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Challenges in Shifting Management Responsibility From Parents to Adolescents With Sickle Cell Disease

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Purpose This study explored the challenges faced by adolescents with sickle cell disease (SCD) and their parents and the work they engage in to progressively shift from parent management to independent adolescent self-management.

Design and methods: A qualitative descriptive focus-group design with semi-structured interviews was used with adolescents (11–18 years) with SCD (HbSS genotype) and their parents/primary caregivers. Interviews were analyzed using content analysis.

Results: Two adolescent focus groups, with a total of 14 adolescents, and two parent focus groups, with a total of 15 parents, described adaptive challenges. Adolescents' adaptive challenges included mastering complex symptom management, communicating about SCD and symptoms, and maintaining control. Parents' adaptive challenges included giving over the complex management, communicating the management with the adolescent, balancing protection against risk with fostering independence, changing a comfortable rhythm, and releasing the adolescent into an "SCD-naive" world. Adolescents' adaptive work included pushing back at parents, defaulting back to parental care, stepping up with time, learning how SCD affects them, and educating friends about SCD. Parents' adaptive work included engaging the adolescent in open dialogue and co-managing with the adolescent.

Conclusions: Shifting management responsibility from parents to adolescents imposes adaptive challenges for both. Future research is needed to develop and test interventions that improve adaptive capacity in adolescents and parents.

Practice implications: Health care providers need to assess the parent–child relationship and their progress in shifting the management responsibility, facilitate discussions to arrive at a shared understanding of the challenges, and collaborate on adaptive work to address these challenges.

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Annually in the United States, around 750,000 children with chronic illnesses and/or disabilities transition from pediatric to adult health care (AHRQ, 2005). Essential

to their readiness for transition is their ability to independently self-manage their condition (Kieckhefer & Trahms, 2000; White, McManus, McAllister, & Cooley, 2012). According to Vygotsky (1978), child cognitive development is fostered within a socially mediated dialectical process in which more competent adults engage children in intentional

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and meaningful interactions to achieve a higher level of functioning. In the context of children with chronic illnesses, the family constitutes an influential social medium where parents serve as the experienced and competent adults providing the scaffolding (Vygotsky, 1978) that adolescents need in order to become more skilled at self-management. While parents assume the primary responsibility for managing their child's condition during childhood, with time parents need to progressively shift a greater proportion of that responsibility to the adolescent in preparation for their transition to adult health care (Sawyer & Aroni, 2005; Schilling, Knafl, & Grey, 2006; White et al., 2012). Adolescence is a critical period in development where autonomy and personal identity are emerging and, therefore, the progressive shifting of chronic illness management responsibility to the adolescent not only improves self-management skills, but also enhances a sense of responsibility and personal control (Blum et al., 1993; Vygotsky, 1978).

Few studies have examined the shifting of management responsibility from the parent to the adolescent with chronic illness and most of these studies were conducted on parents and adolescents with diabetes (Allen, Channon, Lowes, Atwell, & Lane, 2011; Karlsson, Arman, & Wikblad, 2008; Leonard, Garwick, & Adwan, 2005; Schilling et al., 2006; Sullivan-Bolyai et al., 2014; Weinger, O'Donnell, & Ritholz, 2001). Findings from this limited body of literature indicate that the shifting of management responsibility is a complex adaptive process for the adolescent and the parent, both of whom need to adjust to the changes in their roles (Allen et al., 2011; Chilton & Pires-Yfantouda, 2015; Karlsson et al., 2008; Leonard et al., 2005; Sullivan-Bolyai et al., 2014).

Adolescents need to progressively switch roles from being dependent on parental management to functioning as leaders in their own care. Building the capacity to take the lead in the self-management of their conditions requires that adolescents develop additional skills in problem solving, decision making, knowledge about their condition, along with mastery of the relevant technical self-care skills (Bell & Sawyer, 2010; Karlsson et al., 2008; Sawyer & Aroni, 2005).

Concurrently, parents need to gradually relinquish their role as the primary managers of care to the role of advisors and continuing supporters of the adolescent (Allen et al., 2011; Karlsson et al., 2008; Sullivan-Bolyai et al., 2014). While some parents described being able to back off either partially or completely to allow more independent adolescent self-management (Sullivan-Bolyai et al., 2014), other parents described being anxious and uncertain about the extent of the responsibility they can relinquish to the adolescent (Buford, 2004; Sullivan-Bolyai et al., 2014). The parental struggle to progressively relinquish control to the adolescents is often due to fear of worsening health outcomes (Buford, 2004; Hanna & Guthrie, 2000; Sawyer & Aroni, 2005), especially if parents believe that the adolescents are not as competent as they are in managing their condition (Allen et al., 2011). Shifting toward more independent adolescent self-management might

also create conflict between the adolescent and parents as they often disagree on management decisions and long-term health goals (Buford, 2004; Weinger et al., 2001).

While these studies emphasized the challenging nature of shifting the management responsibility from the parents to the adolescent, little has been done to describe specific challenges in depth using the perspectives of adolescents and their parents. A better understanding of these challenges is warranted, particularly in other health care conditions.

In this study we explored the challenges of progressively shifting management responsibility from parents to adolescents with sickle cell disease (SCD). SCD is an ideal condition to study the shifting of management responsibility because of its complexity and unpredictability and the resulting self-management challenges it imposes on individuals and their families. Individuals with SCD suffer from a variety of complications including pain crises, chronic pain, acute chest syndrome, and stroke (Miller & Meier, 2012). The symptoms and complications that accompany this complex chronic condition occur across an unpredictable trajectory that varies among individuals and within the same individual over time (Miller & Meier, 2012). Self-management of SCD entails monitoring symptoms on a daily basis; adhering to aggressive lifelong disease management, including hydroxyurea, chronic transfusion, iron chelation, and pain management; as well as preventive management such as hydration and rest (Miller & Meier, 2012).

