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Developing a Problem-solving Intervention to Improve Self-Management and Transition Readiness in Adolescents with Sickle Cell Disease

Nicole Melita, MA, Yaminette Diaz-Linhart, LCSW, MPH, Patricia L. Kavanagh, MD, Amy Sobota, MD, MPH *

Department of Pediatrics, Boston University Medical Center, Boston, MA, United States of America

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ABSTRACT

Purpose: Adolescents and young adults (AYA) with sickle cell disease (SCD) are at risk for serious complications including increased morbidity and early mortality during their transition from pediatric to adult care. Self-management support may help improve transition outcomes in this vulnerable population. Interventions based on teaching problem solving skills have been shown to improve adherence to therapy for AYA with other chronic disease and is a promising intervention in SCD. We sought patient and parent perspectives on improving self-management and input on the development of a problem-solving education (PSE) intervention.
Design and methods: We held focus groups with AYA with SCD and caregivers to discuss barriers and facilitators of self-management, acceptability of PSE and intervention content and delivery.
Results: Five focus groups were held with AYA ($n = 17$) and caregivers ($n = 15$). Groups participated jointly to discuss self-management and then separately to discuss PSE. Data were analyzed using grounded theory and double-coded until thematic saturation was achieved.
Conclusions: Both groups endorsed PSE as an acceptable intervention. Barriers to self-management included wanting to fit in with peers (AYA) and trouble letting go (parents); facilitators included having a regular routine (AYA) and sharing responsibility (parents). Participants suggested meeting in small groups for PSE sessions rather than individually and adding group sessions for parents.
Practical implications: Understanding AYA and caregivers' perceptions of barriers and facilitators of transition in SCD can help us better prepare AYA for transition. The specifics both groups identified as helpful will guide intervention development.

Purpose

Sickle cell disease (SCD) is a group of inherited blood disorders affecting approximately 100,000 individuals in the United States, mostly racial minorities from disadvantaged backgrounds (Brousseau, Panepinto, Nimmer, & Hoffmann, 2010; DeBaun & Telfair, 2012). Complications of SCD include debilitating episodes of pain, chronic organ damage, stroke and early mortality (Platt et al., 1994). Due to recent advances in medical care the majority of children born with SCD now survive to adulthood and need to develop appropriate self-management skills to successfully transition from pediatric to adult focused care (Lebensburger, Bemrich-Stolz, & Howard, 2012; Quinn, Rogers, McCavit, & Buchanan, 2010; Treadwell, Telfair, Gibson, Johnson, & Osunkwo, 2011).

Transition is a particularly difficult time for adolescents with SCD who often need to change providers at the same time as the pathophysiology of their disease worsens (Platt et al., 1994). Many patients and families have fears about leaving pediatric care and entering the world of adult medicine (Fernandes et al., 2014; Porter, Graff, Lopez, & Hankins, 2014; Sobota, Umeh, & Mack, 2015; Telfair, Ehiri, Loosier, & Baskin, 2004). Patients also face additional barriers to accessing care due to race, poverty and disease-related stigma (DeBaun & Telfair, 2012; Platt et al., 1994). In addition, many pediatric hematology clinics lack appropriate transition programs, and many adult providers feel unprepared to manage the care of AYA with childhood-onset chronic illnesses (Peter, Forke, Ginsburg, & Schwarz, 2009; Sobota, Neufeld, Sprinz, & Heeney, 2011). This results in less access to preventative care, higher rates of acute care utilization and cost, and higher mortality rates in the years after leaving pediatric care (Blinder et al., 2013; Hemker, Brousseau, Yan, Hoffmann, & Panepinto, 2011; Quinn et al., 2010).

While the importance of improving transition services for patients with SCD is becoming widely recognized, there are no specific, replicable interventions shown to improve outcomes for this high-risk population (Bryan, Porter, & Sobota, 2014; DeBaun & Telfair, 2012; Jordan, Swerdlow, & Coates, 2013; Telfair et al., 2004; Wojciechowski, Hurtig, & Dorn, 2002). Many 'transition' programs focus more on the transfer from a pediatric to an adult-focused provider rather than the process

* Corresponding author at: Boston Medical Center, 850 Harrison Avenue, Boston, MA 02118, United States of America.
E-mail address: Amy.sobota@bmc.org (A. Sobota).

