Perceptions of a Self-Management Intervention for Adolescents with Sickle Cell Disease

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Source of Funding/Acknowledgements: This project was supported by the Eunice Kennedy Shriver National Institute of Child Health & Human Development (NICHD) of the National Institutes of Health (NIH) under Award Number R21HD084810. Anna Hood was supported in part by a grant from the National Heart, Lung, and Blood Institute, National Institutes of Health (1F32HL143915). Onengiya Harry was supported in part by a NIH/NICHD grant (T32 HD 68223-7).

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Abstract

Objective: Individuals with sickle cell disease (SCD) are at increased risk for complications from their disease during their adolescent and young adult (AYA) years. The risk of morbidity in AYA with SCD can be decreased with improved self-management. Existing self-management interventions typically focus on one aspect of self-management (e.g., adherence) and do not address factors that activate patients (knowledge, motivation, self-efficacy and social support) to self-manage. Sickle Cell Thrive (SCThrive) is a mixed in-person/online, technology-enhanced (use of a mobile app), group self-management intervention that targets patient activation. To determine the most clinically-significant intervention components, a qualitative study was conducted. Methods: Participants were 19 AYA (*M* age=17.05) with SCD who participated in individual semi-structured phone interviews after completing SCThrive. Interview content was coded using a grounded-theory approach to generate themes related to SCThrive's feasibility, acceptability, and motivation for and impact on self-management. Results: SCThrive was reported to be highly feasible due to the mixed in-person/online format and acceptable because they learned skills to manage SCD in a group of AYAs with SCD. Action planning and pain/mood tracking appeared to be key factors in motivating AYAs for self-management. Participants reported continuing to use self-management skills post-SCThrive (self-efficacy) including applying them to other domains of their lives (e.g., educational/vocational). Conclusions: Study results provide data that can be leveraged to enhance the feasibility, acceptability, and impact of SCThrive and other self-management interventions. Findings can also inform clinical and mHealth interventions to increase self-management in this population.

Key Words: AYA; pediatric; disease management; intervention; qualitative research

Trial Registration: ClinicalTrials.gov identifier: *masked for blind review*

Implications and Impact Statement: AYAs with SCD are a particularly vulnerable group at risk for serious disease complications that could be minimized or prevented with effective self-management. This study showed a self-management intervention delivered in a group format in-vivo and online was acceptable, feasible and motivation for self-management. Participants perceived the peer support component and app as highly beneficial.

Perceptions of a Self-Management Intervention for Adolescents with Sickle Cell Disease

Sickle cell disease (SCD) is a chronic genetic disorder first identified at newborn screening or during infancy. SCD is primarily seen in individuals of African ancestry, with a minority of individuals of Hispanic, Asian Indian, or Middle Eastern descent. There are approximately 100,000 patients in the United States with SCD, of whom 40% are children (Brousseau et al., 2010). Adolescence and young adulthood are particularly vulnerable periods when SCD-related complications increase (e.g., damage to bones, lungs, kidney, or heart due to chronic sickling) (Yawn et al., 2014), and self-management becomes more complicated. Mortality rates for adolescents and young adults (AYAs) are 6-20% higher than most other age groups of patients with SCD (Aduloju et al., 2008; Ballas & Dampier, 2004). On average, AYAs with SCD have significantly more emergency visits than other age groups of patients with SCD (Yusuf et al., 2010) with severe and unpredictable SCD-related pain accounting for most of these visits (Brousseau et al., 2010). AYA are also at risk for overt and silent strokes (37% of patients aged 14 or older) (Bernaudin et al., 2011). The risk of stroke increases into adulthood (DeBaun et al., 2012), and neurologic complications are associated with significant cognitive challenges (Kawadler et al., 2016). Unsurprisingly, frequent hospitalizations and school absences result in social functioning delays and poorer quality of life for AYA with SCD (Barakat et al., 2008; Benton et al., 2007; Palermo et al., 2008).