Adolescence is a particularly vulnerable period for individuals with SCD. Compared to younger children with SCD, adolescents have worse health outcomes including higher rates of complications (Darbari et al., 2012; Lanzkron, Carroll, & Haywood, 2013; Quinn, Rogers, McCavit, & Buchanan, 2010); higher rates of depression and anxiety (Benton, Ifeagwu, & Smith-Whitley, 2007; Jerrell, Tripathi, & McIntyre, 2011); higher utilization of care (Brousseau, Owens, Mosso, Panepinto, & Steiner, 2010; Fosdal & Wojner-Alexandrov, 2007; Lotstein, Inkelas, Hays, Halfon, & Brook, 2008); and higher risk for mortality (Hassell, 2010; Lanzkron et al., 2013; Quinn et al., 2010). Improving health outcomes for this age group mandates assisting adolescents to increasingly engage in self-management (Aujoulat et al., 2014; Sattoe, Hilberink, Peeters, & van Staa, 2014).

Further, SCD is a genetically inherited condition with manifestations occurring in infancy, resulting in the parents' assuming the role of the primary manager of care from the child's birth. By the time their child reaches adolescence, parents have been in the role of the primary manager of care for more than a decade. Shifting management to the adolescent might pose a unique challenge for parents for whom the care management role has become part of their parental identity.

Importantly, individuals with SCD face racial stigma (Institute of Medicine, 2003) as well as disease stigma (Haywood, Tanabe, Naik, Beach, & Lanzkron, 2013). For example, adolescents with SCD reported unmet health care needs where they felt their pain is ignored and misunderstood

as drug-seeking behavior (Erskine, 2012; Telfair, Alexander, Loosier, Alleman-Velez, & Simmons, 2004). Parents reported that they often find themselves obliged to negotiate and advocate on behalf of their children during health care encounters and in their communities (Dyson, Atkin, Culley, Dyson, & Evans, 2011; Graff et al., 2010; Mitchell et al., 2007). These experiences might intensify the role parents play in their adolescents' health, leaving little room for adolescent self-management (Brown, Connelly, Rittle, & Clouse, 2006; Oliver-Carpenter, Barach, Crosby, Valenzuela, & Mitchell, 2011; While & Mullen, 2004).

Very few studies examined self-management in adolescents with SCD (Andemariam et al., 2014; Jordan, Swerdlow, & Coates, 2013; Labore, Mawn, Dixon, & Andemariam, 2015; Newland, 2008; Telfair, Ehiri, Loosier, & Baskin, 2004; Telfair, Myers, & Drezner, 1994; Treadwell, Telfair, Gibson, Johnson, & Osunkwo, 2011) and none directly addressed the challenges of shifting of management responsibility from the parent to the adolescent with SCD (Sawyer, Drew, Yeo, & Britto, 2007). As a result there is a limited understanding of the shifting of the management responsibility from the parent to the adolescent with SCD.

Theoretical Framework

The Adaptive Leadership Framework for Chronic Illness (Anderson et al., 2015) provides useful direction for the study of challenges in shifting management responsibility from the parents to the adolescent with SCD. The framework distinguishes between technical and adaptive types of challenges and draws attention to the collaborative work between the patient, family, and provider necessary to arrive at a shared meaning of the challenges and solutions for increasing the adaptive capacity of both adolescent and parent (Thygeson, Morrissey, & Ulstad, 2010). Technical challenges are clearly defined problems best addressed with clinical expertise, usually of the provider using medical interventions such as prescribing medications. Adaptive challenges are not easily defined, involve many interrelated factors, and require the adolescent/family to do the work required to adapt to a new reality (Thygeson et al., 2010). For example, the use of pain medications constitutes technical work used to address the challenge of pain, while integrating medication management in the adolescent's daily routine at school constitutes an adaptive challenge. Initially, the adolescent might lack the skills or resources to do the adaptive work and thus learning new behaviors is needed to enhance adaptive capacity. The provider's role is to help adolescents and their parents to identify challenges and develop the needed skills to do adaptive work.

The adaptive/technical distinction is very useful when parsing the self-management needs of adolescents with SCD as these adaptive challenges are often on their minds, though rarely addressed in typical clinical encounters (Mitchell et al., 2007). The complexity and unpredictability of SCD (Miller & Meier, 2012) imposes the need for technical as well as adaptive work and the use of collaborative approaches by the

adolescent, parent, and provider (Labore et al., 2015). Given the importance of developing independence in self-management for improved health outcomes, research is needed to understand the challenges that adolescents and parents have in progressively shifting the management responsibility from the parents to the adolescent (Sawyer & Aroni, 2005). Therefore, the purpose of this study was to explore and describe the challenges faced by adolescents with SCD and their parents and the work they engage in to progressively shift from parent management to independent adolescent self-management.

Design and Methods

Study Design

A qualitative, descriptive focus group design was used for this study. Focus groups are useful for gaining in-depth understanding of the participants' perceptions of and experiences with health-related issues. In particular, focus groups are useful and feasible for studying adolescents' perceptions and experiences regarding health-related issues because they acknowledge the adolescents as the experts on their condition (Gibson, 2007; Heary & Hennessy, 2002). Further, the group interaction in focus groups allows participants to react to and build on each other's responses, resulting in richer data that might have not been produced otherwise with individual interviews (Stewart, Shamdasani, & Rook, 2007).

