Title:

Improving Self-Management in Adolescents with Sickle Cell Disease

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Word Count:
Abstract: 247
Main Text: 3460
Figures/Tables: 3/3

Short Title:
Self-Management in Adolescents with SCD

Keywords: AYA, patient activation, disease knowledge, self-efficacy, health motivation, disease management

Abbreviations:

AYA	adolescents and young adults
BA	Behavioral activation
SCD	sickle cell disease
EMR	electronic medical record
HRQOL	Health-related quality of life

Abstract

Background: Sickle cell disease (SCD) is associated with significant medical challenges that often worsen in adolescence when caregivers are beginning to transfer responsibility for disease management. Behavioral activation (BA) is an important precedent to improvements in self-management and ultimately health outcomes; however, few interventions targeting BA have been developed for the SCD population. The goal of the present study was to evaluate a technology-enhanced self-management intervention for adolescents and young adults (AYA) with SCD targeting BA domains (i.e., disease knowledge, self-efficacy, motivation, and self-management skills). **Design/Methods:** Participants were randomized to one of two study arms. SCThrive participants (*N*=26) completed six weekly group sessions, an in-person booster session, and used a companion app (iManage) to record symptoms, progress on goals, and connect with other group members. Each SCHealthEd participant (*N*=27) received six weekly phone calls on SCD-related and general health education topics. All AYAs completed questionnaires assessing BA at baseline and post-treatment. **Results:** Separate mixed ANOVA analyses to assess for the effects of group (SCThrive/SCHealthEd), time (baseline/post-treatment), and group x time interaction indicated that there was a clinically meaningful improvement (8-point change) in self-efficacy, with a medium effect size, $p = .09$, $\eta_2 = .06$, and there was statistically significant improvement in one self-management skill (tracking health), $p = .001$, $d = .71$, among SCThrive participants. **Conclusions:** The results support the potential for a self-management intervention to improve self-efficacy in AYA with SCD. Healthcare providers are encouraged to target BA skills to support self-management of AYA with SCD.

Sickle cell disease (SCD) is associated with significant medical challenges that often worsen in adolescence when caregivers are beginning to transfer responsibility for disease management. SCD primarily affects African-American and Hispanic/Latino youth in the United States and has its first health impact in infancy.[1] Complications including organ damage[2], neurocognitive deficits,[3,4] acute pain and chronic pain,[5,6] and risk for early mortality accelerate in adolescence.[7] Moreover, studies confirm that adolescents and young adults (AYA) with SCD are at increased risk for depression and anxiety, delays in social functioning, and impairments in quality of life.[8-10]

Self-management is defined as "the interaction of health behaviors and related processes that patients and families engage in to care for a chronic condition."[11] Poor self-management by adolescents and young adults (AYA) with SCD (e.g. ignoring a fever, missing clinic appointments, poor adherence to medications) may precipitate health complications that require urgent and costly treatments. In fact, rates of healthcare utilization are highest among this age group.[12] Successful management of SCD requires use of problem solving and positive disease management skills.[13] Yet, data suggest that AYA with SCD often lack the necessary skills and confidence needed to effectively manage their disease.[14,15] Moreover, Abel, Cho, Chadwick-Mansker, D'Souza, Housten, King [16] found that adolescents with SCD reported needing practice in health care and independent living skills to effectively manage their health as an adult.

Studies in other chronic conditions suggest that behavioral activation (BA) precedes improvements in self-management skills.[17] Being activated means that the individual has the knowledge, self-efficacy (confidence), and motivation to develop skills to manage their chronic health condition.[17] High levels of BA are associated with positive health outcomes.[18-20] Studies of adolescents with SCD have shown that those with higher levels of disease knowledge reported

fewer psychological symptoms and increased confidence in self-management.[21] Additionally, low self-efficacy was associated with adverse physical and psychological symptoms,[22-26] whereas high self-efficacy was associated with positive health outcomes during transition.[27] For young adults with SCD, studies have found an association between negative attitudes about transitioning or self-management and poor disease outcomes.[28-30] The reverse has also been demonstrated as higher levels of motivation for transitioning or self-management have been associated with higher HRQL.[31]

Although several SCD-specific self-management interventions have been developed and evaluated, [32-38] the direct association between the larger construct of BA and health outcomes is understudied. Further, interventions must incorporate the social context (e.g., connection with peers) and capitalize on newer technologies to motivate AYAs with SCD in sustainable health behavior change. These factors are important for ensuring AYA with SCD get the support needed to develop the specific health behaviors and make the lifestyle changes necessary to manage SCD. Thus, the current study describes the efficacy of an SCD-self-management intervention (SCThrive) relative to an attention control condition (SCHealthEd) on BA components and health outcomes.

