Providers' Perspectives and Beliefs Regarding Transition to Adult Care for Adolescents with Sickle Cell Disease

By: Joseph Telfair, Leah R. Alexander, Penny S. Loosier, Patty L. Alleman-Velez, and Julie Simmons

Telfair, J., Alexander, L, Loosier, P, Alleman-Velez, P. & Simmons, J. (2004). Provider's Perspectives and Beliefs regarding Transition to Adult Care for Adolescents with SCD. *Journal of Health Care for the Poor and Underserved*, 15(3): 443-461. DOI: 10.1353/hpu.2004.0049

Abstract:
Until recently, few children with chronic illnesses such as sickle cell disease (SCD) lived past late adolescence. Substantial reductions in mortality mean a growing number of adolescents with SCD reach adulthood. Consensus among researchers and health care providers (HCP) from multiple disciplines is that critical attention to and more empirical research on the transition from pediatric to adult care is needed. We address the following questions: (1) How do pediatric and adult providers demonstrate involvement in transition? (2) What is expected of adolescents when they move to adult care? and (3) Do providers think there is a need for a systematic transition program? A cross-sectional, multi-format survey research study utilizing open-ended and forced-choice questions was conducted to compare responses between pediatric and adult providers from multiple disciplines. Data were collected from 227 HCP in three waves. Significant bivariate results ($p < 0.05$) reflected differing opinions regarding transition expectations and program need, especially among female providers, those practicing in urban areas, and providers who treat both adolescent and adult clients in comparison with their counterparts. Discussion includes implications for program development, social service and public health practice, and future research.

Keywords: Sickle cell disease, transition to adult care, adolescent health, health promotion, youth health, provider expectations.

Article:
Health care providers (HCP) from multiple disciplines can play a key role in addressing the issues of transition to adult care for adolescents and young adults with sickle cell disease (SCD) and other special health care needs.[1-3] As defined by Blum and co-workers,[4-8] transition is "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from a child-centered to an adult-oriented health care system" (p. 570). In a consensus statement,[9] the American Academy of Pediatrics along with the American Academy of Family Physicians and the American College of Physicians-American Society of Internal Medicine set a goal that, by 2010, "all physicians who provide primary or subspecialty care to young people with special health care needs 1) understand the rationale for transition from child-oriented to adult-oriented health care; 2) have the knowledge and skills to facilitate that process; and 3) know if, how, and when transfer of care is indicated" (p. 1304). The consensus panel's emphasis on the importance of transition, in turn, prompted others to stress the importance of provider education to fill gaps in transition knowledge.[10-12] However, to date, empirical research establishing a baseline for practice, as well as for the means by which the consensus panel's recommendations have been put into action (e.g., through provider education) is lacking.[13]

As recently as 20 years ago, transition would not have concerned pediatric and adolescent providers. Few children with chronic illnesses, such as SCD, lived past late adolescence. However, early detection through newborn screening, other medical innovations such as prophylactic antibiotic therapy, and improvements in self-care regimens and transfusion therapy[14] have resulted in substantial reductions in morbidity and mortality. Thus, a growing number of young people with SCD are reaching late adolescence and adulthood.[15-19]

Significant medical and technological advances in SCD patient care mean that more adolescents with SCD will be faced with the challenges of moving into adult care and life. Newacheck and associates[20] found that 18% of children studied under 18 years of age had or were presumed to have had a chronic physical, developmental, behavioral, or emotional condition (difficult-to-identify at-risk youth were not included). These children were significantly more likely to experience more days in bed because of illness, more days absent from school, more physician contacts, and more days spent in the hospital than those who did not have special health care needs. They were also significantly more likely to be less satisfied with their medical care and had a greater proportion of unmet health needs. Medical, psychological, social, and education service providers for adolescents and young adults with SCD increasingly are key players not only in adolescent health care but also in the transition to adult care.[8,21-24]

Survival into adolescence and adulthood for young persons with SCD is associated with a number of health problems and concerns, including predisposition to infections, chronic lung disease, cardiac failure, stroke, vaso-occlusive crises, life-threatening anemia, delayed growth, high morbidity associated with pregnancy, and psychosocial considerations such as self-care, coping, readiness for independence, and the process of moving from adolescent- to adult-centered care.[24-26] Unfortunately, without the structure and guidance of a well thought out transition program, many young people with SCD lack basic information about how to negotiate the medical care system competently to shift effectively from pediatric to adult care.[27,28] Often this guidance is either missing in the health care setting [29] or not given priority in the health care infrastructure (e.g., lack of reimbursement options for transition teams under current payment systems, absence of important transition team components).[30-33]

The growing number of adolescents with SCD and other chronic conditions who reach late adolescence and young adulthood and the absence of research into skills needed during the transition to adult care together have made research on transition a high priority. The 2002 consensus statement offered jointly by the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians-American Society of Internal Medicine[3] acknowledged the importance of physicians and other providers in facilitating transitions to adulthood and adult care. (For a more in-depth examination of this goal see "Adolescent Health Care and Transitions" in *The Management of Sickle Cell Disease*.[33]) As a result, some researchers began to look at provider knowledge, barriers, and expectations,[6,10,11] but most provided information derived from focus groups or anecdotal accounts, or used study sample sizes that were too small to draw broad conclusions. This is one of the first broad-based studies; it is based on the use of a survey developed and reviewed (via three Delphi rounds) by the primary investigators and a team of multidisciplinary providers. The focus of the current research is on the opinions and insights of health care providers from multiple disciplines regarding the transition to adult care from pediatric care of adolescents with SCD ages 12 years and older.

