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Perceived Barriers to Clinic Appointments for Adolescents with Sickle Cell Disease

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Abstract

Purpose—The purpose of the study was to examine perceived barriers to clinic attendance and strategies to overcome these barriers for adolescents with sickle cell disease (SCD).

Materials and Methods—This was a two-phased study which utilized focus groups (n = 13) and individual semi-structured interviews (n = 32) with adolescent patients (aged 13–21 years) from three pediatric sickle cell clinics in the Mid-west.

Results—Adolescents identified competing activities, health status, patient-provider relationships, adverse clinic experiences, and forgetting as barriers to clinic attendance. Calendars/reminders and parent reminders were the most commonly reported strategies to facilitate clinic attendance. Adolescents also reported the need for flexible scheduling and improved patient-provider communication.

Discussion—Adolescents with SCD and their families may benefit from on-going education about the importance of attending routine clinic visits. Adherence to clinic appointments for adolescents may be enhanced by developing interventions to decrease forgetting (e.g., phone call reminders, text-messaging) and increase patient satisfaction with clinic visits. Scheduling appointments to accommodate busy schedules/scheduling conflicts (e.g., late clinic hours), providing teen-friendly clinic environments and utilizing technology may also facilitate attendance.

Keywords

patient non-adherence; teenagers; pediatric; focus groups; clinic appointments

Introduction

Sickle Cell Disease (SCD) is a genetic blood disorder affecting about 1 in every 500 African American youth and 1 in every 1000 to 1400 Hispanic youth [1]. SCD can lead to major medical complications including stroke, acute chest syndrome, anemia, organ damage (e.g., kidney, lung), delayed puberty, dactylitis (hand-foot syndrome), infections, bone infarcts,

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neurocognitive deficits, and vaso-occlusive pain crises [2,3]. Medical advances, including the use of hydroxurea [4] and transfusions [5], have resulted in improved treatments for youth with SCD [6,7]; however, patients' access to medical and pharmacological therapies is dependent upon routine follow-up with hematologists who refer patients for services, prescribe and refill medications, and monitor the benefits and side effects of treatments.

SCD practice guidelines recommend that patients ages 2 years and older attend routine clinic appointments every 6 months, and more frequently if needed, to monitor blood levels, assess pulmonary functioning and identify risk factors and complications before they become detrimental to patients (e.g. acute chest syndrome) [1]. In addition, flu shots and other immunizations, which occur at routine appointments, are given as standard of care to prevent infections and potential pain crises [8]. Attending regular clinic appointments may be especially vital during adolescence when SCD-related medical complications, such as priapism and gall bladder disease, and psychosocial difficulties (e.g. anxiety, body dissatisfaction, negative views of sexuality and physical development, social adjustment [2,9,10]) intensify.

“Nonadherence with regularly scheduled clinic appointments represents one of the most costly problems in outpatient care, both in terms of economical and human resources spent” [11]. Poor clinic attendance has been associated with the adolescent developmental period, female gender, minority status, history of previously missed appointments, and lower socioeconomic status (SES) [12,–15]. To our knowledge, no studies have documented rates of nonadherence to clinic appointments for adolescents with SCD; however, the larger chronic illness literature suggests nonadherence rates of 20 to 40% for adolescents and adults [11,12]. Prior data from our own SCD clinic indicates that the nonadherence rate for routine clinic appointments during an eight month period was 46% [16].

Bronfenbrenner's socioecological model provides one way of understanding factors that influence adherence with clinic appointments [17]. The model posits that a child's development/behavior is influenced by interactions with others (e.g., family), experiences in various settings (e.g., school, hospital) and larger systems (e.g., social/political climate). Studies in other chronic illness groups regarding barriers to clinic attendance have identified factors at the micro and macro levels. For example, research has shown a relationship between clinic attendance and individual/developmental level factors such as forgetting [18] and health beliefs [19]. Family factors including parental supervision regarding appointment-making [20] have also been identified. Interactions with the healthcare system appear to also be a contributor to poor clinic attendance, including dissatisfaction with clinical care (e.g., poor communication, multiple physicians providing medical care) [21,22], long waiting periods [21,23], and provider behaviors (e.g., explaining all components of the visit, answering questions) [24]. Furthermore, even the time of the appointment can influence clinic non-attendance, with adolescents missing fewer appointments in the afternoon compared to the morning [25]. Finally, societal and/or cultural factors may place patients with SCD at higher risk for non-adherence with clinic appointments. For example, beliefs regarding mistrust of the healthcare system [26], cultural beliefs about illness [27], socioeconomic status (e.g., transportation issues, lack of insurance) [28,29], presence/absence of social support [30], and past negative experiences with medical teams [24,22] play a key role in determining the motivation to attend routine appointments [29].