Participants

Study participants were recruited by provider- and self-referral from a major pediatric sickle cell center in the southeast United States. Adolescent inclusion criteria were: a) SCD (HbSS genotype), b) 11–18 years, c) English speaking, and d) ability to provide consent/assent. Parent inclusion criteria were: a) primary caregiver of an adolescent with SCD, b) daily interaction with the adolescent, c) English speaking, and d) ability to provide consent. Grandparents and other guardians were eligible to participate as the parent participant if they were the primary caregiver and the guardians for the adolescent. Demographic information for all participants and self-report health information for the adolescents were collected. A semi-structured interview guide with probes was used for the focus group interviews.

Two adolescent focus groups, with a total of 14 adolescents, and two parent focus groups with a total of 15 parents were recruited, convened, and interviewed. Adolescent demographic characteristics and disease characteristics and parent demographic characteristics are summarized in Tables 1 and 2, respectively. The average adolescent participant was 14.4 years, male, African American, had an average of 3.2 pain crises in the last two years, and was on hydroxyurea and pain medications. The average parent participant was 44 years, female, African American, employed, and had a college degree. Parent participants included eleven biological parents, one adoptive parent, two grandmothers, and one godfather.

Table 1 Adolescents' demographic and health characteristics.

	Focus group 1	Focus group 2	Total
n	5	9	14
Mean age (years)	14.2	14.6	14.4
Gender (%)			
Male	3 (60%)	8 (88.9%)	11 (78.6%)
Female	2 (40%)	1 (11.1%)	3 (21.4%)
Race (%)			
African American	3 (60%)	6 (66.7%)	9 (64.3%)
Multi-racial: Reported > 1 race	2 (40%)	3 (33.3%)	5 (35.7%)
Attend school (%)	5 (100%)	9 (100%)	14 (100%)
Intend to apply to college (%)	5 (100%)	9 (100%)	14 (100%)
Mean number of pain crises/last 2 years (range)	4 (0–7)	2.9 (1–5)	3.2 (0–7)
Mean % time in pain/last 2 years (range)	4% (0–20%)	34.4% (0–80%)	23.5% (0–80%)
Mean number of admissions/last year (range)	1 (0–2)	1 (0–3)	1 (0–3)
Mean number of provider visits/last year (range)	4.6 (1–12)	4.6 (2–12)	4.6 (1–12)
Mean number of ED visits/last year (range)	0.4 (0–1)	1.7 (0–5)	1.2 (0–5)
Number of participants on medications (%)			
<i>Hydroxyurea</i>	3 (60%)	8 (88.9%)	11 (78.6%)
<i>Chronic transfusion</i>	2 (40%)	5 (55.6%)	7 (50%)
<i>Pain medications</i>	4 (80%)	9 (100%)	13 (92.9%)

Data Collection Instruments and Procedures

After institutional review board approval was granted, written informed consent was obtained from all parents or guardians and 18-year-old adolescents. Written assent in addition to parental consent was obtained for adolescents younger than 18 years. Adolescent and parent focus groups were conducted concurrently in two separate rooms on two occasions. While focus group methodology has been found to be a useful method for research involving adolescents and

parents (Gibson, 2007; Heary & Hennessy, 2002; Stewart et al., 2007) there remains the possibility that some group members may find talking in a group format intimidating while others might be dominating the discussion. To offset this potential problem, we ensured that the focus group facilitator attempted to control and enable opportunities for participation across members of the focus group. Facilitators were MSN prepared nurses trained in focus group methodology. One facilitator had adult nursing experience and conducted the parent focus groups

Table 2 Parents' demographic characteristics.

	Focus group 1	Focus group 2	Total
n	6	9	15
Parent (%)	4 (66.7%)	8 (88.9%)	12 (80%)
Caregiver (%)	2 (33.3%)	1 (11.1%)	3 (20%)
Mean age (years)	44.7 (37–54)	43.6 (36–63)	44 (36–63)
Gender (%)			
Male	1 (16.7%)	3 (33.3%)	4 (26.7%)
Female	5 (83.3%)	6 (66.7%)	11 (73.3%)
Race (%)			
African American	6 (100%)	7 (77.8%)	13 (86.7%)
Other	0	2 (22.2%)	2 (13.3%)
Marital status (%)			
Single	1 (16.7%)	1 (11.1%)	2 (13.3%)
Married	2 (33.3%)	7 (77.8%)	9 (60%)
Divorced/Separated	3 (50%)	1 (11.1%)	4 (26.7%)
Mean number of children (range)	2 (1–3)	3.4 (2–7)	2.9 (1–7)
Mean number of children with SCD (range)	1 (0–2)	1.6 (1–2)	1.3 (0–2)
Employed (%)	6 (100%)	7 (77.8%)	13 (86.7%)
Education (%)			
High school	0	1 (11.1%)	1 (6.6%)
College	6 (100%)	4 (44.4%)	10 (66.7%)
Graduate	0	4 (44.4%)	4 (26.7%)

and one facilitator had extensive pediatric nursing experience and conducted the adolescent focus groups. In our study, the group process seemed to work well as participants engaged actively within the group and frequently built on each other's responses. Some of our adolescent participants were siblings and some of the adolescents and parents were acquainted with each other outside the focus group, which might have also facilitated participation for the adolescent and parent focus groups.

Focus group discussion guides included the following topical areas: adolescent challenges with managing SCD and adolescent's work for managing SCD for the adolescent focus groups, and parents' challenges with managing SCD and parents' work for managing SCD for the parent focus groups. For example, adolescents were asked about their challenges with managing SCD by posing the grand tour question, "Tell me about the difficulties you have with taking care of your sickle cell". When needed, a probing question such as "tell me more about that" was used. Following the interviews, participants completed the demographic form. Data collection ranged between 60–90 minutes. Participants received a \$50 gift card, lunch during the focus group, and transportation reimbursement.