Background

Transition occurs over time and not cross-sectionally.[31] For the purposes of the research presented in this paper, transition is conceived as a dynamic process[25] with a beginning, a middle, and an end. The beginning phase includes the decision to begin or prepare for the transition. The middle phase, transition readiness, includes logistical and other efforts of preparation for and implementation of the transition. *Transition readiness* encompasses the specific decisions made and actions taken in building the capacity of the adolescent and those in his or her primary medical microsystems (parental caretakers/family and providers) to prepare for, begin, continue, and finish the process of transition.[33,34] Because an increasing number of adolescents with SCD are surviving into adulthood, transition has become a critical issue.[33,34] The final or end stage occurs when the adolescent or young adult not only transfers to an adult care setting but is actively participating in adult care activities, such as working with providers to plan his or her own medical care; deciding if a provider to whom he or she is referred is someone with whom he or she can work; and, if the decision is negative, finding and choosing a different provider. Given the chronicity of SCD, this transition occurs as adolescents move from life skills suitable for childhood or adolescence to adult life skills and as they move from pediatric or child-centered care to adult health care services.[33]

Multidisciplinary provider interventions aimed at addressing the life skill needs of late adolescents with chronic conditions effectively decrease many of the difficulties associated with moving into adulthood and adult medical systems.[16,35,36] Despite this, the availability of these and other long-term comprehensive care services remains limited.[18] Consequently, late adolescents and young adults do not receive much medical care on a regular basis.[9,13,15] A national survey of Directors of Maternal and Child Health (MCH) and other state health programs from the 50 states in the U.S. [17] found that the directors recognized that late adolescents who are chronically ill are at risk for many psychosocial and long-term life skill difficulties. Nonetheless, these directors expressed the view that this population was not a priority for services because, in most children's health initiatives, priority is given to children under 5 years of age. Where services for adolescents do exist, they are often fragmented, despite the fact that high-quality comprehensive health, social, vocational, and educational services can greatly help adolescents with chronic conditions to overcome many of the challenges they face.[10,30,37]

In findings from previous studies on providers' roles in the transition of adolescents with SCD to adult care, providers identified the following as barriers: (1) families and youth being overly dependent on pediatric providers, (2) pediatric providers fostering dependency, and (3) a lack of communication between pediatric and adult providers.[6,31] A communication barrier among providers for different patient populations indicates that there is a need to examine more closely the roles and expectations of SCD care providers from different disciplines. These providers include pediatricians, family practitioners, hematologists, internists, nurse practitioners, social workers, psychologists, and counselors. Differences and similarities among providers must be addressed to achieve successful collaboration.

Few studies have been conducted on transition to adult care for adolescents with chronic conditions.[25,32,33] Most studies that address the transition focus on structural factors (e.g., the availability of established programs and resources).[30] There is a dearth of literature on procedural factors, the actual logistics of the adolescent and her or his family leaving a pediatric care setting and getting established in an adult care environment.[32-34,38] The objective of the present study is to describe and compare responses by provider characteristics (e.g., specialty, discipline, gender, and race or ethnicity) regarding (1) what is done to demonstrate involvement in the transition process; (2)the expectations of adolescents for engagement in adult care; and (3)the perspective of providers on the need for a systematic transition. Thus, the primary research questions here are (1) How do pediatric and adult providers demonstrate involvement in transition? (2) What is expected of adolescents when they move to adult care? and (3) Do providers think there is a need for a systematic transition program?

Methods

Data for the present study come from a cross-sectional qualitative and quantitative questionnaire; the questions are part of the provider version of the Sickle Cell Transfer Questionnaire (P-SCTQ).[32,34] The P-SCTQ is designed to elicit provider-expressed demonstration of transition behaviors, expectations of transition, and opinions regarding the need for a systematic transition survey. The questionnaire is based on observational experiences of pediatric and adult clinicians, interviews with multidisciplinary providers serving adolescents and young adults with SCD, and literature findings regarding issues faced by the SCD population. The primary investigators of the present study and a team of providers from multiple disciplines who were representative of the potential study group wrote the first draft of the P-SCTQ. This draft consisted of four sections: (1) demographics, (2) transfer criteria, (3) transfer concerns, and (4) transfer experiences. Based on investigators' collective expertise, an open-ended questionnaire format was thought to be the most consistent with the utilization-focused, participatory approach of the overall survey. Three Delphi rounds of review[39] were conducted with the first draft of the P-SCTQ by a working team of multidisciplinary providers. Based on the Delphi results, responses were used to generate limited checklists for the open-ended questions, with an open-ended option remaining. After the last Delphi round, a pilot draft was developed and tested with 10 providers at the 2 primary study sites. The development of the P-SCTQ questionnaire domains and their content areas are discussed in the following sections.