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of transition during which adolescents learn to become more independent in managing their health (Fair et al., 2015; Hankins et al., 2012; McDonagh & Hackett, 2008; Sobota et al., 2011).

Previous work has identified self-management skills as the top priority of both young adults with SCD who had transferred out of pediatrics and adult providers accepting these patients into their practice (Sobota et al., 2015; Sobota, Shah, & Mack, 2017). However current models of self-management support, which have proven to be successful for adults with chronic disease, are not developmentally appropriate for adolescents (Crosby et al., 2009; Crosby, Joffe, Peugh, Ware, & Britto, 2016; Lorig et al., 2001; Modi, Crosby, Hines, Drotar, & Mitchell, 2012). Specifically adolescents with SCD have particularly poor clinic attendance rates, which means clinic based programs are not likely to reach patients who may need them the most, and they need to develop self-management skills within the context of a parent-child dyad (Kayle, Tanabe, Shah, Baker-Ward, & Docherty, 2016; Modi et al., 2009; Porter et al., 2014).

Problem solving skills are an integral part of disease self-management, perhaps especially so for adolescents with SCD who need to develop skills to handle both predictable tasks, including adherence to clinic visits and daily medication, and cope with unpredictable events such as managing acute pain or navigating issues at work or school (Bodenheimer, Lorig, Holman, & Grumbach, 2002; DeBaun & Telfair, 2012; Hill-Briggs, 2003; Jenerette & Murdaugh, 2008; Matthie, Jenerette, & McMillan, 2014). Interventions based on problem-solving skills have been shown to improve outcomes in a variety of chronic conditions, mainly in adults, but often require a trained mental health clinician which makes them less accessible for our patient population (Lyons et al., 2015; Schumann, Sutherland, Majid, & Hill-Briggs, 2011).

A more accessible intervention, problem solving education (PSE), is derived from problem solving therapy, a cognitive-behavioral intervention that teaches problem solving skills as a way to cope with life stressors and has been shown to improve outcomes in chronic disease (Hill-Briggs, 2003). PSE consists of a series of sessions in which the participant is guided to select a problem they are facing, establish a goal, generate potential solutions, implement them, and evaluate the outcome (Feinberg et al., 2012). Unlike other cognitive behavior interventions, PSE can be delivered in the community by lay-trained health workers, making it more accessible for patients through community-based delivery and cultural responsiveness of lay health workers (Crosby et al., 2009; Raphael, Rueda, Lion, & Giordano, 2013). PSE has been developed and used successfully in low-income minority populations (Feinberg et al., 2012; Silverstein et al., 2011). These factors make PSE a promising self-management intervention for adolescents with SCD.

While the existing PSE model is promising as a starting point, it has not been used in adolescents, adolescent/parent dyads nor specifically for individuals with SCD. In order to create an effective intervention, we sought to tailor PSE to meet the needs of adolescents with SCD as they learn to manage their own health (Kong, Singh, & Krishnan-Sarin, 2012). We hypothesized that the existing PSE model would need to be adapted in order to make it culturally congruent and relevant for adolescent patients with SCD and their caregivers. The Medical Research Council has outlined an approach for the development and evaluation of complex behavioral interventions (Craig et al., 2008). This study describes our first step in the modeling and exploratory phases, using focus groups to identify components of the intervention. This will lead to our next study, a pilot trial of the efficacy of PSE in improving self-management skills and transition readiness for adolescents with SCD.

Design and methods

We conducted focus groups to identify facilitators and barriers to self-management that could better inform our intervention and to understand participants' preferences for intervention content and delivery. Both adolescents with SCD and their caregivers were involved in the focus groups because both are involved in helping adolescents develop self-management skills and may have different perceptions of what an intervention should contain. Focus groups were utilized instead of individual interviews in order to capture the interaction between individuals, adding to the richness of the data (Krueger & Casey, 2008). This study was approved by the Boston University Medical Center Institutional Review Board.