A detailed description of the SCThrive intervention can be found in Crosby et al. (under review). Briefly, SCThrive consists of group sessions during which facilitators use established cognitive behavioral, motivational interviewing, and social skills strategies to target BA components. SCThrive also used unique components to enhance the developmental and cultural sensitivity of the intervention including incorporation of culturally relevant materials (e.g., self-management app co-designed by AYA with SCD[39]) and newer technologies (e.g., video chat platform). SCHealthEd consisted of weekly 15-20 minute individual phone calls on educational

topics including SCD, complications, treatments, healthy living and navigating health insurance. The goal of this study was to examine the impact of SCThrive on BA components, specifically disease knowledge, self-efficacy, health motivation and self-management skills. We hypothesized that SCThrive participants would demonstrate clinically significant improvements in these BA components post-intervention in comparison to SCHealthEd participants.

Materials and Methods

Participants

Participants were eligible for the study if they met the following criteria: 1) patient of Cincinnati Children's SCD Clinic; 2) confirmed diagnosis of SCD with SS, SB^0Thal, SB^+Thal, SD, or SC genotype; 3) 13-21 years of age; and 4) on or eligible for disease-modifying therapies (e.g., hydroxyurea, chronic transfusions). AYA were excluded if they: 1) had another chronic disease that would complicate measurement of BA (e.g., depression; n=1); 2) were non-English-speaking as all sessions were conducted in English; or 3) had a cognitive or psychiatric disorder that the physician or study facilitators believed would impair study participation (n=4). Patients who desired participation but were not eligible were referred to the SCD Clinic social worker for assistance with self-management skills.

Procedure

Eligible AYAs were identified through the electronic medical record (EMR). Those meeting entry criteria were sent a letter and flyer or approached during a clinic visit. A trained clinical research coordinator (CRC) followed-up with a phone call for those not seen in person. After written informed consent/assent was obtained, AYAs and caregivers completed baseline measures. SCThrive consisted of six weekly scheduled group sessions lasting 90 minutes led by two facilitators (psychologists, psychology fellows, or psychology graduate students); three

sessions were held in-person in a conference room at the hospital, and the other three were held online via the HIPAA-compliant version of Zoom™, a group video chat program. An in-person booster session was held two weeks later at the hospital. Participants who missed a video chat session were permitted to watch a recording of the missed session. This was monitored by the CRC. To minimize participant burden, follow-up study visits were coordinated with clinic visits when possible (see Figure 2 for study timeline). To maximize attendance, the CRC provided reminders via phone call, text, or e-mail.

All SCThrive participants were provided with a companion app, (iManage) and an iPad. Participants were trained to use iManage to record progress on their self-management goals, daily pain and mood symptoms, message other participants in between sessions, and share picture stories about their week. SCThrive participants returned the iPad at the post-treatment assessment (see Table 1).

SCHealthED participants received six weekly 15 minute to 20 minute phone calls via Zoom (audio only) during which the facilitators reviewed SCD-related and general health education topics: Session 1: What is Sickle Cell Disease?; Session 2: It's in the Genes; Session 3: SCD Complications; Session 4: Treatments for SCD; Session 5: Healthy Living with SCD; and Session 6: Navigating Health Insurance. Participants also received a booster phone call two weeks later.

AYAs completed paper questionnaires assessing BA, quality of life, at baseline and post-treatment. Caregivers or AYAs ≥ age 18 completed demographic measures at baseline. Qualitative interviews conducted at follow-up for SCThrive participants to determine the clinically-significant components of the intervention (e.g. feasibility, acceptability, feedback) are reported in a separate manuscript (Crosby, et al., under review).

Randomization

After baseline assessment, the EMR was reviewed to determine disease severity (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) which was based on criteria used in previous research[40] AYA were blocked on age (13-17/18-21 years) and disease severity (severe/not severe), and then randomized using computer-generated tables to one of the study arms (SCThrive or SCHealthEd) to ensure equal distribution across groups.