Effective disease self-management or adoption of a “range of health-enhancing behaviors” (Chronic Illness Alliance, 2020) is critical to decreasing complications and early mortality in chronic illnesses like SCD (Araújo-Soares et al., 2019). Living with SCD requires a high level of self-management, but it is challenging in this population for many reasons. AYAs with more severe SCD-related complications may be required to take daily medications (e.g., hydroxyurea [HU]), receive chronic blood transfusions, and have frequent lab draws (4-12 times per year). These medical contacts require substantial healthcare navigation skills (Barakat et al., 2002). Families of youth with SCD have identified that not having these skills is a significant barrier to care (Crosby et al., 2012). Moreover, the episodic and unpredictable nature of SCD may contribute to AYAs feeling unprepared when their symptoms flare-up, which may decrease motivation due to negative cognitions about their ability to manage their illness. During adolescence, many parents encourage more independence and provide less oversight of adherence to treatments (Walsh et al., 2014). Many AYAs find having more responsibility challenging and struggle to prioritize their medical routine and successfully adhere to medical recommendations (Modi et al., 2009). Specific to AYA with SCD, increased self-management challenges may occur due to lack of access to high-quality care related to risk factors such as minority race and economic disadvantage (Rouse, 2009).

Given the complexity of self-management and barriers to adherence during this developmental period, interventions to improve self-management are critical. Yet, existing interventions for this population typically address a single dimension of self-management (e.g., pain management or medication adherence) (Barakat et al., 2010; Chen et al., 2004). For example, the Hydroxyurea Adherence for Personal Best in Sickle Cell Treatment (HABIT) intervention addressed several SCD-specific self-management barriers by providing support and resources via community health workers. Yet, the primary outcome was HU adherence (Green et al., 2017) rather than general disease self-management. Barakat and colleagues (2010) developed a self-management intervention to improve pain outcomes in patients with SCD. However, they found that the intervention was insufficient and, instead, recommended the development of more comprehensive self-management interventions.

Behavioral activation (BA; or patient activation) is crucial for the success of any self-management intervention as it often precedes changes in self-management. BA is the knowledge, motivation, and self-efficacy, needed to make effective decisions to manage one's health (Greene & Hibbard, 2011). Studies have found that individual components of BA have been associated with better health outcomes. Patients who are *knowledgeable* collaborative partners in managing their health (Greene & Hibbard, 2011), and patients who have *motivation*, or the readiness to make changes, including higher adherence to preventive care and medications (Haarbauer-Krupa et al., 2019; Speller-Brown et al., 2015) have better health outcomes. Some studies measure disease *self-efficacy* or confidence in completing certain health-related tasks as a proxy for self-management. AYA with SCD with higher levels of disease self-efficacy show higher rates of readiness for the transition from pediatric to adult care (Treadwell et al., 2016), a significant self-management milestone. Further, to effectively motivate and engage AYAs with SCD in sustainable health behavior change, the social context (e.g., connection with peers) is developmentally and culturally important. Less social connectedness can have a damaging effect on health and social isolation has been associated with poorer health-related quality of life and medication adherence in SCD (Badawy et al., 2017). Overall, these studies suggest that targeting BA may foster improved self-management in AYA with SCD.

With the goal of increasing BA, we developed a mixed in-person/online, group-based intervention, Sickle Cell Thrive (SCThrive) (see Supplement A) that incorporates a mobile app, to facilitate social support. SCThrive is being evaluated in a randomized clinical trial (RCT) (CTR#: *masked for blind review*) to examine its impact on disease self-efficacy and self-management skills (Crosby, et al., 2020). Although studies of multifaceted interventions such as SCThrive are crucial, they provide limited information about which components the participants perceived as fundamental to the intervention's success. Qualitative evaluations provide valuable supplemental information to help clinicians and researchers understand ways to adapt and improve an intervention (Alderfer & Sood, 2016). Therefore, the current study reports on the qualitative interview data from participants completing the SCThrive intervention to understand the components (mixed in-person/online format, culturally-tailored materials, app) perceived to make SCThrive feasible, acceptable, and motivating for self-management.

Method

Participants

Eligible patients for the study were AYA aged 13-21 years old, diagnosed with SCD, on, or eligible for, disease-modifying therapies (e.g., HU) and completed SCThrive. Exclusion criteria were being non-English-speaking or having a cognitive or psychiatric disorder that the physician or study therapists determined would impair study participation.