Adolescents with SCD between the ages of 13 to 18 years and their caregivers were recruited from two pediatric sickle cell clinics located in Boston. Purposive sampling was used to recruit patients of both genders and a range of ages by sending out a letter describing the study and providing a number to call to get more information or opt out. If no opt-out call was received, a research assistant called each eligible family to invite them to participate. Text reminders were sent the week before, day before, and day of the focus groups.

Each focus group lasted approximately two hours. Upon arrival participants completed an anonymous demographics questionnaire. Food was provided, and child care was offered for anyone who needed it. The first half of the meeting was a joint session led by two trained facilitators (PK and YDL) to discuss barriers and facilitators of developing self-management skills. We held this session with both adolescents and caregivers so we could better determine similarities and differences in their perceptions of transition readiness. Intervention content and delivery discussions with adolescents and caregivers were conducted separately, split into separate groups with one facilitator leading each group. This approach was taken so that adolescents would have an opportunity to share anything they were not comfortable discussing in front of their caregivers.

The focus group guide was developed based on prior work and the published literature, and was further refined by the research team (Fernandes et al., 2014; Schwartz, Tuchman, Hobbie, & Ginsberg, 2011; Sobota et al., 2014). Whole group discussions included questions about management of SCD such as "What is the ideal way for an adolescent or young adult to assume responsibility for their sickle cell disease?" Individual group discussions focused on our proposed intervention with questions such as "What if there was a program that could help you learn ways to solve problems?" The question guide was reviewed after each focus group, but no needed changes were identified.

Each focus group was audio recorded and transcribed identifying speakers by group only (adolescent vs caregiver). Data were analyzed independently by two of the authors (AS and NM) through use of grounded theory and coded with NVivo (Herbert, Sweenie, Kelly, Holmes, & Streisand, 2014). Codes were reviewed by each researcher for consistency, and then analyzed and grouped by theme until thematic saturation was achieved. Findings were triangulated by discussing codes and themes with the focus group leaders (PK and YDL) who did not identify any needed changes to the themes or subthemes.

Results

A total of 17 adolescents and 15 adult caregivers participated in five focus groups. The mean age of the AYA participants was 14.6 years, 59% were female and 41% were born outside of the US. All of the caregivers were female and 73% were born outside of the US (see Table 1).

We identified Four major themes were discussed by the focus group participants; 1) SCD management, 2) transfer of responsibility from caregiver to adolescent, 3) emotional/social support, and 4) cultural expectations. Several subthemes were identified within each major theme, uniquely informing the development of the proposed PSE intervention.

Theme one: SCD management

Managing SCD is a complex task that impacts every aspect of a patient's life. Participants spoke about specific steps they take to remain healthy, and what they felt would be beneficial to improve their self-

management. Specific subthemes include daily self-management tasks, managing acute pain, use of daily reminders, knowledge of SCD, and motivation for self-management.

Daily tasks

Adolescents and caregivers identified methods by which they manage their SCD on a daily basis, which includes taking medication, staying warm and dressing appropriately, maintaining hydration and a healthy diet, and staying rested.

"I drink a lot of water. I eat a lot of vegetables and healthy things, and keep myself warm." (adolescent).

"Eat healthy. And a lot of water." (caregiver).

Acute care

Participants discussed methods for managing acute pain.

"I use heating pad, medicine or like rest, like sleep." (adolescent).

"Getting ahead of the pain before the pain gets to you" (caregiver).

"Sometimes I get pain at school so I just go to the nurse and if I need to rest, first I use a heating pad on where it hurts and then I just rest for 15, 10 minutes, and then I just, once I feel better, I just go back to class and keep hydrated." (AYA).

Daily reminder

Adolescents who said they were comfortable managing their own medications remarked on how useful it was to have a set routine or use an automatic reminder.

"I [take my medicine] when I eat dinner." (adolescent).

"I take my medicine. I try to every day. I have a reminder on my phone to take it" (adolescent).

