Transfer as a Component of the Transition of Adolescents with Sickle Cell Disease to Adult Care: Adolescent, Adult, and Parent Perspectives

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Abstract:

Purpose: There are no empirical studies which assess the transfer needs/concerns of adolescents and young adults with sickle cell disease (SCD) and their primary caretakers. The overall purpose of this research was to determine the issues, concerns, and expectations of adolescents, young adults and primary caretakers with regard to transfer to adult care.

Methods: Participants were recruited from clinics and programs participating in the Duke/UNC Comprehensive Sickle Cell Program. Using a cross-sectional survey design, young adults (n = 60), adolescents (n = 36) and primary caretakers (n = 25) were administered the Sickle Cell Transfer Questionnaire (SCTQ).

Results: Adolescents and young adults with SCD were primarily concerned about how they would pay for medical care and how they would be treated by adult providers. Caretakers were concerned about their teens leaving pediatric care and assuming responsibility for medical care. All three groups reported mixed emotions about leaving pediatric care. There was consensus among the respondents regarding the need for transfer programs and what they should offer. Bivariate analysis revealed that age, education level, and disease severity were statistically significant co-factors influencing the feelings, concerns and opinions of the study participants.

Conclusion: Future longitudinal experimental research is needed to corroborate the results of this study and to assess the effectiveness of transition-related intervention programs for adolescents with SCD and their families.

Keywords: Sickle cell disease, Transition, Transfer Adolescents, Young adults, Primary caretakers, Health care

Article:

Introduction

There is increasing evidence that adolescents with sickle cell disease (SCD) and other chronic conditions are surviving far into adulthood (1-8). This increased survival is attributed to improvements in treatment and management over the last fifteen years (9). In stark contrast, there has been little attention paid to the personal, interpersonal and social life skills needed to function during this period (10). As a result, many adolescents with chronic conditions, their primary caretakers and providers have had a difficult time successfully navigating the process of transition into adult life (2,11-13). One component of the transition process for these adolescents is the transfer from pediatric to adult care. Issues associated with the transfer include: 1) readiness of the adolescent, parent, and provider; 2) competence for self-management; 3) adolescent maturity and independence; 4) parent and provider relinquishment of care responsibility; and, 5) fears, beliefs, and attitudes toward leaving pediatric care.

There has been little research on systematic transition programs to help adolescents with chronic conditions competently move into adult health care and/or begin to deal with the reality of being an adult with a chronic condition (8,14,15). Much of the research that focuses on transition-related issues involves young adults with developmental and/or learning disabilities. These studies have been conducted, for the most part, as part of demonstration projects and/or mandated by special legislation (16,17). These studies have focused primarily on vocational and educational issues, with little emphasis on adult life functioning and independent management of health care—issues that are paramount for young adults with chronic conditions. Although a few studies have begun to address these issues for young adults with chronic conditions (18,19), there is still a dearth of literature and documented studies specific to adolescents with sickle cell disease and other chronic conditions.

Background

The focus of the current research is young people with sickle cell disease and their parents. In the United States, sickle cell disease (SCD) occurs mostly in African-Americans. It is the most common genetic disorder within a specific population, having an incidence of 1 in every 500 live black births (20,21). To date there are about 65,000 individuals with the disorder in the U.S. (20). Recent results from the Cooperative Study of Sickle Cell Disease (CSSCD), a population-based study of the natural history of SCD funded by NHLBI, provided an estimate of the overall life expectancy of individuals with SCD (23). For those with the most common and severe form of the condition (hemoglobin SS) the median age of death was 42 years for males and 48 years for females; and, for those with the second most common and milder form (hemoglobin SC) the median age of death was 60 years for males and 68 years for females (similar to the general African-American population) (23).