Transfer readiness criteria. The HCP's criteria for assessing transfer readiness were based on responses to four open-ended questions asking providers to state the criteria and rationale that determine readiness. Actual transfer readiness criteria were solicited from pediatric and/or family practice providers who provided care for individuals with SCD from birth to 18 years of age (n = 164). The providers were asked: "What criteria do you use in making decisions about which patients to transfer (or not) to an adult treatment program?" Perceived transfer criteria were solicited from adult and/or family practice providers who provided care to individuals 18 years of age and older with SCD (n = 63). These providers were asked: "What criteria do you think is used in making decisions about which patients you will receive from pediatric programs and which ones you may not?" Open-ended questions were used because no published information existed that outlined the actual or perceived criteria used by providers in making transition decisions. It was expected that capturing the decision-making process of providers would provide insights that might facilitate the successful implementation of interventions.

Expectations. The adult health care providers' expectations of the adolescent/young adult's readiness to transfer to adult treatment was assessed based on participants' yes/no responses to a nine-item opinion checklist assessing expectations of the adolescent or young adult at his or her first doctor's visit to an adult HCP. Representative items are: "They would be expected to be seen with their parent or primary caretaker" and "They would be expected to have a good understanding of their chronic condition." Participants were also asked an open-ended question about other expectations not previously listed.

Provider perceptions of transfer. The HCP's perception of the need for and usefulness of a medical care transition program was assessed based on participants' responses to an 11-item yes/no opinion checklist, which allowed for the expression of both positive and negative perceptions of transition programs. Representative items are: "It would make it easier to transfer care" and "Such a program would not be fiscally possible." Participants were again asked an open-ended question about other reasons for their views on this subject.

Demonstrating transition. Participants answered 18 questions about other practice characteristics related to the provision of health care that demonstrate their involvement in the transition process, including questions about the number of patients over 18 years of age seen in pediatric care, whether or not providers treated individuals with SCD, what measures general and family practice providers took to demonstrate transition into adult care, and demographics.

The primary study participants were 227 pediatric and adult medical and psychosocial HCPs sampled in three waves: (1) a random sample of providers at the Duke University-University of North Carolina Comprehensive Sickle Cell Program and its satellite, community-based and state affiliates; (2) a random sample of North Carolina private providers in medical disciplines highly likely to deal with adolescents and/or adults with SCD (e.g., pediatric, internal medicine, general and family practitioners); and (3) a national sample of direct SCD care providers as randomized from the National SCD Center database of annual conference registrants. These provider samples were chosen to represent comprehensively two types of providers: (1) direct providers of care for individuals with SCD; and (2) indirect or potential providers who may provide care for these individuals (e.g., internists, general practitioners). Simple random stratification sampling was used with the first two provider samples mentioned, with every fifth provider selected within a provider specialty area. This sampling technique was chosen as a means of trying to get a workable sample of the providers from multiple disciplines who provide or could provide care for the adolescent/young adult with SCD.[40-42] For the third sample population, all registrants were sampled.

Data were collected over a 3-month period via confidential questionnaire mail-outs to the three sample populations. (A note describing the three sampled populations was sent to the third sample population, highlighting the fact that duplicate questionnaires might be received but that each provider need only complete one.) All participants provided written or verbal consent. The P-SCTQ return rate for the sample was 60%; the return rate varied by category of providers. For example, providers currently serving people with SCD had a return rate of 90%, whereas providers not currently serving persons with SCD had a return rate of only 30%.

Approximately 7% of the returned questionnaires were not usable because they were incomplete or uninterpretable.

Data analysis took place in three steps. The first step was gathering open-ended responses to proposed questions and coding them to create a forced-choice format. Comparative content analysis with selective categorization to code qualitative health care was used to code provider responses to transfer criteria questions and open-ended responses.[43] Project staff members coded each response. Coders were the project social worker, nurse, psychologist, principal investigator, and two research assistants. Determination of themes and later categorical and summary variables were based on a 0.80 or greater intercoder agreement (reliability) score and consistency with the question.[44] Once the acceptable level of coding agreement was reached, categorical and summary variables were developed for use in the initial descriptive analyses. The second step was designed to provide a descriptive demographic profile of the sample and to summarize responses to the P-SCTQ opinion checklist items addressing the study questions of provider expectations, perceptions of a need for a transfer program, and measures used to demonstrate transition. Using SPSS 10.0[45] these analyses allowed for the determination of the most common concerns and opinions of providers regarding the research issues.

The third step in this analysis applied simple bivariate statistics (i.e., chi-square) to examine between and within group associations of select descriptive variables (e.g., racial and specialization differences in responses among providers and within specialties). This allowed for the determination of provider characteristics that were associated with the most common responses to the key study questions (demonstration of transition readiness, transfer expectations, and need for a transfer program).