Measures

Self-efficacy was assessed using the Patient Activation Measure (PAM-13),[41] which has been used extensively in chronic-illness populations and includes 13 statements that measure perceived knowledge, skill, and confidence to manage one's health and health care. Items are rated on a 4-point Likert scale of 1 = "Disagree Strongly" to 3 = "Strongly Agree." Raw scores range from 13 to 52. To calculate the total PAM score, the raw score is divided by the number of items answered (except non-applicable items) and multiplied by 13. Then, this score is transformed to a scale with a theoretical range 0–100, based on calibration tables, with higher PAM scores indicating higher patient activation. This score was then divided into four levels of activation, which reflect developmental progression from being passive with regard to one's health to being proactive: Level 1 (score of 0.0 – 47.0), Level 2 (47.1 – 55.1), Level 3 (55.2 – 72.4), and Level 4 (72.5 – 100) (see Figure 2 for descriptions of the levels of activation).

Self-management skills were assessed in two ways: 1) The Transition Readiness Assessment Questionnaire (TRAQ-5), [42] a well-validated 20-item questionnaire that measures the skills needed to manage a chronic condition independently. Items are rated on a 5-point Likert scale of 1 = "No, I do not know how" to 5 = "Yes, I always do this when I need to" and

divided into 5 subscales: Managing Medication, Appointment Keeping, Tracking Health Issues, Talking with Providers, and Managing Daily Activities. Overall and subscale scores are calculated by averaging the scores of answered items. 2) The UNC TRxANSITION Scale, an interview administered by trained independent evaluators (psychology graduate students) to measure the skills of youth with chronic conditions.[43] Data were only available for 16 participants who returned at follow-up. For the present study, we administered 6 of the 10 possible subscales: Type of Chronic Health Condition, Medications, Adherence, Nutrition, Self-Management Skills, and New Health Care Providers. Each sub-scale is given a score of 0, 0.5 or 1.0, with a maximum possible score of 10. Total and subscale scores were divided by the number of applicable questions in each section to obtain a proportion score that was used in analyses.

SCD Knowledge was assessed via a 25-item disease-specific knowledge questionnaire about SCD pathophysiology, complications, treatments, and self-management (pain management, hydration) developed by the Children's Hospital of Philadelphia and reported in a previous study.[44] A total score was computed based on the number of correct items.

Health Motivation was assessed using the Treatment Self-Regulation Questionnaire (TSRQ), which is a 15-item questionnaire that measures the degree to which motivation is autonomous or self-determined.[45] The TSRQ has 3 subscales that assess autonomous motivation, externally controlled motivation, and amotivation (i.e., lack of motivation); however, the amotivation subscale has been used in so few studies we did not include it in our analyses. AYA rated questions about engaging in or changing a health behavior related to SCD using a 7-point Likert scale ranging from 1 (not at all true) to 7 (very true). Items on the autonomous motivation and externally controlled subscales were averaged to create separate scores and the averages were summed to compute a relative autonomous motivation index.

Health-related Quality of Life (HRQOL). Baseline group differences were assessed using the Pediatric Quality of Life Inventory Sickle Cell Disease Module (PedsQL), [40,46], a 43-item questionnaire with 9 dimensions (pain and hurt, pain impact, pain management and control, worry, emotions, treatment, and communication). The measure was scored consistent with the manual.

For the PAM-13, TRAQ-5, UNC TRxANSITION, TSRQ, and PEDSQL, Cronbach's alphas at baseline in the present study were greater than .85, demonstrating excellent internal consistency. Cronbach's alpha at baseline for the SCD Knowledge questionnaire was .75.

Data Analysis Plan

All analyses were conducted using the R statistical package.[47] Outliers were examined and kept in final analyses if they were not a result of researcher error. No participant data was removed from analyses using this procedure. Preliminary analyses used independent samples t-tests and Chi-squared tests to assess for differences between SCThrive and SCHealthEd groups at baseline. Covariates of age, treatment type, and HRQOL were initially examined, but they did not significantly explain variance for any outcome measure; thus, they were not included in final analyses. We conducted separate mixed ANOVA analyses to assess for the effects of group (SCThrive/SCHealthEd), time (baseline/post-treatment), and group x time interaction for the PAM-13, TRAQ-5, and TSRQ. Power analyses were calculated on the PAM-13, our primary outcome measure. Analyses were conducted using the internal Monte Carlo simulation capabilities of Mplus (Version 1.20). Based on the effect size obtained from published pilot data, we expected the change in baseline/posttreatment Behavioral Activation for the SCThrive intervention group to be $\eta^2 = .14$ (large effect). Based on these assumptions, the desired sample size was 54 participants (N = 27 per group) to achieve power of .80.

