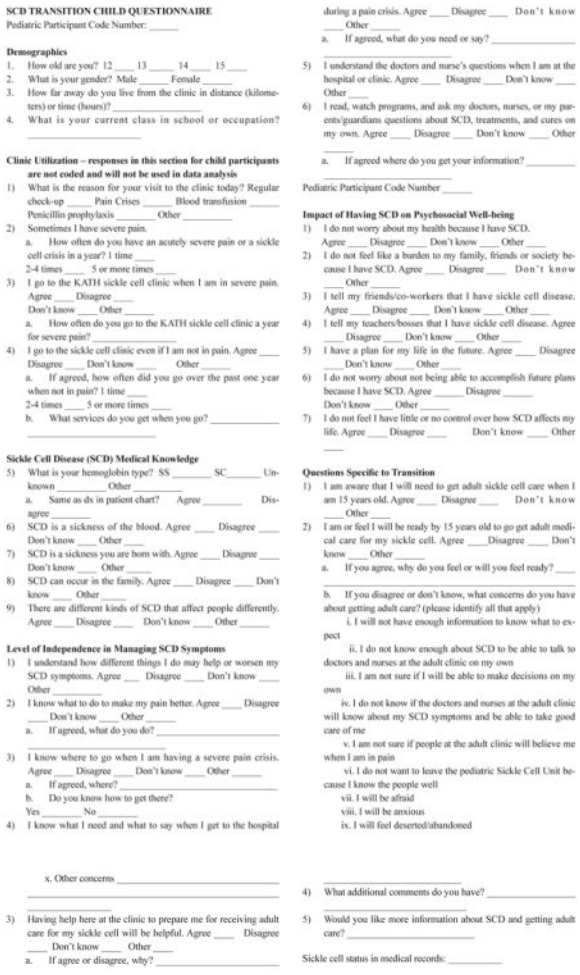
SCD TRANSITION CHILD QUESTIONNAIRE



SCD TRANSITION CHILD QUESTIONNAIRE
Pediatric Participant Code Number: _____

Demographics
1. How old are you? 12 ___ 13 ___ 14 ___ 15 ___
2. What is your gender? Male _____ Female _____
3. How far away do you live from the clinic in distance (kilometers) or time (hours)? _____
4. What is your current class in school or occupation? _____

Clinic Utilization – responses in this section for child participants are not coded and will not be used in data analysis
1) What is the reason for your visit to the clinic today? Regular check-up _____ Pain Crises _____ Blood transfusion _____ Penicillin prophylaxis _____ Other _____
2) Sometimes I have severe pain.
   a. How often do you have an acutely severe pain or a sickle cell crisis in a year? 1 time ___
   2-4 times ___ 5 or more times ___
3) I go to the KATH sickle cell clinic when I am in severe pain. Agree ___ Disagree ___
   Don't know ___ Other _____
   a. How often do you go to the KATH sickle cell clinic a year for severe pain? _____
4) I go to the sickle cell clinic even if I am not in pain. Agree ___ Disagree ___ Don't know ___ Other _____
   a. If agreed, how often did you go over the past one year when not in pain? 1 time ___
   2-4 times ___ 5 or more times ___
   b. What services do you get when you go? _____

Sickle Cell Disease (SCD) Medical Knowledge
5) What is your hemoglobin type? SS _____ SC_____ Unknown _____ Other _____
   a. Same as dx in patient chart? Agree _____ Disagree _____
6) SCD is a sickness of the blood. Agree ___ Disagree ___ Don't know ___ Other ___
7) SCD is a sickness you are born with. Agree ___ Disagree ___ Don't know ___ Other ___
8) SCD can occur in the family. Agree ___ Disagree ___ Don't know ___ Other ___
9) There are different kinds of SCD that affect people differently. Agree ___ Disagree ___ Don't know ___ Other _____

Level of Independence in Managing SCD Symptoms
1) I understand how different things I do may help or worsen my SCD symptoms. Agree ___ Disagree ___ Don't know ___ Other _____
2) I know what to do to make my pain better. Agree ___ Disagree ___ Don't know ___ Other _____
   a. If agreed, what do you do? _____
3) I know where to go when I am having a severe pain crisis. Agree ___ Disagree ___ Don't know ___ Other _____
   a. If agreed, where? _____
   b. Do you know how to get there?
   Yes _____ No _____
4) I know what I need and what to say when I get to the hospital during a pain crisis. Agree ___ Disagree ___ Don't know ___ Other _____
   a. If agreed, what do you need or say? _____
5) I understand the doctors and nurse's questions when I am at the hospital or clinic. Agree ___ Disagree ___ Don't know ___ Other ___
6) I read, watch programs, and ask my doctors, nurses, or my parents/guardians questions about SCD, treatments, and cures on my own. Agree ___ Disagree ___ Don't know ___ Other _____
   a. If agreed where do you get your information? _____

Pediatric Participant Code Number _____

Impact of Having SCD on Psychosocial Well-being
1) I do not worry about my health because I have SCD. Agree ___ Disagree ___ Don't know ___ Other ___
2) I do not feel like a burden to my family, friends or society because I have SCD. Agree ___ Disagree ___ Don't know ___ Other _____
3) I tell my friends/co-workers that I have sickle cell disease. Agree ___ Disagree ___ Don't know ___ Other ___
4) I tell my teachers/bosses that I have sickle cell disease. Agree ___ Disagree ___ Don't know ___ Other ___
5) I have a plan for my life in the future. Agree ___ Disagree ___ Don't know ___ Other ___
6) I do not worry about not being able to accomplish future plans because I have SCD. Agree _____ Disagree _____ Don't know ___ Other _____
7) I do not feel I have little or no control over how SCD affects my life. Agree ___ Disagree ___ Don't know ___ Other ___