Procedures

This study reports qualitative data collected from AYAs with SCD participating in an RCT comparing SCThrive and an individualized health education intervention (Crosby, et al., 2020). AYAs were recruited from a large pediatric medical center via letter, phone call, at clinic appointments, or at an annual SCD-related event. AYA and caregivers (if AYA under age 18) signed consent/assent prior to completing any study procedures after expressing interest. Once consented, participants were block randomized based on age and disease severity into one of four groups (13-17 years severe/non-severe; 18-21 years severe/non-severe) with a block size of six participants (severe = history of acute chest syndrome, prior stroke or more than three vaso-occlusive episodes in the past 3 years; not severe = these complications are not present). The first 22 AYAs completing SCThrive were invited to participate in a 30-45-minute semi-structured telephone interview with a trained research staff member who did not deliver the intervention. To strengthen credibility, interviews were digitally audio-recorded, assigned an identification number to anonymize content, and transcribed for coding (Wu et al., 2016). Participants received $35 compensation for each completed session for a maximum of $245 (i.e., 6 sessions plus 1 booster) and $25 for completing an interview. The Institutional Review Board of the medical center approved the study.

SCThrive Intervention

Theoretical Basis. SCThrive is informed by cognitive behavioral therapy (CBT), motivational interviewing, social skills training, group therapy strategies, and cultural and developmental needs of AYAs with SCD related to autonomy, control, and peer support (Crosby, Ware, et al., 2017). Specifically, SCThrive utilizes CBT strategies to address inaccurate beliefs and negative perceptions about one’s health (Anie & Green, 2015); social skills training (Spence, 2003) to improve health navigation skills; motivational interviewing strategies (Miller & Rollnick, 2012) to promote engagement in self-management behaviors; group exercises, and a mobile application co-designed by AYA with SCD and their providers (Crosby et al., 2017) to improve self-monitoring and social connectedness.

SCThrive incorporates several components to promote cultural sensitivity. These components include emphasizing the importance of being an “active member of the healthcare team” (advocacy), a flexible design (e.g., online and in-person), an assessment of potential stressors related to socioeconomic and ethnic minority status, and inclusion of culturally-relevant content. SCThrive also works to systematically target BA components (knowledge, motivation, and self-efficacy). For example, SCThrive participants received an SCD-specific workbook (Hope and Destiny Jr.; (Hsu et al., 2013) and could track daily symptoms through the app which increased their disease knowledge. AYAs were encouraged to share their illness narrative; an activity that builds feelings of importance and confidence to accelerate motivation. Participants also completed weekly action plans which promotes self-efficacy.

Format. As social support is one of the main influencing factors for BA (Badawy et al., 2017), SCThrive was conducted in a group format. To increase feasibility, SCThrive group sessions were held in-person and online. Specifically, there were six weekly group sessions (three in-person and three online via HIPAA-compliant Zoom, a video conferencing program). Sessions 1, 2, and 6 were in-person and sessions 3, 4, and 5 were online. The format was determined based on the impact of delivery method on utility. A video chat platform was chosen to preserve the personal therapeutic components of in-person contact between facilitators and AYA. Our pilot work underscored the need for this mixed format to overcome participation barriers whilst maintaining engagement (Crosby, et al., 2017). If participants miss a session, they could watch a recording and complete the session evaluation to "make-it-up." Two weeks after the last group session, participants had an in-person/online booster session to review skills.

Sessions last 90 minutes and were facilitated jointly by pediatric psychologists and psychology graduate students. Evidence-based, developmentally-appropriate interactive teaching methods used included brainstorming, video vignettes, skills-training methods (modeling, role-playing, and rehearsal), small group exercises, and large group discussions (sharing action plans). All participants received an iPad with the app preloaded, which included a customizable profile section, and the ability to share photos and message with group members. The app homepage included a copy of the SCThrive group schedule and a link to session handouts. Participants were asked to use the app to track their daily pain and mood symptoms and progress on action plans. Those who complete these tasks, received an additional $5 per session.