Earlier reports described sickle cell disease as a condition of childhood with most youths not living past their teens (24,25). In contrast, progress over the past fifteen years in the diagnosis and treatment of many of SCD's life threatening conditions has led to an extended life expectancy for many (26). As a result, there is clinical consensus that critical attention needs to be focused on the period from adolescence to young adulthood. Many adolescents with sickle cell disease have to deal with provider and public lack of knowledge and understanding of their condition, the stereotype of being socially dysfunctional and the stigmatization of their condition as the "black disease" (27,28). Lepontis (14) and others (29-31) conclude that the need is for adolescents with chronic conditions, like sickle cell disease, to develop both short- and long-term psychological and social skills needed to successfully navigate this developmental period and the medical and social systems in which they function. Adolescence is a difficult time for 'at risk' populations (32,33). Having a chronic condition such as sickle cell disease, struggling with issues of being an African-American youth in our society, being in an age and racial group with high rates of morbidity, mortality and other poor social and health outcomes (e.g., violence, school dropout, teenage pregnancy), compounds this already complex task (34-38). Psychosocial and educational studies of adolescents with sickle cell disease have been predominantly cross-sectional or observational (35,36,38). Findings from these studies have pointed out that medical, family and peer relationships, academic functioning, condition coping strategies, and individual and social system characteristics are factors that influence the psychological and social well-being of these adolescents and young adults.

One of the primary transition issues for adolescents with SCD entering young adulthood is moving from a pediatric treatment system, in which providers have dealt with them and their parents since birth and are generally knowledgeable about their condition; to an adult treatment program/practice that knows less about them and/or their condition, and has generally higher expectations for medical self-management (3,10,19). A transition-focused intervention program that addresses the psychosocial and educational needs of these adolescents and their primary caretakers, as well as those of their health care providers within an ecological framework, is needed. The specific questions to be answered by this study were:

1. What are the concerns of adolescents, their primary caretakers and young adults with SCD regarding the transfer from pediatric to adult health care?
2. How do adolescents, their primary caretakers and young adults with SCD feel about transferring from pediatric to adult medical care?
3. Do adolescents, young adults, and primary caretakers feel that a transfer intervention program is needed?
4. What do adolescents, young adults, and primary caretakers feel a transfer intervention program should offer?

Study Design and Methods

General Data Collection and Study Participants

Cross-sectional survey data were collected over a five month period (August through December 1992) via a series of self-administered or face-to-face interviews of adolescents and young adults with SCD (these two groups were offered a choice of interview method) and a confidential mailed questionnaire for primary caretakers. Primary study participants were 36 adolescents (13 to 19 years of age) and 60 young adults (21 to 30 years of age) and 25 of the adolescents' primary caretakers. Participants were recruited from the Duke/University of North Carolina Comprehensive Pediatric and Adult Sickle Cell Programs and its community-based affiliate, Triad Sickle Cell Anemia Foundation, Inc..

The Data Collection Instrument

The data collection instruments were the adolescent, adult and primary caretaker versions of the non-standardized, sixty-seven item Sickle Cell Transfer Questionnaire (SCTQ). The SCTQ addressed the four exploratory research question domains outlined above. The wording of the instructions for the three versions of the SCTQ were such that a) adults were asked to reflect on their past experiences of transferring from a pediatric to an adult care situation (actual); and b) adolescents and primary caretakers were asked to reflect on what their prospective experience might be when faced with the transfer situation (perceived). The development of the SCTQ question domains and their content areas are discussed below.

The adolescent's, adult's, and primary caretaker's perceived and actual concerns regarding the medical care transfer process were asked by yes/no responses to an opinion checklist (e.g., I was/would be concerned that new staff would not believe when I/my child was in pain, I was/would be concerned about leaving medical people who took/take care of me/my child). Participants were also asked an open-ended question regarding "other concerns".

Study participants' actual and perceived positive and negative feelings regarding the medical care transfer process were based on yes/no responses to an opinion checklist assessing their feelings (i.e., I was/am unsure, I was/would be okay with the transfer). This checklist was adapted from an instrument developed by Hadler and Cottle (39) at the University of North Carolina at Chapel Hill. Hadler and Cottle's measure sought to evaluate the practical and emotional readiness of adolescents with cystic fibrosis to make the transfer from pediatric to adult care. Current study participants were also asked an open-ended question about "other concerns".

The adolescent's, adult's, and primary caretaker's perception of the need for, and use of, a medical care transfer program were based on yes/no responses to an opinion checklist (e.g., it would make it easier to transfer care, it would pay too much attention to sickle cell disease). Participants were also asked an open-ended question regarding "other reasons".

Study participants' perceptions of ideal services of a medical care transfer program were obtained by their "yes" /"no" responses to an opinion checklist (e.g., ways to help me/my child learn more about my/his-her condition, ways to help me care for my/his-her own health care needs). They were also asked an opened-ended question regarding "other services".