Paired samples t-tests with Cohen's d as the measure of effect size were conducted to assess for change in scores on the UNC TRxANSITION Scale (baseline-to-posttreatment) for just the SCThrive intervention group, as data were only available for 6 AYA in the SCHealthEd group posttreatment. Ordinal logistic regression analyses were conducted to assess change in items on the Health Motivation Questionnaire.

Post hoc tests used Holm adjustments to control for Type 1 error. Effect sizes (partial eta-squared; η^2) were calculated for all effects. η^2 = .01, .06, and .14 represented small, medium, and large effect sizes, respectively. We determined statistical significance at an alpha level of $p < .05$ two-tailed.

Results

Sample Characteristics

Eighty-two AYA with SCD were assessed for eligibility from the overall clinic sample. Baseline and posttreatment data were available for 26 AYA in the SCThrive intervention arm and 27 AYA in the SCHealthEd arm. However, only 6 of the 27 of SCHealthED participants completed the post-treatment interview. The participant flowchart (CONSORT diagram) is presented in Figure 1.

A detailed description of AYA characteristics is provided in Table 2. AYA were on average 16 years of age, all identified as African American/Black and the sample was split fairly evenly between males and females. AYA in the SCThrive intervention and SCHealthEd groups did not differ significantly at baseline on any demographic or medical variables, including age, race, gender, genotype, hospitalizations, emergency room visits for pain, stroke status, pain, acute chest syndrome history $p > .05$ in all instances. With regard to HRQOL, AYA in the SCThrive intervention group had significantly higher scores than the SCHealthEd group, $t(32) =$

2.9, $p = .01$, $d = .98$. However, data on HRQOL were only available for 19 participants in the SCThrive intervention and 16 participants in the SCHealthEd group.

Self-Efficacy

ANOVA analyses indicated that self-efficacy or patient activation (PAM-13) increased from baseline to posttreatment for AYA who received the SCThrive intervention compared to AYA who received SCHealthEd. This 8-point change in activation, however, only trended towards significance, but with a medium effect size, $p = .09$, $\eta^2 = .06$ (see Table 3). With regard to activation levels, at baseline, 26 AYA who received the SCThrive intervention, 3 (11.5%) were at Level 1, 1 (3.8%) was at Level 2, 13 (50%) were at Level 3, and 9 (34.6 %) were at Level 4. Post SCThrive intervention no AYA were at Level 1, only 2 (7.7%) were at Level 2, 9 (34.6%) were at Level 3, and 15 (57.7 %) were at Level 4. In contrast, AYA who received SCHealthEd demonstrated little change, with only 1 AYA moving to Level 3 and no change at Level 4. Differences in activation levels following the intervention and between the SCThrive and SCHealthEd were assessed using Chi-squared analyses, but none reached statistical significance, $p > .05$ in all instances (see Figure 2).

Self-Management Skills

There was not a significant change in overall self-management (as measured by the TRAQ-5) following the SCThrive intervention. Analyses of subscales on the TRAQ-5; however, did indicate change in one domain. AYA who received the SCThrive intervention significantly improved their ability to track health information compared to AYA who received SCHealthEd (see Table 3).

Data assessing transition readiness (UNC TRxANSITION Scale) were available for only AYA who received SCThrive (N = 16). Overall scores on the scale did not differ significantly

following intervention; however, individual subscales provided additional information. Medications and Nutrition subscales did not significantly change for AYA following the intervention. Adherence significantly declined following the intervention $t(15) = 2.67$, $p = .02$, $d = .74$ (see Figure 3). In contrast, the Chronic Health $t(15) = -3.17$, $p = .006$, $d = .79$, Self-Management $t(15) = -2.84$, $p = .001$, $d = .71$, and Health Providers $t(15) = -2.33$, $p = .04$, $d = .58$ scales significantly improved following the intervention.

SCD Knowledge

ANOVA analyses revealed that SCD Knowledge significantly increased from baseline for SCHealthEd (M = 19.52, SD = 2.99, range = 14 to 25) and SCThrive participants (M = 19.65, SD = 3.51, range = 9 to 24) compared to posttreatment for SCHealthEd (M = 20.24, SD = 3.41, range = 11 to 24) and SCThrive participants (M = 19.96, SD = 4.72, range = 7 to 25), $F(3, 102) = 588.2$, $p < .001$, $\eta_{p2} = .95$. However, there was no significant main effect of group or a group x time interaction, $p > .05$.