After each focus group, the two facilitators met, shared, and discussed field notes. The digital recordings were transcribed verbatim into an electronic transcript. Transcription was conducted by an experienced and well-trained transcriptionist, and transcripts were proofed against the audio recordings by the first author (MK) who conducted the adolescent focus groups. To maintain confidentiality, pseudonyms were used for study participants.

Data Analysis

Transcripts were analyzed using content analysis (Bernard & Ryan, 2010; Hsieh & Shannon, 2005). Parent focus groups transcripts and adolescent focus groups transcripts were coded and analyzed separately. Digital transcripts were viewed using ATLAS.ti 6 (Scientific Software Development GmbH, Berlin, 2011), a text analysis program. Each transcript was read to get a general feel for the data and incorporate field notes. Next, transcripts were coded. Provisional codes based on the Adaptive Leadership Framework for Chronic Illness (Anderson et al., 2015), namely technical and adaptive challenges and technical and adaptive work, were used as classification categories. Open coding was then used to identify challenges and work. This integrated approach of using deductive and inductive coding (Bradley, Curry, & Devers, 2007) allowed the researchers to go beyond the general concepts in the framework. A code book was developed and iteratively refined throughout the analysis and included codes, field notes, and evolving ideas. The first author (MK) developed the initial code set and applied them to 50% of the transcripts. A second coder (SD), with extensive coding experience, reviewed the initial 50% of coding and consensus was used to refine the codes and arrive at 100% agreement on applied codes. Once all transcripts were coded, categories were identified for parent focus groups and adolescent focus groups across codes by

searching for patterns and links, variation in data, consequence, and context (Richards, 2013) within each focus group type (parent and adolescent focus groups). The salience of particular codes was determined based on frequency, pervasiveness, similarities and differences across focus groups, and the relation to the framework (Bernard & Ryan, 2010). Codes were abstracted into a matrix that included focus group characteristics, abstracted text, code, category, and relevant context. Trustworthiness and rigor of the analysis procedure was constantly assessed and supported by the use of a systematic coding procedure employing two coders, an audit trail of all analysis decisions, and detailed description of each code and category.

Results

When asked about the challenges they have with SCD and the work they do to manage it, both adolescents and parents predominantly discussed challenges and work that were adaptive in nature. Neither group described challenges or work that would be categorized as technical.

Adolescent Adaptive Challenges

Adolescents described three classes of adaptive challenges to self-manage SCD: mastering complex symptom management, communicating about SCD and symptoms, and maintaining control. These challenges were related to their condition and how it affected their lives as adolescents.

Mastering Complex Symptom Management

The adolescents discussed the challenge of managing the complex symptoms associated with SCD. Although they discussed several self-care strategies, they still struggled with managing the unpredictability of the symptoms.

14 year old female: "It's difficult because you don't know when or what's going to happen, sometimes it's going to hurt your chest; sometimes you get a really bad headache. You just don't know what to do."

Further, the adolescents discussed how because of the unpredictable symptoms, SCD interrupted their lives and they missed out on significant events. The unpredictability of symptoms impacted socialization with peers and was seen as one of the most distressing aspects of symptoms.

16 year old male: "I was nominated for Mr. Freshman, and then I had a pain crisis. So I couldn't go to the dance. It just messed up everything and it just came at the most random times. You don't feel an initial pain or an initial sense, it just happens to you."

Communicating About SCD and Symptoms

The adolescents felt challenged in communicating to others; including parents, peers, teachers, and providers about their SCD and associated symptoms. Some preferred to manage symptoms alone rather than seek help from a parent. They also preferred to manage symptoms at home,

rather than seek help from a provider. This challenge resided in the nature of SCD symptoms, such as pain crises, which are subjective and not visible to others.

The adolescents expressed a particular frustration with having to explain over and over again to teachers and peers that they had SCD, how SCD affected them and what they needed to do to prevent and manage symptoms.

14 year old male: "Sometimes they [coaches and teachers] forget and you'll be running the mile and they'll see you slowing down and they'll pressure you 'go, go' and you have to remind them that you still have sickle cell, it doesn't go away. They thought it would go away."

Further, the adolescents discussed how they were selective with whom they disclosed having SCD and chose to tell a small group of trusted friends and teachers.

15 year old female: "I will tell some [friends], but I don't tell males I have sickle cell. Partly because I told one before and that changed our whole relationship."

14 year old female: "I don't talk to nobody about it because I don't want them to feel sorry for me because I have sickle cell. I just don't talk to people about it except my mom, my parents, my brothers."

Maintaining Control

Because of the unpredictable nature of the symptoms and their incapacitating effect, the adolescents struggled with maintaining control over what happened to them. SCD disrupted normality and their daily life, leaving them little control over what activities they can engage in. This lack of control left them feeling stuck with SCD for a lifetime with few options available.

15 year old female: "It's hard because I can have pain at any time and last for maybe a week, two weeks. I hate taking my hydroxyurea because I have to take it for the rest of my life. I could get the bone marrow transplant I could die and my mom really doesn't want me to. So I'm just going to have to deal with it. And I just want to be like every other kid that doesn't have sickle cell. It's hard dealing with it but it won't go away. I wish it would but it won't."

Adolescent Adaptive Work

The adolescents engaged in several types of adaptive work to address the challenges associated with more independent self-management including: pushing back at parents, defaulting back to parental care, stepping up with time, learning how SCD affects them, and educating friends about SCD. These strategies were aimed toward achieving more autonomy for the adolescent.