Questions regarding the type of medical care program the adolescent or adult currently attends (general medicine or specialized program), whether or not the adult receives care in an adult program, the young adult's satisfaction with his/her transfer experience (if any), and general demographic questions, were also asked. All SCTQ study questions and checklists were developed specifically for this pilot study, based on a consensus of patient/parent clinical concerns expressed in individual and focus group sessions with direct health care providers (psychosocial and biomedical) and researchers.

The SCTQ return rate for the total sample was 65%. The study consent forms were approved by the Committee on the Protection of Human Subjects of the School of Medicine, UNC Chapel Hill.

Analyses

Data analysis involved two steps. The first involved a univariate descriptive breakdown of the sample demographically (e.g., race, gender, employment status) and by responses to the SCTQ opinion checklist items. Using SPSSX-PC+, this analysis allowed for the determination of those concerns and opinions which were most important to study participants. The second step involved using simple bivariate statistics (i.e., chi-square) to examine within-group associations of selective descriptive variables. These analyses allowed for the determination of characteristics which were most likely associated with the key study variables of transfer concerns, transfer program needs, feelings regarding transfer, and transition services.

Results

Demographic Characteristics

Demographic characteristics of the three groups are listed in Table 1.

Transfer Concerns

Overall, 44% of the adolescents, 50% of the young adults and 68% of the primary caretakers in the sample indicated five or more concerns (out of 16) associated with the transfer process. For adolescents, the major concerns were being treated as an adult (40%); how they would pay for their medical treatment (40%); and whether adult health care providers would understand how SCD affects them as individuals.

The primary concerns for young adults when they transferred from pediatric to adult care were: how they would pay for their medical care (56%); whether or not adult health care providers would understand how sickle cell disease affects them as individuals (44%); that new medical staff would not believe them when they were in pain (42%); and leaving the pediatric care program (40%).

For primary caretakers, 60% (15 of the group) were concerned about their teen leaving the pediatric care program; 48% (12) were concerned that adult providers would not understand how sickle cell disease affects their teen; 44% (11) were concerned about whether their teen would be able to take responsibility for their general medical care and be able to manage pain episodes on their own; and, 40% (10) were concerned that new staff would not believe their teen when he/she was in pain.

Transfer Related Emotions/Feelings

Findings indicate that adolescents have mixed emotions/feelings regarding the transfer process. Sixty-seven percent indicated they would be "okay" with the transfer to adult care programs and 42% felt it would be the right time to move. On the other hand, 56% would be nervous and 50% would feel unsure about transferring to adult care programs.

Similarly, young adults had mixed feelings/emotions about their transfer experience. Sixty-eight percent reported feeling fearful, 46% felt unsure, and 42% felt nervous. On the other hand, 42% felt "okay" with the transfer, and 41% felt it was the right time to move into adult care.

Table 1. Demographic Characteristics of the Sample

Characteristic	Adolescents %	Adolescents N	Adult %	Adult N	Caretakers %	Caretakers N
Race						
African American	100%	(36)	92%	(55)	100%	(25)
Other	—	—	8%	(5)	—	—
Gender						
Male	42%	(15)	55%	(33)	3%	(3)
Female	58%	(21)	45%	(27)	97%	(22)
Age (Years)						
< 12	3%	(1)	—	—	—	—
13–18	91%	(33)	3%	(2)	—	—
19–24	6%	(2)	42%	(25)	—	—
25–35	—	—	55%	(33)	36%	(9)
36–45	—	—	—	—	40%	(10)
> 46	—	—	—	—	24%	(6)
Hemoglobin Type						
SS	64%	(23)	48%	(29)	—	—
SC/S-β Thalassemia	33%	(12)	32%	(19)	—	—
Unknown/missing	3%	(1)	20%	(8)	—	—
Highest Education Level						
Elementary	8%	(3)	—	—	—	—
Jr. high/high school	92%	(32)	51%	(31)	52%	(13)
1 or more yrs. college	—	—	49%	(29)	48%	(12)
Marital Status						
Single	100%	(36)	85%	(51)	40%	(10)
Married	—	—	15%	(9)	60%	(15)
Employment Status						
Student	92%	(33)	18%	(11)	4%	(1)
Disabled	3%	(1)	40%	(24)	4%	(1)
Employed	—	—	28%	(17)	76%	(19)
Unemployed	6%	(2)	13%	(8)	16%	(4)
Total	100%	(36)	100%	(60)	100%	(25)