SCD knowledge

Both adolescents and caregivers expressed a desire for more information about particular SCD-related care topics. This was a specific area both groups felt could be addressed during the intervention. One important distinction made by the caregiver group emphasized that adolescents might listen better if the teaching came from someone other than a parent.

"For my daughter, a lot of it is just having information and understanding her disease." (caregiver).

"Like make sure you're taking care of yourself and what you should do in a time of crisis." (adolescent).

"I think if he have someone else other than me educating him on his disease, how much he can help himself to stay away from being, getting to crisis, I think he will listen" (caregiver).

Motivation

Adolescents commented on reasons they were increasingly motivated to manage their own health such as the recognition that their caregivers wouldn't always be there for them and in order to achieve their own goals.

"Most of the time, I try to do things myself 'cause my mom isn't, she's not always gonna be there, so I need to know how to take care of myself." (adolescent).

"I mainly don't want to be in the hospital….because I like school…. If I don't take my medicine, I can't go to school because I'm sick and I don't like being sick." (adolescent).

"I'm motivated to start because I like feeling mature." (adolescent).

"I'm really motivated to drink a lot of water because ever since I was little, I wanted to be a pilot and I loved flying, but flying dehydrates you, so it's really motivating me to drink more water so I can reach my goals." (adolescent).

Theme two: transfer of responsibility from caregiver to adolescent

Participants discussed practical ways to help encourage independence in adolescents and the emotional impact on caregivers of allowing them to have more autonomy. Specific subthemes identified include sharing responsibility between caregivers and adolescents, how caregivers can 'let go', feeling that caregivers have less control when their children become adolescents, the importance of adolescents talking directly to health care providers and teachers, and the need to involve caregivers in the intervention.

Sharing responsibility

Several caregivers spoke about how they were able to gradually reduce the amount of involvement they had with their child's medical care. Adolescents also spoke about how they gradually began to take on more of their own care. Compromising or finding a shared solution was mentioned in several groups.

"I'm in the [clinic] room, but I'll just sit back, 'cause he has to have time to talk to them" (caregiver).

"Ever since I was little, like I understood what was going on. So, my parents help, but as I'm older, I know like what to do" (adolescent).

Table 1
Demographics of participants.

AYA ($n = 17$; *n*, %N)		Adult caregivers ($n = 15$; *n*, %N)	
Age		Age	
13	6 (35%)	35–44	3 (20%)
14	3 (18%)	45–54	10 (67%)
15	5 (29%)	65+	2 (13%)
17	1 (6%)		
18	2 (12%)		
Gender		Gender	
Male	7 (41%)	Male	0
Female	10 (59%)	Female	15 (100%)
Race		Race	
African American	17 (100%)	African American	14 (93%)
Other	0	other	1 (7%)
Genotype		N/A	
SS or S/beta0	12 (71%)		
SC or S/beta+	2 (18%)		
Other	1 (6%)		
I don't know	2 (12%)		
Born in the US		Born in the US	
Yes	10 (59%)	Yes	4 (37%)
No	7 (41%)	No	11 (73%)

"Like, she gave me responsibility, but she still tell me like all through the way, and she teach me how to do the things." (adolescent).

"He's gonna be 14 and we try to work together….He doesn't want to wear the jacket. He wants to wear a different one. So we compromise….He said you know, mom, I don' want to wear that jacket, but I'm gonna layer, which I'm good with." (caregiver).

Letting go

Caregivers talked extensively about the difficulty of letting go and allowing their child to become more independent because of the risks of the disease.

"Letting your child manage more of that is very scary" (caregiver).

"I feel that I still have time to be his caregiver and ensure that he doesn't die." (caregiver).

"She wants me to let go now, but I'm not. I'm not. I'm not ready." (caregiver).

Less control

Caregivers said that they felt like they had less say over the behaviors of their teenage children compared to when they were younger.

"He has grown up to be 18, so one of the problems that we having is I'm not in much of a control, like when he was eight, nine, 10" (caregiver).

"When they're young, they just do what you want… but teenagers are a little harder" (caregiver).