Content. SCThrive content included disease-specific education and instruction in self-management tools/skills. Specific components are education about SCD, communication and problem-solving skills, pain and mood management, mind management, and health management (e.g., managing symptoms, emergencies, treatments, decision-making, healthy lifestyle behaviors). Health management components also included skill building and role-play exercises to improve healthcare navigation through familiarization with *MyChart* and tracking appointments and medications. A booster session focused on a review of SCD, maintenance of skills learned, and preparing for the transition to adult care (see Supplement A for a description of each session).

Post-SCThrive Semi-Structured Interview

Interview questions were open-ended and were adapted from Kashikar-Zuck et al. (2016). This method offered direction for AYA to respond with relevant information as well as the flexibility to provided detailed responses with depth and context. Questions were not modified during data collection and examined SCThrive's *feasibility* (e.g., "How did you feel about the length of each session?") including the format of the SCThrive program (e.g., "What did you think of the format with some groups in person and others online?"); *acceptability* (e.g., "Was this program a useful/ appropriate for helping you manage your SCD?") including the content (e.g., "Did you learn new things about your SCD from the program? What stands out?"); *motivation for self-management* (e.g., "During the program, did you use any of the skills you learned in group at home? Can you tell me about some of those techniques you're still using?"); *impact on self-management* (e.g., "Compared to before you started this program, have you seen any improvements in how you're taking care of your health?"); and integration of the *app* (e.g., "If you could make one change to the app, what would it be?"). Full set of interview questions is available by request.

Data Analysis

Verbatim responses from the transcripts were systematically coded line-by-line to identify key themes using a Grounded Theory approach (Glaser & Strauss, 2017). Two clinical psychologists (N.J. and L.C.) trained in qualitative analyses reviewed 5 transcripts and identified core concepts related to *feasibility, acceptability, motivation, and impact* of SCThrive, as well as participants' thoughts about the *app.* Next, they met to discuss their observations and developed a codebook (coding paradigm) which they applied to the remaining transcripts. Inductive reasoning was used to identify new concepts that were not captured by the codebook. This iterative process continued until there was agreement that all concepts had been captured (saturation achieved). A third trained coder and medical postdoctoral fellow (O.H.) double coded all interviews; all coders met to identify themes and resolve any differences. When discrepancies occurred, all coders re-reviewed transcripts for contextual information to achieve a consensus interpretation. When responses overlapped with more than one domain, coders assigned responses to the category that best represented the content.

Results

Twenty-seven AYA were randomized to the SCThrive intervention, data from 1 AYA was excluded because of a cognitive impairment. Of the 26 AYA who completed SCThrive, the first 22 AYA were approached. 21 AYA agreed to participate in interviews, with one declining due to a lack of interest. Two of the 21 were lost to follow up, and, in turn, did not complete interviews. The remaining 4 AYA were not approached as saturation was achieved. Thus, interviews were conducted, coded, and analyzed for 19 AYAs (see Table 1). Attendance at sessions was generally high. Two sessions had attendance of 92%, 2 sessions had 96% attendance, 1 session had 100% attendance, and the booster session had 96% attendance. Three participants had make-up sessions (i.e., watched at a later date).

Feasibility

AYAs were unanimously positive about the group format due to the opportunity to meet other AYAs with SCD and most preferred in-person classes rather than online. Although the flexible design was convenient, they felt more connected with their peers when they met in person. A few AYAs had difficulties with the technology, such as not being able to hear other participants in the program. The 8-week time frame was “just right” for most AYAs and only two participants desired additional sessions. Some AYAs noted that competing demands (e.g., work) were a challenge to participation and recommended changing the start time for sessions (Table 2).

Acceptability

All but one AYAs found SCThrive beneficial for learning about how to manage SCD and that they would recommend it and the Hope and Destiny Jr. book (Hsu et al., 2013) to other AYAs with SCD. One AYA described, “The stroke, I didn’t know about the stroke. That was a big one for me and . . . the fact that I know that I could have a stroke is life changing almost.” Participants also reported enjoying being in a group with other AYAs with SCD and about half (47%) reported having a family member involved was beneficial. The top content areas reported were action planning (74%), communication skills (63%), healthy lifestyle habits (water intake, sleep, exercise, healthy eating; 63%), and managing pain, mood, fatigue (58%).