The reasons adolescents with SCD fail to keep appointments have not been fully elucidated and a majority of studies have used quantitative survey methods [24] and medical record reviews [31] to determine significant patient correlates. Thus, the objective of the current study was to examine patient reported barriers to and motivating strategies for clinic

attendance for adolescents with SCD, a population at high-risk for nonadherence. Qualitative research methods were chosen because they are often useful when exploring complex, multi-faceted issues. Specifically, focus groups and semi-structured interviews would allow for the generation of disease specific constructs, their relationships, and context.

Materials and Methods

Study Design

This study utilized a qualitative research design to examine adolescent perceptions of barriers to clinic appointments and motivating strategies to improve attendance. Phase I of the study consisted of focus groups with adolescent patients recruited from a comprehensive sickle cell clinic within an urban pediatric medical center in the Midwest (lead site). Phase II consisted of the development and administration of a semi-structured interview, which incorporated findings from both Phase I focus groups and the larger literature. In an effort to ensure that the semi-structured interview was generalizable to other settings, the following steps were taken: 1) adolescents participating in Phase I and Phase II were mutually exclusive, and 2) the semi-structured interviews were conducted with adolescents at two other urban Midwestern medical centers.

Phase I—The goal of Phase I of the study was to identify any SCD-specific barriers to clinic attendance and strategies to improve clinic attendance. Since attendance rates are most variable for patients in the transition age group (14–21 years old), these patients were targeted for participation in the focus groups. Sixty-seven adolescents were eligible and mailed a letter inviting them to participate in the discussion groups. The letter was followed by a phone call from the primary investigators providing them with additional information about the study and inviting them to participate. Nine patients refused on the phone and 12 patients were unable to be contacted (e.g. wrong number). Twenty-nine patients agreed to participate and were sent directions and a reminder card. Ten patients did not show up to the focus groups which were held at a site in the community that was easily accessible by public transportation and had free parking. A meal was served and then adolescents were invited into a room to begin the focus group discussion. Focus groups lasted approximately 1.5 hours and participants were reimbursed with \$50 gift certificates for their time, participation and transportation. Both focus groups were facilitated by the same moderator and conducted in the format recommended by Krueger [32] (See Table 1 for a list of focus group questions).

Nurses were asked to provide clinic attendance ratings for each adolescent participant to ensure that all facets of the population were represented (i.e. patients with poor and good clinic attendance). Nurses rated participant clinic attendance during the past two years in one of three categories: a) poor adherence (attended 0–1 visits out of 4 for two years), b) moderate adherence (attended 2–3 out of 4 visits for two years), or c) high adherence (attended 4 out of 4 visits for two years).

Phase II—Adolescent patients from three sites were interviewed individually about barriers to attending clinic appointments and strategies to improve clinic attendance. Participants completed Phase II of the study as part of an annual research and education event that included an educational program for patients with SCD and family members. All patients followed by the three SCD centers were invited to participate via mail and a follow-up phone call. For the purpose of this study, only adolescents between the ages of 13 to 18 years and their parents were included in the analyses. Adolescent interviews were conducted in private rooms. Participants were asked to provide information regarding clinic attendance

in the past year, barriers to attending clinic appointments, and strategies to help them consistently attend clinic appointments using the Disease Management and Barriers Interview-Sickle Cell Disease (DMI-SCD: Adolescent Version) [33]. Adolescents were given a list of 22 possible barriers which they could select (e.g., forgetting, too busy, transportation). They were also encouraged to independently elicit responses. Adolescents were also asked to identify strategies that helped them attend clinic appointments in the past. In addition, parents were asked to complete a demographics form and medical history questionnaire, which queried parents about the number of hospitalizations, emergency room visits, and clinic visits attended in the past year.

For both phases of the study, written informed consent (assent) was obtained from parents/guardians of each adolescent and young adult prior to participation. The study was approved by the Institutional Review Boards at each site.