Results

Participating providers were diverse in disciplinary specialty and population served; in this, they reflect the provider constellation drawn upon by persons with SCD. Nearly two thirds of the respondents (62%) were Caucasian. Twenty-nine percent were African American, with an additional 9% from other racial and ethnic minority groups (Asian, Latino). Of the 227 providers sampled, 61% were female. Twenty-three percent (n = 53) reported practicing in rural, and while 77% (n = 174) practiced in urban areas. As noted, the P-SCTQ return rate for the whole sample was 60%; providers currently serving SCD patients had a return rate of 90%, whereas providers not currently serving SCD patients had a return rate of only 30%. Approximately 7% of the returned questionnaires were not usable because they were incomplete or uninterpretable. On the basis of our sample method, we determined that providers who did not respond were similar on most demographic variables except specialty area (e.g., more internists did not respond than responded) and location (e.g., more rural practitioners did not respond than responded).

Demonstration of transition. Of the providers surveyed about the activities in which they engaged to demonstrate transition, 67% (n = 73) responded that they did something to demonstrate transition (e.g., stop seeing patient with his or her family, have family conference to discuss transition; for further examples; Table 2).In comparing responses concerning provider characteristics, nurse practitioners (86%) were more likely than other specialty groups to demonstrate transition ($p < 0.01$). Eighty-one percent of family practitioners reported that they did not do anything to demonstrate transition. Providers treating both adolescent and adult populations were more likely to demonstrate transition ($p < 0.05$). Female providers were more likely to indicate that they did something to demonstrate transition ($p < 0.05$), as were those providers practicing in urban areas ($p < 0.05$).

Summarizing the open-ended responses from adult and pediatric providers, the five methods of transition that respondents identified were (1) ceasing to see patients with their parents, (2) encouraging patients to accept more responsibility, (3) providing literature, (4) making the patient more financially responsible, and (5) having family conferences to discuss transition. The likelihood of practicing these specific methods varied by provider's specialty, population served, gender, race or ethnicity, and region served. Although the difference was not significant, family practitioners were more likely than any of the other health care providers to employ methods 1, 2, and 3. Furthermore, hematologists were significantly more likely than other providers to employ method 5 ($p < 0.05$). Providers who treated adolescents and adults were significantly more likely than those

who treated only one or the other group to employ method 3 ($p < 0.05$), method 4 ($p < 0.05$), and method 5 ($p < 0.05$). A larger percentage of male than female providers employed methods 1 and 4; female providers were more likely than male providers to employ methods 2, 3, and 5. Although not significant in every instance, minority providers were more likely than nonminority providers to employ methods 2, 3, 4 ($p < 0.05$), and 5.

Table 1.

DEMOGRAPHIC CHARACTERISTCIS OF THE PROVIDER SAMPLE BY POPULATION SERVED

Variable	Population Served (N)			
	Adolescent	Adult	Both	Total(%)
Gender				
Female	88	23	27	138 (61)
Male	50	15	24	89 (39)
Race				
African American	27	15	24	66 (29)
Caucasian	97	20	24	141 (62)
Other	14	3	3	20 (9)
Primary specialty				
Hematologist	26	8	3	37 (16)
Family practitioner	0	3	17	20 (9)
Internist	0	10	1	11 (5)
Pediatrician	43	0	1	44 (19)
Nurse practitioner	52	14	9	75 (33)
Social worker/ psychologist/counselor	17	3	20	40 (18)
Setting				
Rural	22	8	23	53 (23)
Urban	116	30	28	174 (77)

Expectations in adult settings. The nine expectations for an adolescent or young adult who is seen in an adult or family/generalist practice for the first time are illustrated in Table 3. There was little difference in provider characteristics concerning expectation of an adolescent or young adult moving into an adult care setting. However, expectations differed significantly according to the types of patients the provider typically serves. Many providers (44%) who served only adult populations expected the patient to complete a screening device or survey prior to being seen ($p = 0.05$). The majority (70%) of providers serving both adolescent and adult populations expected the patient to be seen with their parent or primary care taker ($p < 0.001$); conversely, 67% of adult-only providers would not expect this ($p < 0.001$). Male and female providers have similar expectations for the adolescent in transition.

Minority providers were much more likely than Caucasian providers to have relatively high expectations of the adolescent patient. For example, 44% of the minority providers would expect the patient to complete a screening device or questionnaire prior to being seen, compared with only 26% of Caucasian providers ($p < 0.05$). Eighty-one percent would expect the patient to have a good understanding of their illness ($p < 0.001$), compared with only 51% of Caucasian providers. Three-fourths (75%) would expect the patient to demonstrate good home health management skills ($p < 0.001$), compared with only 46% of Caucasian providers. Similarly,

75% would expect the patient to demonstrate a working knowledge of the medical system ($p < 0.001$), compared with only 46% of Caucasian providers.

Setting did not correlate with many of the expectations listed in Table 3. A similar percentage of rural and urban providers agreed with every expectation except for one. A significantly larger percentage of urban than rural providers (26% versus 19% for rural providers) expected the patient to make arrangements for his or her financial obligations ($p < 0.05$).

Table 2.