Pushing Back at Parents

One strategy that the adolescents used to address the challenges of acquiring more independent self-management

was to push back at parents for more control. Adolescents described situations where parents were perceived as overprotective with care, described their frustration with the overprotection, and expressed the need for more autonomy.

16 year old male: "And now that I'm older, when I go out with my friends, she's like, you need to drink water. Mom I know! I'm sixteen years old I'm going to be an adult soon. Gosh! So maybe if my mom would give me a little bit more space, then maybe I know all this stuff."

The adolescents were also frustrated with parents taking over the management and pushed back for more decision making control.

15 year old male: "[Don't ask] what number are you at [pain score]! [Ask] do you need medicine, is the medicine working? Your five might be different than my five so how do you judge for me. By this point I pretty much know my body and how it works."

Defaulting Back to Parental Care

Despite pushing back at parents, the adolescents described how they defaulted back to parental care when they could not control their symptoms. According to the adolescents, parents were trusted caregivers who knew exactly what to do in these situations. The adolescents seemed to default back to the parent for comfort and support as well as complex symptom management.

14 year old female: "My mother helps me a lot and she will know when I have a crisis, it's just instinct. So, I go to my mom every time I have a crisis because she knows how to handle it really well than anybody else. Every parent in here knows what's up because they know what to do."

Stepping Up With Time

The older adolescents explained to the younger adolescents in the group how they stepped up to take more responsibility of their care as they got older. Their taking on more responsibility included taking medications and scheduling clinic appointments on their own, with little interjection from parents. Parents still checked on their progress, but the adolescents took a more proactive role in their management.

18 year old female: "Once you get older it's like 'oh wait I'm different, I really have to take care of myself.' You feel more responsible."

17 year old male: "As you get older you have to try to take more responsibility for taking care of yourself. You said this is my mom's job. That's not bad but at the same time you want to know this stuff because if you have to go to the hospital, you need to be able to answer

questions because if they have to wait for your mom they can't do anything until she gets there."

Learning How SCD Affects Them

This strategy was also particularly evident with the older adolescents in the group. The adolescents discussed how they were attuned to their symptoms and were trying to understand how SCD affected them so that they could attempt to prevent pain crises. The adolescents discussed the self-care strategies they used to prevent pain crises, such as resting when tired and taking pain medications and hydrating before engaging in physical activity.

17 year old male: "What I always do before running I take Ibuprofen and keep a water bottle with me. I know I'm going to be doing a lot of physical stuff, I'm going to go ahead and take this pain medicine."

Educating Friends About SCD

The adolescents discussed how they strategically educated friends about their condition. Again, this strategy was evident among the older adolescents and appeared to serve two purposes: fitting in with peers and ensuring peer support. Educating friends about SCD and how it affected them appeared to help the adolescents with their relationship with friends, because friends, for example, understood their absences during hospitalization. Further, friends who knew how SCD affected them could be a source of support for the adolescent during pain crises.

16 year old male: "I'd rather them [friends] know about what I have so that if I'm not here for a week they're not thinking I'm just ditching them. They kind of know my routine."

17 year old male: "Your friends will try to take care of you. Make sure you're with people that if something happens then they'll help you, do what needs to get done if you can't yourself."

Parent Adaptive Challenges

Parents' adaptive challenges included giving over the complex management, communicating the management with the adolescent, balancing protection against risk with fostering independence, changing a comfortable rhythm, and releasing the adolescent into an "SCD-naive" world. The parents' challenges were related to the complexity of SCD, lack of public understanding of SCD, the adolescent's development, and their own comfort with the status quo.

Giving Over the Complex Management

Mirroring the adolescents' challenge of taking on responsibility of managing complex symptoms was the parents' challenge of shifting the complex management to

the adolescents. Parents felt that they had mastered the complex symptom management for SCD because they were engaged in the management since the birth of their child. Parents described the many ways they had learned to navigate through clinical and knowledge sources, including self-education, professional recommendations, and firsthand experience with family members with SCD. Their management decisions were based on the triangulation of different sources and what they called "parental instinct." They looked at all management advice from providers with a skeptical eye and triangulated different sources of information to eventually decide on the best course of action for their child. Mentoring the adolescent to master this strategy constituted a challenge for them particularly amidst a disease trajectory that was unpredictable.

Mother of 13 year old female: "Once you learn that they have [SCD], I looked at every possible outlet. I can give seminars on it. So when I explain to someone what my daughter is dealing with, there is no question you can ask me that I can't answer... it's all for me parent instinct. Because you're giving me this option as an alternative I'm not, my daughter is not a guinea pig."

The parents felt the need to stay in control of the management because they feared that the adolescent might not be able to handle the full complexity of care. The parents described periods in which they were able to step back and allow the adolescent some independence in management, but in general they felt the need to pay close attention to the adolescents' health status with close monitoring and assessment of hydration, diet, and medications.

Mother of a 15 year old male: "the reason why I feel protective is I think my son won't take care of himself like I would."

Mother of an 18 year old male and 15 year old female: "That's my fear because I stay on him. You were healthier when you were younger because I could control you more [others agreeing]... it's making sure that I'm on it with the medicine, I'm on it for the hydration. Those are my two things, if nothing else I do that day that my child has their medication and he is hydrated and happy and we've made it."

The parents struggled with giving over to the adolescent the monitoring portion of SCD symptom management. They expressed that they have had many years of experience understanding how their adolescent responded to SCD and they had developed the expertise in monitoring and managing symptoms. Paradoxically, they felt that their adolescent lacked this experience.

Mother of a 16 year old male: "We've had 16, 18 years to learn, to watch them and to see 'okay the eyes are turning yellow, this is happening, that's happening' to learn what goes on with him. He thinks he knows

himself. You actually know him better than he knows himself right now. I was the one dragging him to the hospital and I remember all those IVs and crazy chest x-rays; he doesn't!"