Participants

Phase I—Two focus groups were conducted with thirteen adolescent patients (four in one group and nine in the other group), representing approximately 19.4% of the eligible patient population. Participants in the focus groups were all African-American and ranged in age from 14 to 21 years ($M = 16.54$, $SD = 2.47$). Fifty-four percent of the sample was female and the median education level was 10th grade. The majority of patients had Hgb SS disease (84.6%) and the remainder had Hgb S β^+ Thal (15.4%). Based on nurse ratings, approximately one-third of the sample (38.5%) was classified as demonstrating poor adherence with clinic appointments (i.e. attended 0–1 visits out of 4 for two years), 23.1% were classified as moderately adherent (i.e. attended 2–3 out of 4 visits for two years), and 38.5% were classified as highly adherent (i.e. attended 2–3 out of 4 visits for two years).

Phase II—Thirty-two adolescents participated in this Phase of the study. The mean age was 15.5 years ($SD = 1.7$) and 47% were female. The majority of patients had Hgb SS disease (61.5%) and the remainder had Hgb SC (27.7%) and Hgb S β^+ Thal (10.8%). Parents reported that children had been hospitalized 1.4 ($SD = 2.2$) times, with 2.5 ($SD = 4.8$) emergency room visits in the past year. Regarding self-reported adherence to clinic appointments, adolescents reported that they attended an average of 2.7 ($SD = 1.0$) visits, with 6% reporting that they had not attended any clinic visit and 13% reporting that they had only attended clinic once in the past year.

Data Analysis

Phase I—All focus groups were audiotaped, transcribed, and the transcriptions were checked for accuracy. Focus group data was analyzed and summarized separately using consensus ratings among three trained coders. Consistent with standard procedures [32], each coder independently read the transcript before coding to facilitate understanding of the depth and breadth of information discussed in the focus group. Coders then met as a group to determine consensus themes. When a difference occurred, it was discussed and resolved by consensus. Major and minor themes are summarized below.

Phase II—The major themes identified in Phase I were utilized as potential barriers in the DMI-SCD. Descriptive data (e.g. frequencies, means, standard deviations) regarding self-reported clinic attendance, barriers to clinic attendance and strategies to improve attendance was analyzed using SPSS version 15.0 (SPSS, Inc., Chicago, Ill.).

Results

Domain 1: Individual Level Factors

Participants reported several themes related to the adolescent's developmental level, disease management skills, and health status as important to decision-making about clinic appointments. A common theme identified across both phases of the study involved the preference of adolescents to miss appointments due to competing activities involving school or peers. Specifically, participants in the focus groups reported they would reschedule or no-show for a clinic appointment if they were attending a birthday party or had a homework assignment. Similarly, several adolescent patients (n=7) in Phase II also reported that decisions were influenced by competing activities, as well as forgetting the appointment (n=3).

Focus group participants commented on wanting the clinic waiting room to be more developmentally appropriate. For example, one adolescent stated, "Separate the waiting area for the teens away from the waiting area for the kids." Another participant added, "Two separate clinics. Change the surroundings, too. Have teen magazines available. Have basketball magazines available. More stuff for older kids not just little kid toys all over the place." Adolescents also reported that clinic-sponsored incentives (e.g., gift certificates) would increase the likelihood that they would attend appointments.

Older adolescents in the focus groups reported using aids such as calendars or planners to keep track of appointments. For example, focus group participants reported that if they "write it [the appointment] out on calendar" or "keep a planner," they were more likely to attend clinic appointments. Adolescents in Phase II also reported that using calendars/reminder strategies (n=10) helped them remember appointments.

The health status of the adolescent also appeared to influence attendance. Some focus group participants reported not wanting to attend clinic visits when they feel well. For example, one participant stated, "If I feel good, why go?" Likewise some participants in Phase II (n = 2) reported that feeling well or healthy influenced their attendance. However, some participants in Phase II participants (n=2) reported that feeling tired or unwell made them not want to go to the clinic.

Domain 2: Family Factors

Adolescents with SCD identified one major family factor that influenced clinic attendance. Participants reported that they are more likely to attend a clinic appointment if their parents/caregivers were involved. Some participants reported that their "mom keeps up with it for me" and that this strategy was very effective. Adolescents in Phase II (n=12) also indicated that parent reminders helped them remember clinic appointments.

Domain 3: Hospital-Related Factors

Adolescent participants in the study identified several factors related to their interactions with the hospital system as influencing their attendance to clinic appointments. One of the major factors reported was the relationship with providers (clinic/hospital staff). Focus group participants who reported that they felt very comfortable with the hospital staff stated that this made it easier for them to attend clinic appointments. Other focus group members expressed their dissatisfaction with staff members who they felt were not adequately trained to conduct medical procedures and/or to work with patients with SCD. One focus group member stated, "They just let anybody stick you. Newcomers do blood work. I don't like that." Another stated, "Staff, all staff, even receptionist/secretary, should know how to deal with sickle cell patients."