Helping AYA work directly with schools and the health care system

Both adolescents and caregivers gave examples of the importance of adolescents in taking ownership of discussions with teachers and health care providers and thought guidance in how to do this would be helpful.

"My daughter will push and say like 'I need to be able to do this on my own'" (caregiver).

"I really want them to talk about easier ways to get your work up, easier ways to communicate with teachers" (adolescent).

Involving caregivers in intervention

Participants emphasized the importance of having their own intervention group to increase their knowledge on aspects of responsibility transfer in order to better support their children.

"I feel like the parents could have their own group where they talk about how they help the child, like know what to do when they get older" (adolescent).

"Just getting the groups together….for them and for the parents… would be a big deal." (caregiver).

Theme three: social/emotional support

Both caregivers and adolescents emphasized the importance of social and emotional support, and how this plays a role in self-management behaviors. Specific subtheme include emotional support, disclosure of diagnosis to peers, the desire to fit in, and having the intervention delivered in a group setting and a community location.

Emotional support

Throughout the discussion participants spoke eloquently about how important emotional support is from their care team.

"Part of the transition is that supportive environment" (adolescent).

"Because we're looking for support system, so anything to help build one would be great. It would be great." (caregiver).

Disclosure of diagnosis to peers

Several adolescents commented on how difficult it is to let their peers know about their disease, and yet how crucial social support is. With this came the need to teach peers about SCD to reduce stigma and misunderstandings.

"I have a lot of friends that don't know my condition and I don't really feel comfortable telling them." (adolescent).

"I feel like I want my friends to know but I feel like they would somehow treat me differently if they knew, but I want to show them what I have, and why I missed so many days of school." (adolescent).

"They used to laugh at me because I couldn't play in the snow or I couldn't be outside for long periods of time and it was cold." (adolescent).

Wanting to fit in with peers

Adolescents spoke about many situations in which SCD self-management strategies conflicted with their desire to fit in with their peers, such as dressing appropriately for the weather, taking breaks while playing sports, and taking their medication.

"And I don't want a bus, 'cause I want to take…the MBTA bus like every other kid." (adolescent).

"[Teenagers] are more thinking of to make a fashion statement than keeping themselves healthy." (adolescent).

Groups rather than individual

In every focus group the idea of providing the intervention in small groups was suggested. Both adolescents and caregivers thought it would be helpful to learn with and from others in the same situation. Adolescents did not think it was important to have them divided by gender.

"A group, because then you would be around people who have the same thing as you" (adolescent).

"You're with a group of all these people who have the same thing as you and they share experiences and you share experiences and you can bounce ideas off of each other" (caregiver).

"I feel like it doesn't matter the gender, because we all have the same thing" (adolescent).

Community location

Adolescents and caregivers felt strongly about having the groups meet outside of Boston. Teens did not want to meet at the hospital.

"Everything seems to happen in Boston…and it's probably hard. It's hard on the parents, it's hard on the kids. So you want to make things easier and more accessible." (caregiver) (Telfair, Myers, & Drezner, 1994).

"Do it somewhere they can meet but that's not either in the hospital or at home" (adolescent).

Theme four: cultural experiences

All of our participants identified as African-American, and a majority were born outside of the US. These characteristics influenced their experiences in living with SCD in different ways, as captured through the subthemes which include cultural expectations of SCD, the desire to have an intervention provider with some knowledge of SCD, and the impact of race on the development of independence.

Cultural expectations

Caregivers, many of whom were born outside of the US, discussed different cultural views of SCD and its treatment.

"I come from Nigeria, they thought my sickle cell's a deadly disease that you're not gonna last for long…. This is back home mentality. [here] If you stay on point and take your medicine, you feel better" (caregiver).

"But pain management is a big thing, and we grew up in an environment thinking that medication or taking too many tablets is bad" (caregiver).

Interventionist with experience in SCD

The groups thought that the age, gender, or cultural background of the individual providing the intervention was less important than having someone who either has SCD or is knowledgeable about it.

"Someone who went through the whole procedure" (adolescent).

Race

Race, and its impact on safety, was also identified as a factor in caregivers finding it difficult to give their adolescent children independence.