Communicating the Management With the Adolescent

Parallel to the adolescents' challenges of communicating symptoms, the parents also described how adolescents are often reluctant to talk to parents about their symptoms and, therefore, managing symptoms became more difficult.

Grandmother of 11 year old and 13 year old males: "My eldest grandson tends not to want to go to the hospital so he doesn't let us know when he's in pain, so it makes handling his crisis really difficult."

Mother of 16 year old male: "I know when he's going through crisis when I get the water bill, or if I wake up and my thermostat is at 90 degrees and he has a heating pad and a blanket on him. 'Why didn't you tell me you are in pain?'"

The parents also expressed difficulty in talking to their adolescent about their care. They were fearful about shifting management responsibility to their adolescent because conflicts often arouse. For the parents, communicating their thoughts on disease management at this age was a challenge because the adolescents were often not "receptive" to parental opinion.

Mother of 16 year old male: "I feel he needs to get to know himself and that's tough during the teenage years because they're not real receptive to your parental opinions and advice at this age."

Mother of 16 year old adopted male: "It's kind of a hard balance to make sure they understand these things in a way that they'll receive it. That's just the harder part shifting some of that responsibility."

Balancing Protection Against Risk With Fostering Independence

The parents described the challenge of balancing protecting the adolescent from SCD complications and allowing the adolescent opportunities to become more independent. The parents worried that the adolescent might be willing to take "extreme" risks for better quality of life and this was a situation that the parents were not comfortable with.

Mother of 18 year old female: "What broke my heart was somebody put it in her head about the bone marrow transfusion. She asked the doctor, and the doctor was like 'it's like a one in ten chance [survival]'. And my little girl actually looked at us and said 'I'd rather take the chance.' And I thought- Now that tore me up, I cried. You'd rather risk death than go through what you're going through!"

Finding the balance between close oversight of the care needs imposed by SCD and allowing the adolescent to explore and experience the world was often very difficult for the parents. The parents talked about feeling torn between fostering growth and independence for the adolescent and preventing complications.

Mother of 18 year old male: "I remember my first snowfall with him. My oldest son went outside and I won't let him go because I was just so 'Oh my Gosh, he will have a crisis', but he was like 'I'm going to miss everything, I hate these sickle cell.' And I was like 'Oh Gosh, okay, I'm going to layer you off'. And with the sports he didn't like it, which was a good thing for me."

Mother of 14 year old female: "You never want it to be one of those things where you've restricted them from so much and now they can't [do things]. I have two other kids that are very active in sports. Sometimes I stop her 'no you can't participate in anything' and she'll throw that at me 'Why are you hindering me? You think I'm sick mom!' So now she's doing ballet, she's doing hip hop dance. I'm like 'you know you're doing too much.'"

Changing a Comfortable Rhythm

The parents described how they and their adolescents live through "pockets of time" because of the unpredictability of SCD. The parents described how across the years they learned how to move between the periods of illness and health and manage the needs of the adolescent. They had developed a "rhythm to living life".

Mother of 18 year old female and 14 years old male: "what is tricky about sickle cell is it's there every day, but you don't live it every day. It's like pockets of times when you're dealing with it. Our son just got out of the hospital and re-entering into life is always challenging after a hospital stay. He was like 'I'm afraid it is going to happen again.' ...but you have to look at it like making deposits, you are feeling good, let's make our deposits, when it happens again then we'll make the withdrawals.' And I'm telling myself that! It takes us almost a week to kind of get [back to normal]. That first week we're still dealing with the pain, we're backing it down, so it's like that re-entry into life, it can be bumpy."

Shifting care responsibility to the adolescent was a challenge because it forced the parents to change their rhythm and risk the balance they had achieved and to take on yet another task of mentoring the adolescent in SCD management.

Mother of 14 year old female: "I got her balanceIt's just that how do you feel separating yourself from your child, knowing that they're going through that. That's the hard part! And she's big now 'mom I can take care of

myself. 'What did you call me? Mom! Exactly! Let me do my job please!'"

Releasing the Adolescent Into an "SCD-Naive" World

The parents felt that there was a lack of awareness about SCD, both in their immediate circle and in the community they live in and that created a challenge for them to trust that the adolescent will receive the support they needed when the parents were not present. Parents shared stories of how their awareness about SCD was through their firsthand experience with it.

Mother of 14 year old female: "There really hasn't been much that people knew about it until you start having kids, or you know family members that have it. And so many people are oblivious to the fact that this is serious. We run into it at school, 'oh what is that?' 'What do you mean, what is it? I've known it for the last fourteen years! Why you don't know about it!'"

The parents felt that it was necessary for them to advocate for the adolescent and make sure that their needs are met, especially at school.

Godfather of 17 year old male: "I'm not sure that a lot of people at school understood that he needed to go to that water fountain or restroom, please do not hinder him because I might come back looking."

Mother of 15 year old female: "When she was in the elementary school, the teacher wouldn't let her go to the bathroom. I said just get up and walk out, [if] they say anything tell them to call your mom. And then the principal called and I said 'I told her to walk out. My daughter has sickle cell, when she needs to get water or whatever, she needs to do it. She isn't going to ask anybody because her mom told her to do it.'"

Mother of 14 year old female: "That must be our slogan I'll deal with them."

Parent Adaptive Work

In contrast to the adolescents, parents described less adaptive work to address the adaptive challenges of shifting the management responsibility. Coping with the unpredictable day to day care needs of the adolescent with SCD appeared to be taxing for parents, who, on top of the complex management, need to develop strategies to mentor the adolescent toward independent self-management. The parents' adaptive work included: engaging the adolescent in open dialogue and co-managing with the adolescent.