Satisfaction with care also appeared to influence patient attendance. Focus group participants discussed their dissatisfaction with communication among staff members. One participant stated, “You are asked the same questions by several people. They should communicate with one another so I don’t have to repeat the same stories over and over,” and “A doctor will talk to you but he is not the doctor who checks up on you.” In Phase II adolescent patients identified having difficulty understanding physician instructions (n=1), and being uncomfortable with treatments (n=1) as factors that influenced their adherence with clinic appointments. Most of the focus group participants discussed their dissatisfaction with clinic wait times. One adolescent stated, “If the appointment is at 2:30, you should see the doctor at 2:30, not 3:00.” Another participant reported, “They sometimes forget about you when you are in the rooms,” and another stated, “You wait in one room and then go to another room and wait some more.”

Adolescents in the focus groups indicated that clinic appointment times did not always meet their needs. In general, focus group members’ comments indicated a desire for flexibility in scheduling appointments. For example, some group members preferred to have appointments scheduled in the mornings while others would rather attend clinic appointments in the afternoons or evenings. Focus group members also discussed the need to schedule appointments on more than one day per week because they may have school or activity conflicts. One group member stated “have clinic on more than just one day. More choices of times and days.”

Domain 4: Sociocultural Factors

As may be expected due to their developmental level, adolescents identified few sociocultural barriers, with the exception of participants in Phase II who identified transportation as a barrier to clinic attendance (n = 2).

Discussion

This study is a first and necessary step to identifying patient perceived barriers and motivating strategies to improve clinic attendance for adolescents with SCD. The qualitative research design is a strength to this study, as major themes from the focus groups conducted at one site were used as possible barrier responses in a disease-specific adherence assessment tool administered to adolescents at two other sites. Study results suggest several barriers to attending clinic appointments for adolescents with SCD, including individual, family, hospital-related, and sociocultural factors.

At the individual level, competing activities and forgetting were identified as the key barriers to nonadherence to clinic appointments. Behavioral interventions targeted at the use of memory aids (e.g., calendars, new innovative text reminders) may serve to reduce these barriers [18,29,34]. Similarly, healthcare teams may wish to help adolescents with SCD and their families problem-solve strategies to incorporate treatment and clinic appointments into daily routines without disrupting developmentally-appropriate activities, such as homework and socialization [35]. In addition, there appears to be a complex relationship between adolescent health status (feeling well/ ill) and clinic attendance. For some adolescents, feeling well makes it less likely that they will attend clinic visits while for others feeling well may increase their attendance. This suggests that a two-pronged intervention approach will likely be needed to improve clinic attendance. For adolescents indicating they do not attend clinic visits when they are feeling well, intervention efforts may need to focus on prevention services (keeping them well); however, a different approach will be needed to reach adolescents who do not want to attend when they feel ill (e.g., parental encouragement and supervision).

Not surprisingly developmental factors were influential in adolescents' decision making about appointments. Although adolescents with SCD may understand that good healthcare is important, developmental factors such as need for autonomy and independence (i.e. need to schedule appointments at convenient times) and focus on peer relationships (i.e. birthday parties, practices) may undermine their ability to attend clinic appointments. Providing education about the benefits of routine disease management [28] and management of disease flare-ups may enhance internal motivation and health outcomes. Education should be provided through teen-friendly media to reinforce the importance of monitoring clinical status to minimize morbidity, and ultimately, improve long-term health, particularly since some adolescents in the study described themselves as the primary decision makers about clinic attendance.

Data from this study also suggests that patient-provider relationships are an important factor associated with nonadherence to clinic appointments for this population. Adolescents with positive relationships with providers reported that it increased their desire to attend clinic appointments. A patient's attitude about their providers' style of behavior has been found to be a significant predictor of patient satisfaction, which in turn has been found to be associated with the intention to keep scheduled follow-up appointments [24]. Previous research and data from the current study support the notion that effective self-management requires a reciprocal relationship between adolescents and their physicians to maintain and improve health [36].

In this study, family support was identified as a method to facilitate appointment-keeping. The literature also supports the importance of parents and family members in adherence to health care appointments. In fact, research has shown that parental involvement is critical to promote good adherence to clinic appointments [37,38] and treatment [39], even during adolescence when the need for autonomy increases. Specific to SCD, research has indicated that social support plays a critical role in promoting adherence to clinic attendance and other health behaviors [36,37]. Future studies are needed to better understand when families transfer disease management responsibilities to the adolescent.