"Being a teenager and African-American in Boston is chaotic. I might die before I reach 19 or 21 for gang violence or police brutality. So she doesn't want me out much anymore." (adolescent).

Discussion

This study explores the perspectives of adolescents with SCD and their caregivers on the development of self-management skills and their suggestions for the development of a novel PSE based intervention. Overall, adolescents were highly motivated to begin managing their own health, and both adolescents and caregivers recognized the need for help in supporting this developing independence. Our findings on specific content areas and delivery methods that would be most acceptable to families make a significant contribution to a field where there are few proven interventions (Campbell et al., 2016).

While the importance of transition services to improve outcomes for AYA with chronic diseases is widely recognized, there is a dearth of evidence-based interventions. A 2016 Cochrane review found only four such studies to include which showed at best slight improvement in transition readiness scores and no significant difference in disease related outcomes (Campbell et al., 2016). There is low to moderate strength evidence of interventions in diabetes that have led to lower HbA1C levels in AYA patients (Gabriel, McManus, Rogers, & White, 2017). One such pilot study, which was also based on cognitive behavioral therapy, included small group meetings and found an improvement of 1.5% in HbA1c for AYA with diabetes (Viner, Christie, Taylor, & Hey, 2003). This focus on motivation and behavior change rather than knowledge is similar to what is imagined for a novel PSE based intervention. The present study gathered rich data on how adolescents with SCD and caregivers think that PSE could be beneficial to them, thus providing vital insight on intervention development.

As expected, adolescents in the present study commented on typical ways to stay healthy with SCD—drinking water, staying warm, and taking medication regularly. In addition to these routine behaviors, participants also talked about how they have learned to manage unpredictable painful episodes. While these are not novel findings, the frequency with which they came up in focus groups, and the animated discussions that happened between adolescents and caregivers, highlights how important these scenarios are as a component in a PSE based intervention. Sharing tips for accomplishing these basic self-management tasks may be a key benefit of having group PSE sessions. As noted in previous studies it was encouraging to hear how motivated the adolescents were to figure out ways to stay healthy in order to meet their personal goals (Kayle et al., 2016; Porter et al., 2014; Yawn et al., 2014). Given that PSE is based on individual goal setting, this finding may be key for adapting the intervention to address the nature of the goals described by the participants.

A major theme of the importance of 'fitting in' was discussed by both adolescents and caregivers in this study. Teens discussed how this need is often in contrast to steps taken to manage their illness, such as taking breaks during sports or dressing more warmly. Teens with other chronic illnesses, such as diabetes, also worry about how self-care behaviors will be perceived by their peers (Yang, Lou, Lien, & Gau, 2017). While this fear is not unique to our patients, we know that individuals with SCD face life-long stigma based on their disease, including some specific situations such as delayed puberty which may have a significant impact on transition (Jenerette & Brewer, 2010; Jenerette, Brewer, Edwards, Mishel, & Gil, 2013). Meeting in groups, as suggested by almost all participants in our study, may add an important level of social support to our intervention.

Caregivers who participated in our focus groups indicated a significant level of concern in 'letting go' and allowing adolescents to manage their disease independently. This concern on the part of caregivers, that their teen will have a worse outcome if allowed to make their own health care decisions, has also been found in other studies (Anie, Telfair, & Group, 2005; Hauser & Dorn, 1999; Wojciechowski et al., 2002). However a novel finding of the present study was how the intersection of race and diagnosis affect the comfort of caregivers in allowing their adolescent children to develop independence. Understanding that caregivers may not feel safe allowing their adolescent children to be outside on their own because of fear of violence will be important in both developing our intervention and in how health care providers talk to parents about transition.

Both adolescents and caregivers commented on the gradual shift in responsibilities from caregiver to child. This concept of 'shared management' and the important role caregivers play in transition is highlighted in the transition literature (Cooley, Sagerman, and of Pediatrics, A. A., of Family Physicians, A. A., of Physicians, A. C., Group, T. C. R. A., 2011; Kieckhefer & Trahms, 2000; Sawicki, Heller, Demars, & Robinson, 2014; Schwartz et al., 2011). Despite this fact, few interventions explicitly provide support to caregivers on the transfer of disease management to their child. In the present study, both AYA and caregivers felt it was important for caregivers to be involved in the transition process by having their own group sessions. Doing so will make the proposed PSE intervention unique in that it will focus on the role of both parties in shifting responsibility from parent to teen.