Engaging the Adolescent in Open Dialogue

One strategy the parents described was engaging the adolescent in open dialogue about SCD and its management. Parents hoped that engaging in these discussions will equip

the adolescent with a better understanding of their condition and its management.

Grandmother of 15 year old male: "We always talk. It's communicating, teaching him, 'I can see that you're not feeling it. Tell me how you feel' and, but now it's mostly I have to remind him 'take your medicine.' He'll drink the water. He's eating better, so I can kind of lean back a little bit."

Co-Managing With the Adolescent

Another strategy that the parents described was collaborating with the adolescent on SCD management. While some parents would do what is needed, other parents stepped back to allow the adolescent to take on responsibility for their care. Stepping back did not mean that the parents completely let go of management; they still overlooked care and monitored the adolescent management.

Mother of 18 year old male: "He's responsible for his own medication, but I did step back and just let him, the time that I stepped back I said I've watched you for the last two weeks and you've taken your medicine around five times. I just gave him some tips: 'set an alarm, your phone to remind yourself because I'm not always going to be able to remind you.'"

Discussion

This study explored the challenges that adolescents with SCD and their parents face and the work they do to shift the management responsibility from the parents to the adolescent. To our knowledge, this is the first study to examine this shifting work and the challenges that it brings for both adolescent with SCD and their parents.

For the adolescents in our study, complex unpredictable symptoms made it difficult to take on the self-management responsibility. The addition of the non-normative stressors of complex SCD management layered on top of normative developmental challenges and transitions faced by adolescents (Kennedy, Gask, & Rogers, 2005). The adolescents also struggled with maintaining control over the events in their lives because of the unpredictability of SCD. This challenge is particularly significant given that achieving autonomy and independence are important developmental milestones for adolescents. The adolescents addressed this challenge with adaptive work directed at having more autonomy over their management, including understanding how SCD affected them, pushing back at parents and over time stepping up for more decision making responsibility.

Accepting responsibility of care also requires that the adolescents be able to advocate for themselves. The adolescents in our study were reluctant to discuss their condition with their peers and teachers and some did not disclose symptoms to parents and providers. The adaptive work they did to address the challenge of communicating symptoms to others was to educate their friends on SCD and

to default back to their parents for disease management and support. Educating friends about SCD helped the adolescents to maintain their social relationships with friends and to tap into their friends' assistance with SCD management when needed. Defaulting back to parents for SCD management served to elicit parental expertise when the situation was beyond what the adolescents could manage on their own. Parents also served as a source of comfort and support to the adolescents.

The adolescents' struggle with managing complex symptoms was mirrored by parents' hesitation to fully shift the management responsibility to the adolescent, because parents felt that the adolescent lacked their level of expertise in SCD management. Mentoring the adolescent to master disease management and triangulate different knowledge sources as the parents had done over the years constituted a challenge for the parents, particularly amidst an unpredictable disease trajectory. The parents also worried that the adolescent might be willing to take "extreme" risks for better quality of life. This situation made it difficult for them to shift the management decision making to the adolescent because they felt the need to remain in control to ensure the adolescent's wellbeing. Perhaps the greatest challenge for the parents was to balance fostering the adolescents' independence with maintaining their wellbeing. In the case of SCD this challenge comes with a grave cost: hospitalization and sickle cell crises. The parents' adaptive work to address these challenges included engaging the adolescent in discussions about their condition and how they are responding to it as well as collaborating with the adolescent on SCD management.

Interestingly, the adolescents and parents in our study discussed only adaptive challenges and adaptive work and neither discussed technical challenges or technical work. Similarly, [Palladino and Helgeson \(2013\)](#) found that adolescents, parents and physicians agreed that youth with diabetes were more proficient at technical medical skills (e.g. insulin administration) than adaptive life-style behaviors such as diet and exercise. [Chilton and Pires-Yfantouda \(2015\)](#) also found that acquiring self-management responsibility for adolescents with diabetes was more adaptive in nature. For example, they found that integrating self-management in social contexts such as school was difficult for adolescents with diabetes because they perceived that managing diabetes at school elicited negative attention from peers. These findings along with our findings emphasize the importance of adaptive challenges and adaptive behaviors in self-management and indicate the need for more research focused on assisting adolescents with chronic illness and their parents in addressing adaptive challenges with shifting management responsibility to the adolescent.

Our finding that adolescents had a more proactive role in their care as they got older was not surprising and is consistent with the older adolescent's development of autonomy. Similarly, [Labore et al. \(2015\)](#) found that participants in their study reported taking more control of SCD management

between the ages of 16 and 24 years. Findings from the diabetes literature also indicate that adolescents engaged in more self-management with increasing age ([Kelo, Martikainen, & Eriksson, 2011](#); [Palmer et al., 2004](#); [Schilling et al., 2006](#)). However, [Palmer et al. \(2004\)](#) found that child's age and physical maturation, rather than their level of competence and autonomy, explained the mother's transfer of responsibility for diabetes management. On the other hand, [Buford \(2004\)](#) found that mothers of children with asthma responded to specific cues, such as the child taking initiatives, to involve their children more in asthma management. Relying on chronological age for shifting management responsibility might be risky. Age is not congruent with competency, and shifting care responsibility should be based on the adolescent's maturity, self-efficacy, and ability to assume responsibility of care ([Young, Lord, Patel, Gruhn, & Jaser, 2014](#)). These findings call for more research focused on assessing the adolescent's readiness and their competency in taking on more management responsibility.