Table 2. Priorities for Transfer Intervention Programs as Identified by 50% or More of Participants in Each Group

Adolescents:
- Ways to help solve health care problems
- Provide info about adult health care programs
- Ways to care for own health needs
- Ways to help educate others about SCD
- Ways to help adult health care providers understand new patients

Young Adults:
- Provide info about adult health care programs
- Ways to care for own health needs
- Ways to deal with other health care people/situations
- Ways to learn more about sickle cell disease
- Ways to educate others about sickle cell disease

Parents:
- Ways to deal with other health care people/situations
- Ways to care for own health needs
- Ways to educate others about sickle cell disease
- Provide info about adult health care programs
- Ways to meet adult health care providers
- Ways to help solve health care problems

Lastly, primary caretakers indicated they also had mixed emotions/feelings about the transfer of their adolescents to adult care. Almost half of the primary caretakers felt they would be "okay" with the transfer of their teen to adult care, and 44% felt they would be excited/happy about the transfer. On the other hand, 48% indicated they would feel unsure about their child's transfer to adult care.

Reasons For a Transfer Intervention Program

Reasons for a transfer intervention program provided by the three study groups are listed in Table 2. There was a 45% or greater agreement on all "reasons to have a transfer intervention program" statements listed in the SCTQ across all groups. The one exception was that 44% of the adolescents felt that transfer programs would give them "more control over health care decisions and life". Two reasons for not having transfer programs were included in the checklist. Fewer than 10% of each group checked a reason for not having a program: enough help is already provided for them (SCD) or it would focus too much on sickle cell disease.

Program Offerings

Suggestions for components of an ideal transfer intervention program provided by the adolescent, young adult and primary caretaker samples are listed in Table 3. There was a 50% or greater agreement on all eleven "what transfer intervention programs should offer" statements listed in the SCTQ across all groups, However, only 44% of adolescents agreed with the statement that programs should offer "ways to help parents let their adolescents grow up".

Bi-Variate Analyses

Adolescents

Older adolescents (age $\geq$ 16 years) were more likely to agree with the idea of transferring to adult care (86% vs. 55%, $p < .04$) than younger adolescents. Consistent with this finding, adolescents who attended high school were more likely to agree with the idea of transferring to adult care than those still in the middle school (78% vs. 42%, $p < .03$).

Severity of the disease was associated with feeling unsure about making the transition into adult care. Sixty-five percent of the adolescents with the more severe form of sickle cell disease, HGB-SS, reported feeling unsure as compared with only 23% of those with the less severe form of the disease, HGB-SC-S. Adolescents with HGB-SS were also significantly more concerned about whether adult health care providers would understand them and how sickle cell disease affects them (50% vs. 15%) than those with HGB-SC ($p < .03$).

Young Adults

Young adult males were significantly more concerned about being seen as drug-seeking than young adult females (58% vs. 17%, $p < .002$).

Young adults in comprehensive sickle cell programs were less concerned about being misunderstood by adult health care providers (28% vs. 67%, $p < .005$) and were less likely to report feeling nervous (33% vs. 60%, $p < .05$) about moving into adult care than young adults in other types of programs. Feelings of worry and nervousness were also associated with age within the sample of young adults. The older adults in the sample (age 25 years) reported more nervousness (57% vs. 30%, $p < .04$) and worry (43% vs. 19%, $p < .04$) at the time of transition than younger adults. Older adults were also more concerned about being seen as drug-seeking (57% vs. 15%, $p < .004$).

Young adults with one year or more of college, reported that they felt it was the right time to move when they transferred to adult care (63% vs. 38%, $p < .05$) as compared with those with only a high school education. Young adults with more education were more concerned about how they would pay for their medical care (64%) than those with less education (36%), $p < .02$.

Table 3. What Transfer Intervention Programs Should Offer as Identified by 50% or More of Participants in Each Group

*Program Offerings:**
Provide information about adult care programs
Ways to meet adult health care providers
Ways to help me solve problems having regarding my health care
Ways to help me care for my own health needs
Ways to help me be on my own
Ways to help me learn more about my condition
Ways to help me educate others about my condition
Provide someone to talk to when I need it
Ways to help my parents let their adolescents grow up†
Ways to help adult health care providers understand my needs and feelings as a new patient
Ways to deal with other health care people and situations: like the emergency room, insurance companies, hospital staff, etc.