Impact on Self-Management

Knowledge. AYAs reported increased knowledge about the relationships between stress, pain, and mood, and how to improve each area. The most frequently mentioned topics were pain management (58%), communicating with doctors or others about SCD (47%), problem solving/decision-making (47%), mind management skills (42%) and the importance of staying hydrated (42%). Fewer AYAs reported learning new information about SCD. One AYA reported, “Personally, I already knew the skills before I started because I went to psychology when I was younger so for me, I already knew most of the skills.”

Motivation. AYA were generally open to trying new skills, and most reported that action planning motivated them to be more active in their healthcare (advocacy) and change their behavior. Completing these plans increased their confidence in managing their health. AYAs also reported tracking pain and mood in the app motivated them to act and understand the relationship between pain and mood. Specifically, one AYA said, “I kind of knew pain and mood were mixed together but never really knew how much they were connected.”

Self-Efficacy. More than half of AYAs reported improvement in overall self-management and confidence in the use of the following skills: action planning (74%), giving or taking negative feedback (63%), deep breathing (58%), problem-solving (47%), and distraction/positive thinking (37%). AYAs reported continuing to use these skills Post-SCThrive: action planning (47%), giving or taking negative feedback (47%), deep breathing 32%), and distraction/positive thinking (37%). Participants reported using these skills to manage other life stressors (e.g. action planning to prioritize paying school fees rather than insurance, problem solving when transportation challenges, giving/taking negative feedback with family members when something was accidentally broken, deep breathing to control mood). One AYA shared, "Been feeling more positive and happy. The deep breathing has helped 'cause when something negative happens, instead of getting mad all day, I take a couple of deep breaths and I'm calm."

Mobile app

AYAs generally described the app as easy to use, with one AYA stating, "It just took a little bit of time throughout the day." When asked what they liked about the app, they reported tracking their pain and mood. One AYA indicated, "I liked how I could track my pain and my mood and how it correlated with each other." Most liked other app features, but features such as messaging, and the team page were used less often. AYAs desired easier access to the app, including the ability to download it on personal cell phones. One AYA expressed, "Yeah, I would download it immediately if on the app store." Only a minority of AYA reported any technical difficulties with the app.

Overall Themes

The group format was described as both acceptable and feasible by AYA suggesting that this is an important component related to the success of SCThrive. Additionally, the limited number of technical difficulties improved feasibility and likely supported continued use of the virtual platform and app. There were no group differences identified by gender, but younger AYA seemed to find SCThrive more beneficial and those with the greatest clinical severity (i.e., HbSS genotype) provided more information about their pain.

Discussion

AYAs with SCD are at an increased risk for early mortality, which could be reduced with effective disease management. With the goal of targeting BA, we developed an innovative, technology-enhanced, group self-management intervention for AYAs with SCD: SCThrive. Post-intervention semi-structured interviews revealed that SCThrive participants perceived that specific components of the intervention increased its feasibility, acceptability, and motivated them to engage in managing their SCD. The use of video-conferencing enabled AYA to attend some sessions remotely. The combination of online and in-person classes was perceived by participants to increase the feasibility of SCThrive possibly because it decreased interference with competing activities which have been identified as key barrier to adherence in this population (Crosby et al., 2009). It is also consistent with research illustrating that there is value in augmenting in-person relationships with virtual social support (Cole et al., 2017). Despite appreciating the flexibility that the combined format allowed, participants noted that they preferred meeting in-person because of the increased social support. As many group interventions have now moved to an online format, our findings suggest that consideration of the intervention interactivity, aesthetics, credibility, and opportunities for participants to chat informally with each other is critical to foster social connectedness.

Participants identified several components of the program that contributed to its acceptability. Participants valued the group format, which allowed for peer support and to feel connected with others with SCD. Across a range of chronic conditions, social support has been identified as a protective factor (Rueger et al., 2016) and is important for overall well-being, especially for AYA (Chu et al., 2010). Participants also found that action-planning which involves setting self-management goals and being held accountable for their goals by the group, was beneficial. This is encouraging, as action planning and goal setting have been identified as key drivers of health behavior change in AYAs with SCD (Crosby, Joffe, et al., 2017) and individuals with other chronic conditions (Lorig et al., 2014) and highly rated in similar interventions with AYA with SCD.