Peer support has been mentioned as a protective factor in other studies of adolescents with chronic disease, and peer coaches have been found to have a positive impact on chronic disease self-management for adult, specifically low income or minority populations (Goldman, Ghorob, Eyre, & Bodenheimer, 2013; Raphael et al., 2013; Sattoe, Jedeloo, & van Staa, 2013). This aligns closely with the findings of the present study, namely that adolescents wanted the intervention provider to have some experience with SCD. In contrast to other studies however, where adolescents with chronic disease responded favorably to a peer close to their age, our participants felt that age was less important (Garvey et al., 2014).

We know that clinic adherence is a significant barrier for adolescents with SCD, and that young adults value a flexible approach to transition planning (Crosby et al., 2009; Sobota et al., 2015). There is also data to suggest that living further away form a sickle cell center is a risk factor for poor transition (Andemariam et al., 2014). Therefore, holding PSE sessions in the community rather than the hospital, and having evening and weekend options, has the potential to make our work more successful.

There is increasing evidence that cultural tailoring may increase the acceptability of self-management interventions among minority populations (Nam, Janson, Stotts, Chesla, & Kron, 2012). A novel finding of the present study was the role that country of origin plays in families' understanding of what SCD is, what medications are for, and how much responsibility a child should have in their own care. This emphasizes the importance of considering the variety of cultural experiences specific to SCD when developing a tailored intervention. In addition, a larger number of caregivers were born outside of the US compared to adolescents, many of whom were born in the US and may therefore be more culturally assimilated. As transition focuses on the patient/caregiver dyad understanding, and helping families navigate, this potential cultural divide will be an important part of developing our PSE intervention.

Practical implications

This study shows that both adolescents and caregivers are eager to learn ways to help adolescents with SCD become more independent in managing their own health. While the ultimate goal of this study is to inform intervention development, health care providers can use the findings from the focus groups to improve clinical care and education of this target population. Nurses are uniquely well positioned to support the gradual transition of responsibility form parent to teen by speaking directly to adolescents during visits, asking them to start answering questions about their own health, and providing additional education about SCD. Motivational interviewing techniques are a useful way to engage adolescents in care and ensure that their goals are taken into account. We heard from both adolescents and caregivers that they learn best from one another, or from someone with experience with SCD. However in most clinic settings, education is provided in a one-on-one manner by a provider without firsthand knowledge of the disease. Health care teams should consider including a nurse-educator who has lived experience with SCD to hold group sessions which would provide social support and education in a setting that may be better suited to this patient population.

Conclusions

Though adolescents and caregivers have adapted management techniques to facilitate their transition from pediatric to adult medical care, barriers still exist across medical, personal and educational environments. Applying PSE as an intervention for both caregivers and teens could improve self-management and transition readiness in this vulnerable population.

There are several limitations to our study. As a qualitative study done in an urban setting, our findings may be less generalizable to other geographic locations. The majority of caregivers, and a significant proportion of patients, were born outside of the US, which may also limit our study's generalizability to more US born populations. However, this also provided a novel cultural finding that will be valuable for intervention development. Our next step is to develop the tailored intervention and run an adaptive pilot study, before moving on to a larger scale trial. Overall this study lays the foundation for the development of a unique PSE based intervention to improve outcomes for these vulnerable patients.

Conflict of interest

None.

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Author statement

Nicole Melita: methodology, formal analysis, writing-review and editing. **Yaminette Diaz-Linhart**: methodology, investigation, validation, writing-review and editing. **Patricia L Kavanagh**: methodology, investigation, validation, writing-review and editing. **Amy Sobota**: conceptualization, methodology, formal analysis, writing-original draft, writing-review and editing, supervision, funding acquisition.

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