*Questions stated in third person for caretaker questionnaire
†Only 45% of the adolescents and adults identified this offer

Primary Caretakers

Married caretakers in the sample were significantly more likely to report that they would feel relieved when their child transferred to adult care (80% vs. 20% of unmarried parents, $p < .04$); and 71% felt it would be the right time for their children to move on as compared with 29% of unmarried parents ($p < .05$). Older caretakers (age 40 years) were more concerned about whether adult health care providers would understand how SCD affects their child (83% vs. 17%, $p < .02$) than younger parents. Older caretakers were also more worried about whether their child would have to take responsibility for him/herself than younger parents (82% vs. 18%, $p < .04$).

Primary caretakers of adolescents receiving care in sickle cell centers were more likely to agree with the idea of their child moving into adult care programs (92% vs. 8%, $p < .01$) and were less concerned than caretakers of teens receiving care in other settings about their child being able to talk to health care providers about SCD (25% vs. 75%, $p < .05$).

Discussion

The goal of this research was to assess whether or not a sample of adolescents and young adults with sickle cell disease and their primary caretakers: a) had concerns about the transfer from pediatric to adult care; b) recognized and acknowledged a need for programs to assist adolescents and their families in transferring from pediatric to adult care programs; and c) had positive or negative feelings about the transfer process.

Adolescents as they reflect on the future and young adults reflecting on the past arc primarily concerned about how to pay for medical care. Primary caretakers, however, do not cite payment for medical care as a primary concern. Because caretakers have been the principal managers of their adolescents' care perhaps they recognize or have knowledge about ways to handle payment problems about which adolescents and young adults are not aware (e.g., medicaid.) Interestingly, adults with one or more years of college were more concerned about how they would pay for medical care than those who were not as well educated. Because of the broader vocational opportunities available to the more educated group, they probably have encountered or anticipate encountering negative experiences with employers (potential employers) with regard to health insurance coverage (e.g., pre-existing condition clauses). Those less educated or unemployed may be less concerned because of their eligibility for government medical care assistance.

The fact that adolescents, young adults and their primary caretakers are concerned about whether adult health care providers would understand how sickle cell disease affects them as individuals indicates a lack of information and programs aimed at introducing adolescents and young adults to adult health care providers. Although not cited by adolescents and young adults, primary caretakers are concerned about their adolescent's ability to manage their own care. This kind of concern is not uncommon for parents of adolescents with a chronic condition who have been very involved in their child's care for many years and might have difficulty letting go without assistance and direction from health care providers.

Further, older adolescents are more comfortable with the idea of transferring to adult care than younger adolescents. Prior to participating in the study, younger adolescents probably have not thought much about issues of transition, whereas older adolescents are forced to contemplate similar issues in other aspects of their lives—e.g., what to do after high school. It is also not surprising that adolescents with the more severe form of the disease express more concern about transferring into adult care. Their relationship with the pediatric providers has been lengthy and more intense and their parents' involvement in their medical care has probably been more extensive than those adolescents with less severe forms of SCD.

All three groups expressed mixed emotions about transferring from pediatric to adult care. While they recognize the need to move out of pediatric care, they are not sure about what to expect and have little knowledge of adult care programs. It is not surprising that they would feel unsure about leaving providers with whom they've developed a relationship over many years. A protracted period of preparation for transfer could alleviate such feelings of insecurity. It appears that receiving care in comprehensive sickle cell programs does alleviate some transfer-related concerns for young adults with SCD and primary caretakers of adolescents with SCD.

Adolescents, their primary caretakers and young adults with SCD are in agreement about the reasons transfer intervention programs are necessary and what the content and focus of these programs should be. The theme of the identified reasons was one of empowerment and support that allows the adolescent to move more competently into adult care. This theme was reflected in the overwhelming agreement among the participants that transfer intervention programs would: a) provide a chance for the adolescent and his/her family to know more about what to expect in adult settings; b) provide more support for adolescents in meeting their health care needs; c) allow adolescents/young adults to be treated as adults; and, d) provide opportunities for adolescents to meet other adults with SCD who are doing well. The high level of consensus here can and should influence the development of models for interventions to facilitate the transfer process. Future longitudinal experimental research is needed to address the transition-related needs of adolescents with SCD and their families.

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