We also found that the parents in our study continued to maintain oversight over the adolescent's management, an approach that was reflected in both the adolescent and the parent focus groups. Other studies have similarly found that adolescents with diabetes hovered between independent self-management and relying on parental decision making, while parents continued to provide support and advice in management decision making ([Allen et al., 2011](#); [Karlsson et al., 2008](#); [Sullivan-Bolyai et al., 2014](#)). In two diabetes reviews, parental involvement in care was significantly associated with better adolescent treatment adherence ([Dashiff, Hardeman, & McLain, 2008](#); [Young et al., 2014](#)). Productive parental communication characterized by support, involvement, and warmth was associated with better metabolic control and treatment adherence, while problematic parental communication characterized by conflict, negative affect, and control was associated with worse metabolic control, self-care, and quality of life in the adolescent ([Dashiff et al., 2008](#)). Similarly, [Labore et al. \(2015\)](#) found that young adults with SCD appreciated maternal involvement in care and viewed maternal involvement as essential to them transitioning to self-management. Balancing monitoring the adolescent with enhancing the adolescent's self-efficacy should be attempted ([Young et al., 2014](#)).

Parent-Adolescent communication on disease management was found to be a challenge for both the parents and adolescents in our study. To overcome this challenge, parents engaged the adolescents in open dialogue about SCD, its management, and the adolescent's response to it. Adolescents with diabetes viewed open parental communication that encouraged responsibility, discussed the adolescent struggles, and recognized progress as supportive ([Dashiff et al., 2008](#); [Young et al., 2014](#)). Encouraging parent-adolescent communication on disease management might be a useful intervention in building the adolescent's capacity in self-management. Research exploring the feasibility and effectiveness of interventions aimed on facilitating parent-adolescent communication is needed.

A review by Kelo et al. (2011) found that mothers of adolescents with diabetes built supportive networks with teachers, nurses, and peers at school and expected the school to provide support and be involved in diabetes management. In contrast, the adolescents and parents in our study described that teachers and peers did not understand the gravity of SCD and were not supportive of SCD management. Parents described having to aggressively advocate on their child's behalf at the school. Our finding is in line with other research on SCD where parents of children with SCD often find themselves obliged to negotiate and advocate on behalf of their children during health care encounters and in the community (Dyson et al., 2011; Graff et al., 2010; Mitchell et al., 2007). When tailored to the adolescent's need, parental advocacy was associated with better coping strategies, better utilization of health care services, and decreased anxiety and depressive symptoms; however, this often led to parents taking a predominant role in their child's health (Brown et al., 2006; Oliver-Carpenter et al., 2011; While & Mullen, 2004) and to disagreement between the adolescent and parent about disease management (Burlaw, Telfair, Colangelo, & Wright, 2000; Erskine, 2012).

Study Limitations

Our study recruitment was limited to one medical center, which might limit the external validity of the study. However, the center from which the participants were recruited is a major referral center in the southeast United States, and participants from a geographical radius of up to 100 miles from the center were recruited to the study. Our adolescent and parent samples were mostly African Americans. However, this is expected given that SCD occurs predominately in African Americans in the United States (Hassell, 2010). Our adolescent sample consisted mostly of male participants, with only three female adolescents. Yet, our adolescent sample was similar to reported population estimates in the mean number of hospital admissions and emergency department use (Paulukonis et al., 2014). Finally, our parent sample had at least a high school education and consisted mostly of female caregivers. The educational level of our parent sample might limit the generalizability of our findings to other parent samples. The fact that the majority of the adolescents' primary caregivers were female was not surprising; studies report on the important role that female caregivers play in the care of the chronically ill in the African American population (Becker, Gates, & Newsom, 2004; Jenerette & Valrie, 2010). Despite these limitations, this study contributes in-depth understanding of the challenges that adolescents with SCD and their parents face in shifting the management responsibility from the perspectives of adolescents and parents.

Implications for Practice and Research

Vygotsky emphasized the role of social forces, including parental guidance and interaction, teacher instruction, and language in child development (Miller, 1993). Within this framework, enhancing self-management capacity in the

adolescent requires an iterative process of parent–adolescent communication. It might be easier for everyone concerned to maintain the status quo with the parents in full charge of the management, particularly if their strategies have been successful in maintaining the adolescent relatively healthy. While this approach might be effective when the adolescent is residing with the parent, self-management becomes a challenge when the adolescent leaves the home, for example, to college. Health care providers need to collaborate with parents and adolescents to incrementally shift the responsibility of disease management (Young et al., 2014). Health care providers need to assess the parent–child relationship and their progress in shifting the management responsibility, facilitate discussions to arrive on a shared understanding of the challenges they are having with shifting the management responsibility, and collaborate on adaptive work to address these challenges.

Our study described the challenges that adolescent with SCD and their parents face with shifting the management responsibility. Further research should explore the challenges adolescents with other chronic conditions and their parents face in shifting the management responsibility to understand the challenges across conditions and the unique challenges specific to certain conditions, including those involving neurological sequelae or cognitive deficits. Further research should also assess the adolescent's readiness and their competency in taking on more management responsibility as well as develop and test interventions aimed at facilitating the shifting of management responsibility from the parent to the adolescent with chronic illness.

Conclusions

Shifting management responsibility from the parents to the adolescent with SCD is a critical and challenging process. Our findings indicate that the challenges that adolescents and parents face are adaptive-type challenges, rather than technical-type challenges. While technical-type challenges are easily fixed with technical work, more complex adaptive work is needed to address adaptive-type challenges (Anderson et al., 2015), making the shifting of management responsibility more complex. However, collaboration and goal-setting across the adolescents–parent–provider triad will assist in facilitating the progressive shift of self-management responsibility from parents to adolescents and thus improve outcomes for adolescents with SCD and their parents.

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