With respect to external factors, adolescents in the study identified sociocultural factors including transportation and previous negative/adverse clinic experiences (e.g., unpleasant interactions, scheduling issues) as barriers to clinic attendance. These findings are generally consistent with previous research regarding clinic attendance in children/adolescents with other chronic illnesses. For example, health beliefs and structural barriers (e.g., transportation) have been reported in adults with diabetes [40].

The current study also identified strategies that may motivate adolescents with SCD to attend clinic appointments. Flexible scheduling and the use of memory aids (e.g., reminders, calendars) were identified as key methods to improve clinic attendance. Adolescents in the study also provided very practical strategies for making waiting rooms developmentally appropriate, making clinic visits more efficient, and improving communication among clinic staff. In the extant literature, researchers have reported that patients who felt more satisfied with their health care visit or had visits scheduled at a convenient time, were more likely to attend another appointment [24,31]. Specific to adolescents, Litt and Cuskey (1994) found that appointment keeping was higher when adolescents reported greater satisfaction with their clinic care [22].

Future studies should examine the success of using the strategies identified in this study to improve appointment-keeping within this population. As previously mentioned, reminders via mail, phone, and email might minimize the likelihood for adolescents and their parents to forget about appointments. Given the significant increase in the use of technology by

adolescents, additional research on methods that utilize current technology (e.g., text messaging, emailing) should be investigated to determine if this serves to enhance clinic attendance for this population [41]. Several studies have developed and tested interventions to improve clinic attendance for both children and adults (e.g., telephone and written reminders - both personal and computer-generated) [18,29,34], incentives [34,42], and contracting with patients [42]; however, these have not been utilized with adolescents with SCD.

Although this study increases our understanding of the barriers associated with clinic attendance and strategies that may improve appointment-keeping for adolescents with SCD, several limitations exist. First, the sample size was small and consisted of convenience/volunteer samples. This limitation is notable given that patients who had the highest rates of non-adherence may not have been represented in the sample. However, it is important to note that between 18%–39% of adolescents across the two phases represent patients who attended clinic visits zero to one time per year. Second, although the study was designed to obtain broad perspectives (via focus groups) and then specific strategies (via interviews), focus groups and interviews were conducted with different participants. This heterogeneity in participants limits the continuity of the findings from Phase I to Phase II. However, it also strengthens the study such that patients' responses in Phase II were not biased by their participation in Phase I. Finally, it is unclear how the identification of barriers and strategies to clinic attendance relates to actual clinic attendance. Future studies need to examine this important link.

Despite the limitations, these data provide implications for developing disease-specific interventions to improve adherence to clinical appointments for adolescents with SCD. A potential intervention approach is for health care teams to routinely discuss barriers to attending follow-up visits and problem solve around these issues with adolescent patients and their families. The health care team should also focus on building and maintaining a developmentally appropriate and culturally competent relationship with the adolescent to promote sharing of barriers. Additionally, adolescent-focused strategies to improve clinic attendance may be more likely to be accepted if they are recommended by other adolescents. In fact, our team is currently piloting a computer-based intervention to improve clinic attendance that highlights both our understanding of barriers to appointment-keeping and problem-solving strategies to enhance adherence to follow-up clinic appointments. In summary, consistent with the findings from a meta-analysis conducted by Roter and colleagues, effective strategies for improving clinic attendance for adolescents with SCD should be comprehensive and multi-pronged [43], as these types of interventions may be more effective than a single strategy to improve clinic attendance.

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Table 1

Focus Group Topics and Questions

Topic	Questions
Barriers	<ol style="list-style-type: none"> 1. What gets in the way of attending clinic appointments? 2. How important is your clinic appointment to you? 3. Does a hospital stay have an impact on coming to the clinic? In what way?
Motivating Strategies	<ol style="list-style-type: none"> 1. What helps you remember your appointment? 2. How do you feel about staff calling with reminder calls for appointments and other activities? 3. What would you like to gain/ get out of clinic appointments?
Clinic Logistics	<ol style="list-style-type: none"> 1. What do you like best about the clinic and it's transition program? 2. What do you like the least about the clinic and it's transition program? 3. What could be done to improve the TAYA clinic? 4. What would make the clinic more appealing to you and other teens/ young adults? 5. Any advice or suggestions you would like to give staff for dealing with the care of other teens and young adults?