Participants also reported enjoying tracking pain and mood symptoms via the app. In a review of eHealth interventions for SCD, Badawy et al. (2018) found that AYA with SCD wanted access to mobile apps to support self-management. However, many commercially available apps lack rigorous evaluation and may contain inaccurate information (Badawy et al., 2018). In contrast, the app was co-developed by AYA and healthcare professionals and has undergone initial evaluation (Crosby, et al., 2017) thereby increasing its appeal. The app may have also helped to bridge the social support gap, allowing participants to maintain social connections during the weeks when the sessions were online. This is consistent with prior research in which AYA with asthma reported that they highly valued connecting through a self-management app (Roberts et al., 2016).

AYA with SCD viewed SCThrive as having a positive impact on their self-management and many of them described increased use of self-management skills. For example, participants reported increased hydration, an important skill for SCD. AYA also reported that they felt more confident in managing their stress (mind management), pain, and mood and were motivated by action planning and the app pain and mood tracker. We believe these activities contributed to the perception of SCThrive as impactful because they targeted disease knowledge, motivation and self-efficacy key elements of BA (Hibbard et al., 2007).

Limitations

This study was conducted at a single SCD center in the United States and reported only perspectives of those participating in one arm of a two-arm RCT. It is unclear if the perspectives are representative of AYA with SCD from other geographical regions or the three participants who did not complete interviews and those who completed SCThrive later in the trial. Health literacy of AYA was not formally assessed. Given the cognitive difficulties experienced by patients with SCD (Kawadler et al., 2016), it will be useful for future studies to assess whether the readability and comprehension of the content is appropriate. SCThrive participants did, however, complete a measure of SCD Knowledge at baseline with overall scores in the 75th percentile, indicating good SCD literacy (Crosby et al., 2020).

In the development of self-management interventions, it is important to consider potential barriers to implementation in real-world settings. In this study, groups were facilitated by psychologists or psychology graduate students. Although it is recommended that these professionals be integrated into SCD clinic services (Consensus Report- SCD, 2020), this is not possible at all centers. Further, if a participant could not attend a group, they could watch a recording of the session and receive compensation for their time. This flexibility may not always be possible in clinical settings. It is also difficult to know how much compensation and not having to submit charges to their insurance companies impacted participation. Of interest, AYA used the iManage app messaging and team page features infrequently, which is a limitation of the current study. However, it is plausible that AYA may have used these features more often had they been available on their personal cell phones, which suggests an advantage of transfer to a real-world setting.

Clinical Implications

Clinical psychologists who work with AYA with SCD are encouraged to use our qualitative findings. Across the board, patients were very excited to learn about the interconnections between stress, pain, and mood, and reported that learning how to manage each was extremely helpful. Moreover, out of the many self-management skills taught, AYAs particularly enjoyed learning deep breathing, distraction techniques, and positive thinking. Healthy habits especially sleep and hydration were other topics that many found helpful. An important theme that emerged was the benefit of peer connections with those who had similar experiences and including family and peers in their goal setting. Learning skills with peers led to deeper engagement, increased buy-in, and more interest in practicing and using newly learned self-management strategies. Learning how to effectively communicate with the medical team and make effective decisions were highly regarded. Increased advocacy skills are especially important, as the lack of SCD awareness among adult providers and in the larger community may make AYA feel that they have to educate others and negotiate their right to quality care once they transfer to adult providers (Haarbauer-Krupa et al., 2019).

Implementation of all aspects of the intervention will not be possible in all settings. In the absence of group sessions, psychologists could review these self-management topics and encourage AYA and family members or peers to develop parallel action plans with progress communicated via phone or via EMR-based patient portal. Psychologists could also have patients develop their action plans in a paper and pencil format and/or monitor deep-breathing and relaxation on their personal mobile devices. Psychologists could encourage AYA to practice communication skills with extended family (e.g., coaches, cousins) and provide scenarios that help AYA practice decision-making. Finally, after our mobile app has been tested in a multi-site study, the next step is to have it freely available for download.