METHODS HEALTH CARE PROVIDERS USER TO DEMONSTRATE TRANSITION, BY CATEGORY OF PROVIDER

	Demonstrate Transition		Method 1		Method 2		Method 3		Method 4		Method 5	
	% Agree	p	% Agree	p	% Agree	p	% Agree	p	% Agree	p	% Agree	p
Provider specialty		0.00		NS		NS		NS		NS		0.04
Hematologist	79		60		87		73		33		80	
Family practitioner	19		100		100		100		33		33	
Nurse practitioner	86		47		97		77		19		63	
Social worker/ psychologist/ counselor	56		50		100		50		0		0	
Pediatrician												
Population served		0.03		NS		NS		0.02	0.02			0.04
Child/adolescent	79		54		93		65		11		74	
Adults	75		67		100		100		33		33	
Both	54		58		92		92		40		46	
Gender		0.03		0.06		NS		NS		NS		NS
Male	55		57		91		76		33		48	
Female	75		55		94		77		18		69	
Race/ethnicity		NS		NS		NS		NS		0.04		NS
Caucasian	62		62		92		76		12		68	
Minority	75		49		94		77		33		57	
Setting		0.00		NS		NS		NS		NS		NS
Rural	29		57		86		100		17		43	
Urban	76		55		94		74		23		64	

Method 1: Stop seeing patient with their parents; Method 2: Encourage patients to accept more responsibility; Method 3: Provide literature for patients to read; Method 4: Make patient financially responsible for their bill; Method 5: Have family conference to discuss transition.
Abbreviations: % agree, percent of providers who agree with transition method; *p*, Level of significance (chi-square); NS, not significant.

Need for systematic transition programs. Eighty-nine percent of respondents indicated a need for a systematic transition process. The seven reasons given for a transition program being beneficial are listed in Table 4.

In comparing responses by demographic characteristic, well over half of the population agreed with each specific reason for a systematic transition program, regardless of specialty, population served, gender, race/ethnicity, or setting. Although most of the differences among the groups were not significant, child and adolescent providers were significantly more likely than other providers to believe that a systematic transition program would provide more support in helping patients meet their care needs than they would have in the absence of such a program ($p < 0.05$).

Table 3.

EXPECTATION OF ADOLESCENT OR YOUNG ADULT SEEN IN PRACTICE SETTINGS

	Expect 1		Expect 2		Expect 3		Expect 4		Expect 5		Expect 6		Expect 7		Expect 8		Expect 9	
	% Agree	p	% Agree	p	% Agree	p	% Agree	p	% Agree	p	% Agree	p	% Agree	p	% Agree	p	% Agree	p
Specialty		NS		NS		NS		NS		0.01		NS		NS		NS		NS
Hematologist	80		35		55		20		60		55		50		55		55	
Family practitioner	73		33		60		67		60		47		47		53		60	
Internist	80		70		50		60		60		50		70		70		70	
Nurse Practitioner	86		36		58		36		67		58		50		61		67	
Social worker/	70		29		61		22		71		71		36		57		46	
Pediatrician	82		18		46		55		73		73		64		73		36	
Population		NS		0.05		0.00		NS		NS		NS		NS		NS		NS
Child/adolescent	75		20		70		31		65		58		53		53		46	
Adults	86		44		33		39		61		53		47		67		69	
Both	75		41		64		43		71		68		48		61		57	
Gender		NS		NS		NS		NS		NS		NS		NS		NS		NS
Male	72		45		57		45		66		55		51		60		55	
Female	82		29		56		33		66		63		48		60		58	
Race/ethnicity		NS		0.04				NS		NS		0.00		0.00		NS		0.00	NS
Caucasian	72		26		59		35		51		46		43		46		50	
Minority	85		44		54		41		81		75		56		75		64	
Setting		NS		NS		NS		0.03		NS		NS		NS		NS		NS
Rural	78		36		58		53		61		58		58		64		47	
Urban	79		35		56		31		68		61		45		58		61	

Expectation 1: Would be expected to have an adequate knowledge of their past medical history.
Expectation 2: Would be expected to complete a screening device or questionnaire prior to being see.
Expectation 3: Would be expected to be seen with their parent or primary caretaker.
Expectation 4: Would be expected to have made arrangements for financial obligations.
Expectation 5: Would be expected to have a good understanding of their chronic condition.
Expectation 6: Would be expected to demonstrate good home health management skills.
Expectation 7: Would be expected to demonstrate an understanding of the complications of SCD.
Expectation 8: Would be expected to demonstrate a working knowledge of the medical system.
Expectation 9: Would be expected to demonstrate some level of parental/family. independence.
Abbreviations: % agree, percent of providers who agree with expectation; *p*, level of significance; NS, not significant.

Table 4.