Questions Specific to Transition
1) I am aware that I will need to get adult sickle cell care when I am 15 years old. Agree ___ Disagree ___ Don't know ___ Other ___
2) I am or feel I will be ready by 15 years old to go get adult medical care for my sickle cell. Agree ___Disagree ___ Don't know ___ Other _____
   a. If you agree, why do you feel or will you feel ready? ___
   b. If you disagree or don't know, what concerns do you have about getting adult care? (please identify all that apply)
      i. I will not have enough information to know what to expect
      ii. I do not know enough about SCD to be able to talk to doctors and nurses at the adult clinic on my own
      iii. I am not sure if I will be able to make decisions on my own
      iv. I do not know if the doctors and nurses at the adult clinic will know about my SCD symptoms and be able to take good care of me
      v. I am not sure if people at the adult clinic will believe me when I am in pain
      vi. I do not want to leave the pediatric Sickle Cell Unit because I know the people well
      vii. I will be afraid
      viii. I will be anxious
      ix. I will feel deserted/abandoned
      x. Other concerns _____
3) Having help here at the clinic to prepare me for receiving adult care for my sickle cell will be helpful. Agree ___ Disagree ___ Don't know ___ Other ___
   a. If agree or disagree, why? _____
4) What additional comments do you have? _____
5) Would you like more information about SCD and getting adult care? _____

Sickle cell status in medical records: _____

Table 1

Demographics of child (N = 46) and adult participants (N = 46).

Variables (child)	N (%)	Variables (adult)	N (%)
Gender		Relationship to child	
Male	18 (39)	Parent	32 (70)
Female	28 (61)	Non-parent	14 (30)
Age (years)		Age (years)	
Mean age (years)	13	All adults mean age (range)	39.8 (18–70)
12	18 (39)	Parents mean age (range)	42.7 (31–55)
13	15 (33)	Non-parents mean age (range)	33.1 (18–70)
14	9 (19)		
15	4 (9)		
Education†		Education (Parent)†	
Junior high school (7–9th grade)	28 (61)	Beyond secondary school	3 (7)
Primary school (4–6th grade)	17 (37)	Up to Secondary school only	19 (41)
		Primary school	5 (11)
		No school	2 (4)
		Education (Non-parent)†	
		Beyond secondary school	2 (4)
		Up to Secondary school only	9 (20)
		Primary school	3 (7)
		No school	0 (0)
Distance lived from clinic			
<1 hour	39 (85)		
1+ hours	6 (13)		
Don’t Know	1 (2)		
Child’s SCD‡ Diagnosis			
HbSS¶	27 (59)		
HbSC¶	16 (35)		
Unavailable	3 (6)		

†Percentages may not add up to 100% for some missing responses;

‡Sickle Cell Disease;

¶Hemoglobin SS or Hemoglobin SC.

Table 2

Comparison of proportion of children (N=46) and adults (N=46) agreeing to questionnaire statements.

Questionnaire Statements	Child N (%)	Adult N (%)	p-value
SCD[≠] Medical Knowledge			
Knows own/child's hemoglobin type	18 (39)	29 (63)	0.02*
SCD is a sickness of the blood	28 (61)	32 (70)	0.38
SCD is a sickness with which you are born	34 (74)	33 (72)	0.81
SCD can occur in the family	24 (52)	21 (46)	0.53
There are different kinds of SCD that affect individuals differently	29 (63)	21 (46)	0.09
Independent Management of Symptoms			
Understands how different activities may help or worsen SCD symptoms	31 (67)	37 (80)	0.15
Knows what to do to make the pain better	28 (61)	29 (63)	0.83
Takes oral pain and/or maintenance medication	14 (50)	12 (41)	
Massages and/or uses topical ointment	8 (28)	7 (24)	
Both medications and massage/topical ointment	3 (11)	3 (10)	
Other	3 (11)	7 (24)	
Knows where to go when having a pain crisis	39 (85)	34 (74)	0.2
Knows medical care needed and what to say when gets to the hospital in pain crisis	33 (72)	31 (67)	0.53
Understands the doctors' and nurses' questions when at the hospital or clinic	40 (87)	44 (96)	0.14
Learns about SCD, treatments, and cures on own	22 (48)	21 (46)	0.83
Watch television programs on SCD	8 (36)	7 (33)	
Ask family members about disease	6 (27)	10 (48)	
Both TV programs and asking family	5 (23)	3 (14)	
Other	3 (14)	1 (5)	
Impact of Having SCD on Psychosocial Well-being			
Worries about health because of SCD	35 (76)	22 (48)	0.01*
Feels like a burden to family, friends or society because of SCD	13 (28)	3 (6)	0.01*
Tells friends/co-workers about having SCD	17 (37)	17 (37)	1
Tells teachers/bosses about having SCD	32 (70)	33 (72)	0.82
Has plans for life in the future	44 (96)	43 (93)	0.65
Worries about not being able to accomplish future plans because of SCD	12 (26)	8 (17)	0.82
Feels has little or no control over how SCD affects life	7 (15)	5 (11)	1
Transition Preparation			
Aware of need to transfer when 15 years old	16 (35)	17 (37)	0.83
Ready to transfer to adult care for SCD by age 15	33 (72)	34 (74)	0.81
Desire for more information on SCD and adult care	44 (97)	46 (100)	-

*statistically significant;

[≠]Sickle cell disease.