Conclusions

AYAs with SCD are a particularly vulnerable group at risk for serious disease complications that could be minimized or prevented with effective self-management. SCThrive is a technology-enhanced, culturally-tailored, group-based self-management intervention for AYA with SCD. This study used qualitative methods to understand the intervention components that made SCThrive feasible, acceptable, and motivating for self-management. The social support component and app were described as influential. Future studies should explore the effectiveness of the intervention on key clinical and psychosocial outcomes. Clinical psychologists should consider using action planning/goal setting with a social support component to facilitate self-management in AYA with SCD.

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Table 1. Demographic and Medical Characteristics of Participants

	N = 19
Mean (SD) [range]	
Age in years	17.1 (2.2) [13 – 21]
Emergency room visits in previous 12 months (N = 14)	2.6 (2.4) [0 – 8]
% of emergency room visits for pain	71%
N (%)	
Female	11 (58)
African-American	19 (100)
SCD genotype HbSS	10 (53)
SCD genotype HbSC	6 (32)
SCD genotype HbSβ + thalassemia/ HbSD	3 (15)
No. of participants who have previously experienced acute chest syndrome	11 (58)
No. of participants who have previously experienced stroke	0 (0)
Families/patients with public insurance	9 (47)
Families/patients with private insurance	8 (42)
Families/patients with no insurance	2 (11)
Mother’s Education: less than high school	4 (21)
Mother’s Education: high school graduate	3 (16)
Mother’s Education: some college or certification	5 (26)
Mother’s Education: college graduate	4 (21)
Mother’s Education: graduate or professional degree	3 (16)

Sample demographics were consistent with data from the overall clinic sample (N = 88) at the time of baseline, including mean age (M = 16.62, SD = 2.54), gender (53% female; 47% male) and SCD genotype (60% HbSS; 30% HbSC; and 7% HbSβ thalassemia). HbSS = hemoglobin genotype SS; HbSC = hemoglobin genotype SC; HbSβ thalassemia = hemoglobin genotype sickle beta; SD = standard deviation; SCD = sickle cell disease

Table 2. Themes Supporting Feasibility, Acceptability and Impact of SCThrive

Themes Identified	**Percentage of AYA with SCD**
Feasibility	
Preferred in-person classes	95%
Online sessions more convenient	53%
Liked the length of SCThrive intervention	89%
Competing demands affected participation	16%
Acceptability	
Beneficial for leaning about SCD	95%
Enjoyed the group format	68%
Impact	
Learned new information	26%
Action planning motivation behavior change	74%
Learned the connection between pain and mood	54%
Improved self-management and confidence	59%
Used skills following SCThrive	
Mobile App	
Easy to use	79%
Liked being able to track pain and mood	53%
Liked the app features	58%
Would like easier access to the app	68%
Technical difficulties	16%

Note. AYA = adolescents and young adults; SCD = Sickle cell disease

Supplement A. Description of SCThrive Session Content

Session Type	General Content	Example Activity	Description of Activity	Intervention Target
1 	Sickle Cell Disease 101	Introduction to the app	In addition to discussing SCD and symptoms, facilitator introduces the app as a way to tell their story (customize profile, three-picture story), set and track progress on goals, track daily pain and mood, connect with other group members via messaging, and set daily reminders and an individual to receive a secondary reminder (family/friend).	Self-efficacy, motivation, family/social support
2 	Communication & Problem Solving	“Givin’ it” Skill	Discuss importance of good communication when we have a chronic condition. Introduce steps to giving difficult feedback (handout). Group leaders role-play skill (e.g., sibling borrows something and gives it back in bad shape), a volunteer role-plays with leader, then participants role-play with one another. May do example related to interactions with medical team.	Skills, self-efficacy, family/social support
3 	Pain & Mood Management	Gate Control Theory of Pain and Diaphragmatic Breathing	Introduce how the body feels or interprets pain (facilitator draws body diagram) then teach and practice diaphragmatic, “belly”,	Mood, self-efficacy, skills,