REASONS FOR SYSTEMATIC TRANSITION PROGRAM[a]

	Reason 1		Reason 2		Reason 3		Reason 4		Reason 5		Reason 6		Reason 7	
	% Agree	p	% Agree	p	% Agree	p	% Agree	p	% Agree	p	% Agree	p	% Agree	p
Provider specialty		NS		NS		NS		NS		NS		NS		NS
Hematologist	94		94		80		86		77		91		80	
Family practitioner	81		81		81		75		75		88		88	
Internist	78		100		89		56		67		100		100	
Nurse practitioner	86		94		90		77		74		86		86	
Social worker/ Psychologist/ Counselor	75		81		86		81		78		83		89	
Pediatrician														
Population served		NS		NS		.03		NS		NS		NS		NS
Child/adolescent	86		91		92		78		68		86		82	
Adults	82		91		76		79		76		91		97	
Both	75		84		86		80		80		82		82	
Gender		NS		NS		NS		NS		NS		NS		NS
Male	78		87		85		80		65		87		80	
Female	85		91		90		78		76		85		87	
Race/ethnicity		NS		NS		NS		NS		NS		NS		NS
Caucasian	83		89		88		74		71		83		81	
Minority	82		90		89		85		73		89		90	
Setting		NS		NS		NS		NS		NS		NS		NS
Rural	78		87		91		74		63		83		80	
Urban	84		90		82		80		74		87		86	

[a]89% of all providers in the sample responded that a systematic transition program is needed.
Reason 1: It would make it easier to transfer care.
Reason 2: Patients would know more about what to expect.
Reason 3: It would provide more support in helping patients meet their case needs.
Reason 4: It would provide a mechanism for providers to address issues that lead to negative patient outcomes.
Reason 5: It would promote patient independence.
Reason 6: It would promote better communication between providers.
Reason 7: It would promote better communication between providers, primary caretakers, and the patient.
Abbreviations: % agree, percent of providers who agree with reason; *p*, level of significance; NS, not significant.

Discussion

This study had three aims: (1) to understand what providers from multiple disciplines did that demonstrated their involvement in the transition process; (2) to elucidate what is expected of adolescents when they transfer to an adult care system; and (3) to gauge whether or not providers from different disciplines believe there is a need for a systematic transition program.

Most providers, regardless of specialty, agreed that a transition program was necessary, but few actually did anything to demonstrate their involvement in the transition process, highlighting the need for increased guidance and education at both a practice and an institutional or systems level. Interestingly, although a significant majority of providers serving both adolescent and adult populations would expect the patient to be seen with their parent or primary caretaker, a significant proportion of adult-only providers did not expect this, which may point to the adult providers' expectation of greater responsibility on the part of the adolescent moving into adult care.

Upon initial examination, it appeared that minority providers were likely to expect much more than their Caucasian counterparts from the adolescent moving to adult health care. In an earlier manuscript by Telfair,

Myers, and Drezner,[34] further analysis was done to explore possible links between provider's ethnicity and the increased expectations placed on these adolescents. Based on this analysis, expecting the patient to be seen with a parent was the only remaining statistically significant expectation ($p > 0.05$); however, the concept of differential expectations based on provider race or ethnicity remains interesting. Because the majority of providers in this study were Caucasian, a larger sample of minority providers serving adolescents with SCD should be examined to determine if the findings hinted at by the data collected here achieve significance. To date, we are not aware of any SCD studies looking at provider expectations differing by race or ethnicity.

There are further limitations of this study. For comparison purposes, it would have been beneficial to have a group of providers who treat adolescents with other chronic conditions in addition to providers treating adolescents with SCD. Second, the sample size is not as large as was desired. However, a representative sample was obtained, along with a reasonable response rate. Finally, a low response rate from internists and providers in rural areas did not allow for as thorough an understanding of their views, as would be desired.

Lessons learned from this and related studies, as well as anecdotal comments from providers, suggest that a good transition program must, at a minimum, take a comprehensive approach that is more than one or two 'hand-off' visits to adult providers. It must be a program that is built into the overall care plan for the young person that begins when he or she is a young adolescent. Such a program must have clear goals for medical care(goals that are developmentally appropriate in focusing on adolescent and young adult health issues such as disease knowledge and self-care skills, sexuality, risky behaviors), education (focused on the client, family, providers from multiple disciplines, and the community in which the young person lives) and support,(in the form of case management designed to develop and enhance social and psychological well-being and focus on self-sufficiency and independence).

Medical care with an adolescent/young adult requires a physician and nurse/physician assistant at a minimum. If resources are available, a social worker and/or case manager should be added to the team. The program must be the usual source of care for the young person and be designed to provide health care maintenance to address his or her acute and chronic illness needs (or be linked to such a program). The design for care should include ongoing explanations (to the client and his or her family) and discussions of how the young person's condition affects him or her (and why). These discussions must include a respect for the opinions, concerns, and cultural values of the young person and his or her family members. Finally, as part of the structure and function of the medical care program, there be must good working relationships and communication between pediatric/adolescent and adult providers (e.g., primary care providers, specialists, and adjunct providers). Such relationships must be tempered with realism for a given setting because such relationships are more easily described than created or maintained.[46]

Education of the young person, his or her family, other providers (from multiple disciplines), and community members must emphasize outcomes that demonstrate knowledge and skills obtained. For the young person, these outcomes should include a clear articulation of how his or her condition affects him or her, the clear demonstration of independent (adult) life skills (such as getting him- or herself to care alone), and a clear demonstration of knowledge of and skills in negotiating health care and related systems such as social services (e.g., negotiating for good care in the absence of adult specialists). Family and community members must demonstrate understanding and support of the young person in these knowledge and skill areas. Education and training must be based on a clear understanding of adolescent and young adult developmental issues and must be designed to assist the adolescent and his or her family to achieve competence in the knowledge and skill areas described.