			breathing as one pain management strategy that can be effective in closing pain gates.	family/social support
4 	Mind Management	Positive Thinking	Discuss impact of thoughts on feelings and behavior. Give examples of both negative and positive self-talk and introduce common thinking errors. Members identify their “go-to” thinking errors and we work together to change some negative thoughts into thoughts that are more realistic and more helpful. Use both non-SCD and SCD specific examples.	Cognitive restructuring, self-efficacy, skills, family/social support
5 	Health Management I	Managing SCD Symptoms	After facilitating discussions about common symptoms of SCD, discuss ways to manage those symptoms. E.g., have group identify what can trigger SCD pain episodes, then brainstorms ways to prevent SCD pain. Then discuss infection, acute chest, eye problems, growth problems, and stroke.	Knowledge, skills, self-efficacy, resources, family/social support
6 	Health Management 2	Healthy Lifestyle Behaviors	Discuss importance of water intake, physical activity, sleep and healthy eating with focus on SCD-specific information. Encourage group participation through brainstorms (e.g., “What are some ways	Skills, knowledge, self-efficacy, resources,

			to help someone drink enough water?", "What are some other reasons to exercise?", etc.).	family/social support
Booster 	Review	SCD Jeopardy!	Divide group in to two teams (each team picks a team name). This game reviews areas important to managing SCD such as SCD vocabulary, self-management strategies, healthy lifestyle behaviors, and information about a new, but important, topic: healthcare transition.	Self-efficacy, motivation, family/social support

Supplement B. Additional Favorable Quotes from AYA about SCThrive Feasibility, Acceptability, Impact, and the Mobile App

Subtheme	**FEASIBILITY**
Mixed Format (Online and In-Person)	“[Online sessions] were more convenient. I didn’t have to meet personally.” “I like in-person better. It was easier to focus, and I got to see others and classmates.”
Group format	“I liked the group setting, because you did it with other people. You could get their opinion on how they thought about it or their perspective on their life and something that we learned that can better our lives.”
	ACCEPTABILITY
Recommend SCThrive to others	“I would give it a 10.”
SCD-Specific Content	“I would say it’s very great. It’s helpful, very helpful. You will learn how to treat your sickle cell problems and your crises. Like they teach you everything about sickle cell that you might not have known.”
Social Connectedness	“I like the fact that we are in a group and teens your age, so they know what we are going through, what they are going though currently, and we are more than likely to be more comfortable around people who share interest or have something in common with.”

	IMPACT
Knowledge	“Positive thinking because I have a lot of negative thought(s) because I have sickle cell disease. I think I can’t do something. But with positive thinking. I think even though I have sickle cell I can’t let it stop me and that I can do things.”
Improvements in Self-Management	“I like the action plans…like planning out what I need to do to better myself on a daily basis.” “When I’m having a pretty bad day because of my pain, then I will do one of the breathing techniques, and it will make my day better, because the pain goes away.” “I’ve been taking my medicine more, being more on the healthy side. Eating and exercise are a little better now.”
Motivation for Self-Management (e.g., Action Planning, Pain and Mood)	“I used positive thinking just recently ‘cause I didn’t get a scholarship I applied for; I did some positive thinking instead of blaming myself. I said ‘there are more I can apply for and there is one that is a good match, so it will all be okay.’”
Self-efficacy for self-management	“I’ve been going out with friends more. I guess I feel more confident going out compared to before the class, [because now] I would know what to say and what to do if something were to happen.”
	MOBILE APP

Ease of Use	“It was easy to use.”
Pain and mood tracking	“The pain diary – I think that was really helpful.” “The pain diary helped me recognize patterns in my mood and pain.”
Interest in accessing the app in future	“Encourage people to download the app for themselves on their phones.”

Supplement C. AYA Recommendations About the Feasibility, Acceptability, Impact, and Mobile App of SCThrive

Subtheme	**FEASIBILITY**
Mixed Format (Online and In-Person)	"I would've wanted more in-person sessions."
	ACCEPTABILITY
Recommend SCThrive to others	"It depends on their age and how affected by it they are."
SCD-Specific Content	"Talk about transitioning and the process . . . good experience, bad experience, what to expect"
	IMPACT
Knowledge	"It wasn't that useful because I am an older patient, so I already knew a lot of the information."
Motivation for Self-Management (e.g., Action Planning, Pain and Mood)	"I don't really use the skills unless I'm not feeling well.
	MOBILE APP
Pain and mood tracking	"I didn't use it during the study but in the future if I was having really bad pain, I would track it."