The goals of the program for support in the form of case management must clearly describe relevant activities.[8] These activities include adolescent, young adult, and family asset and risk assessment; coordination (liaison) with providers and specialists; coordination with other institutions (e.g., schools and mental health, vocational rehabilitation, and community resources); and negotiation of health care and related systems. Listening; demonstrating respect for opinions, concerns, and cultural values of the young person, family, and community;

providing advice specific to problem solving; and including family and significant others in decision making are all important in providing support to the adolescent in transition.

There is little disagreement about the need for transition programs. Young people with SCD are now expected to survive and thrive in adulthood. However, our research reveals a concurrent desire for a systematic transition process and a lack of consensus among multidisciplinary providers about the best way to assist young people with SCD in making the transition into adulthood and adult care. This lack of consensus suggests that further provider education, protocol development, and evidence-based practice experiences are needed to ensure provider comfort, competence, and involvement in the provision of a successful transition.

Acknowledgments:
This study was supported in part by the National Heart, Lung, and Blood Institute Grant 1P60HL58418-01 (J.T.), the Maternal and Child Health Bureau of the Health Resources and Services Administration Grant 1 U93 MC 00217-01 (J.T.), and the Multi-Site Study of Transition of Adolescents and Young Adults with Sickle Cell Disease Collaborative Group. Preparation of this manuscript was co-facilitated by the infrastructure and resources provided by the NIH CFAR Core Grant P30 AI27767 (J.T, P.S.L.). We would like to thank the providers who took time to reply to the questionnaire, making this study possible.

Endnotes:

1. Adolescent health care and transitions. In: National Institutes of Health, National Heart, Lung, and Blood Institute. The management of sickle cell disease. (NIH Pub. no. 2002:35-40.) Bethesda, MD: National Institutes of Health, National Heart, Lung, and Blood Institute, 2002.
2. Health Resources and Services Administration. Achieving success for all children and youth with special health care: a draft document. Rockville, MD: Maternal and Child Health Bureau, HRSA, U.S. DHHS, 2001.
3. Betz CL, Redcay G. Lessons learned from providing transition service to adolescents with special health care needs. Issues Compr Pediatr Nurs 2002 Apr-Jun; 25(2):129-49.
4. Blum RW, Garell D, Hodgman CH, et al. Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. J Adolesc Health 1993 Nov; 14(7):570-6.
5. Lewis-Gary MD. Transitioning to adult health care facilities for young adults with a chronic condition. Pediatr Nurs 2001 Sep-Oct; 27(5):521-4.
6. Hausner ES, Dorn L. Transitioning adolescents with sickle cell disease to adult-centered care. Pediatr Nurs 1999 Sep-Oct; 25(5):479-88.
7. Reiss J, Gibson R. Health care transitions: destinations unknown. Pediatrics 2002 Dec; 110(6 Pt 2):1307-14.
8. Wojciechowski EA, Hurtig A, Dorn L. A natural history study of adolescents and young adults with sickle cell disease as they transfer to adult care: a need for case management services. J Pediatr Nurs 2002 Feb; 17(1):18-27.
9. American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians-American Society of Internal Medicine. A consensus statement on health care transitions for young adults with special health care needs. Pediatrics 2002 Dec; 110(6 Pt 2):1304-6.
10. Magrab PR, Millar HEC, eds. Growing up and getting medical care: youth with special health care needs. In: Proceedings of the Surgeon General's conference, Washington, DC: March 3-15, 1989:1-3. Jekyll Island, Georgia: Georgetown University Child Development Center, 1989.
11. Scal P. Transition for youth with chronic conditions: primary care physicians' approaches. Pediatrics 2002 Dec; 110(6 Pt 2):1315-21.
12. Sawyer SM, Blair S, Bowes G. Chronic illness in adolescents: transfer or transition to adult services? J Paediatr Child Health 1997 Apr; 33(2):88-90.
13. Reese FL, Smith WR. Psychological determinants of health care utilization in sickle cell disease patients. Ann Behav Med 1997 Spring; 19(2):171-8.
14. Castro O, Chicoye L, Greenberg J, et al. Brighter horizons for sickle cell disease. Patient Care 1994 Aug;28(8):26-44.

15. Schidlow D, Fiel S. Life beyond pediatrics: transition of chronically ill adolescents from pediatric to adult health care systems. Med Clin North Am 1990 Sep; 74(5):1113-20.
16. White P, Shear ES. Transition/job readiness for adolescents with juvenile arthritis and other chronic illness. J Rheumatol Suppl 1992 Apr; 33:23-7.
17. Blum RW, Okinow NA. Teenagers at risk—a national perspective of state level services for adolescents with chronic illness of disability: executive summary. Connections 1993. Connections: The Newsletter of the National Center for Youth with Disabilities. Vol. 3, No. 3 (supplement):1-8 July.
18. Perrin JM, Guyer B, Lawrence JM. Health care services for children and adolescents. Future of Our Children: U.S. Health Care for Children 1992. Feb; 2(2)58-77.
19. Wierenga KJ, Hambleton IR, Lewis NA. Survival estimates for patients with homozygous sickle-cell disease in Jamaica: a clinic-based population study. Lancet 2001 Mar 3; 357(9257):680-3.
20. Newacheck PW, Strickland B, Shonkoff JP, et al. An epidemiologic profile of children with special health care needs. Pediatrics 1998 Jul; 102(1 Pt 1):117-23.
21. Thompson RJ Jr, Gil KM, Abrams MR, et al. Stress, coping, and psychological adjustment of adults with sickle cell disease. J Consult Clin Psychol 1992 Jun; 60(3):433-40.
22. Thompson RJ Jr, Gustafson KE, Hamlett KW, et al. Stress, coping, and family functioning in the psychological adjustment of mothers of children and adolescents with cystic fibrosis. J Pediatr Psychol 1992 Oct; 17(5):573-85.
23. Wallander JL, Varni JW. Social support and adjustment in chronically ill and handicapped children. Am J Community Psychol 1989 Apr; 17(2):185-201.
24. Rosen D. Between two worlds: bridging the cultures of child health and adult medicine. J Adolesc Health 1995 Jul; 17(1):10-6.
25. National Center for Youth with Disabilities. Transition from child to adult health care services: a national survey. Minneapolis: University of Minnesota, 1996.
26. Creating pathways for transition: the CHOICES transition project, 1996-1999. Lexington: Kentucky Commission for Children with Special Health Care Needs and Shriners Hospitals for Children, 1999.
27. Betz CL, Redcay G. Lessons learned from providing transition services to adolescents with special health care needs. Issues Compr Pediatr Nurs 2002 Apr-Jun; 25(2):129-49.
28. Betz CL. Adolescent transition: a nursing concern. Pediatr Nurs 1998 Jan-Feb;24(1):23-8; quiz 29-30.
29. Hergenroeder AC. The transition into adulthood for children and youth with special health care needs. Tex Med 2002 Feb; 98(2):51-8.
30. Scal P, Evans T, Blozis S, et al. Trends in transition from pediatric to adult health care services for young adults with chronic conditions. J Adolesc Health 1999 Apr;24(4):259-64.
31. White PH. Success on the road to adulthood. Issues and hurdles for adolescents with disabilities. Rheum Dis Clin North Am 1997 Aug; 23(3):697-707.
32. Telfair J, Myers J, Drezner S. Transfer as a component of the transition of adolescents with sickle cell disease to adult care: adolescent, adult, and parent perspectives. J Adolesc Health 1994 Nov;15(7):558-65.
33. Bridges, K (lead), Telfair, J (contributing). Adolescent health care and transitions. In: National Institutes of Health, National Heart, Lung, and Blood Institute. The management of sickle cell disease. (NIH Pub. no. 2002:35-40.) Washington, DC: National Institutes of Health, National Heart, Lung, and Blood Institute, 2002.
34. Telfair J, Myers J, Drezner S. Does race influence the provision of care to persons with sickle cell disease: perspectives of multi-disciplinary providers. J Health Care Poor Underserved 1998 May;9(2):184-95.
35. Richardson SA. Transition to adulthood. In: Stein REK, ed. Caring for children with chronic illness: issues and strategies. New York: Springer, 1989.
36. Rojewski J. A rural based transition model for students with learning disabilities: a demonstration. J Learn Disabil 1989 Dec; 22(10):613-20.
37. Baskin ML, Collins MH, Brown F, et al. Psychosocial considerations in sickle cell disease (SCD): the transition from adolescence to young adulthood. J Clin Psychol Med 1998 Vol.5 No. 3 Sep;5(3):315-41.
38. Betz CL. Facilitating the transition of adolescents with chronic conditions from pediatric to adult health care and community settings. Issues Compr Pediatr Nurs 1998 Apr-Jun; 21(2):97-115.

39. Denzin NK, Lincoln YS. Handbook of qualitative research. Newbury Park, CA: Sage Publications, 2000.
40. Henry GT. Practical sampling. Newbury Park, CA: Sage Publications, 1990.
41. Fowler FJ Jr. Survey research methods. Newbury, CA: SAGE Publications, 1999.
42. Rea LM, Parker RA. Designing and conducting survey research. San Francisco: Jossey Bass Publishers, 1997.
43. Strauss AL. Qualitative analysis for social scientists. Cambridge, UK: Cambridge University Press, 1989.
44. Kirk J, Miller ML. Reliability and validity in qualitative research. Newbury Park, CA: Sage Publications, 1986.
45. Nousis MJ. SPSS-Windows Version 10.0. Chicago: SPSS Inc., 1994.
46. Clare, N. Management of sickle cell disease would improve if doctors listened more to patients. BMJ 1998 Mar 21; 316(7135):935.