Health Motivation

Motivation for maintaining behaviors was similar for the SCThrive intervention and SCHealthEd groups. The autonomous and externally controlled motivation subscales and the overall relative autonomous motivation index on the TSRQ did not significantly differ between groups, from baseline to posttreatment and there was not a group by time interaction, $ps > .05$ in all instances.

DISCUSSION

BA is an important precedent to changes in self-management and ultimately health outcomes. We developed a self-management intervention targeting BA domains (SCThrive) for AYA with SCD. Our findings suggest that SCThrive led to clinically important changes in

patient activation/self-efficacy. Given that a 1-point change in PAM-13 score has been associated with 2 to 3% improvement in medication adherence and fewer inpatient admits,[48] the 8-point change found in this study equates to meaningful change. Further, a closer examination of activation levels showed that by the end of the SCThrive intervention, all but two AYA either felt confident that they could take action or that they were actively participating in their health care. The change was not statistically significant despite obtaining the power necessary to detect differences. This could be due to a number of factors including measure sensitivity, the strength of the intervention, and/or confounding factors.

There is emerging evidence that digital health interventions can improve self-management outcomes for individuals with SCD.[49] SCThrive participants in this study consistently used the iManage app to track their symptoms, progress on goals, and communicate with other AYA. Given AYA report that the iManage app was beneficial (Crosby et al. under review), it is possible that the significant improvement in tracking health following SCThrive was influenced by use of the iManage app. Another contributor may have been the process of developing a weekly action plan that served to focus their attention on health symptoms, thereby building skills in this area. Future studies could determine the most effective intervention components.

Self-management skills are often measured solely by patient's reporting on their level of mastery of a specific skill (e.g., taking medications as prescribed). One of the strengths of the current study is a structured interview by an independent evaluator was also used. The passive nature of the self-report measure (TRAQ-5) could have resulted in some AYA overestimating their skills. In contrast, the UNC TRxANSITION Scale[43] required AYA to demonstrate their knowledge/skills. For example, adherence as measured by the UNC

TRxANSITION decreased from pre to post; however, it could be that participants overestimated their adherence prior to the intervention and had a more accurate perception of their medication adherence once they began tracking it via action plans or iManage. Alternatively, the interview format may have been anxiety-provoking for some AYA and could have interfered with their ability to recall information. Hence, using both types of measures may be the best option in future studies.

Additionally, given that AYA with SCD often experience cognitive deficits, particularly related to executive function,[3] it is possible that our participants may have less insight into their behavior. In future studies, cognitive testing would need to occur along with assessment of self-management skills to provide more clarity. It is notable that SCHealthED participants failed to complete their post-treatment interview. Since the reasons for this are unclear, it will be important to identify and address barriers in future studies. The statistically significant changes found from pre to post in our small sample suggest that UNC TRxANSITION may be sensitive to change in this population, although additional studies are needed to confirm these findings.

Correct responses on the SCD Knowledge questionnaire were generally high at baseline (above 75%), but notably, only 43% of participants from either group knew that treating pain symptoms at home was their best option. In addition, only 34% of participants answered that penicillin is used to decrease infection rather than as a treatment for pain (51%). Although scores were high at baseline, they still improved posttreatment; however, there were no differences between the intervention and attentional control groups. Our results suggest that review of SCD-related and general health education topics can improve knowledge, even when knowledge levels are generally high.

Limitations

Regarding our study design, the intervention contained multiple components, the influence of specific components are not known. Isolating the most useful intervention components (e.g., action plans, iManage) would be important for future work, but would require a much larger sample and likely a factorial design. Similarly, the SCHealthEd group received phone calls; therefore, it is not clear if in-person sessions would have been more efficacious. Further, our study ended after 3 months. It is possible that substantive changes in AYA behavior require longer than 8-12 weeks, and short-term changes may not be sustained.

This study was conducted at a single SCD center in the Midwest, and the cohort may not be representative of the larger SCD population and the sample size was small. There was also no examination of the impact on the intervention on clinical outcomes. Another limitation is the absence of post-intervention interviews in the SCHealthED group and only 16 interviews in the SCThrive intervention group, future research with a larger SCD cohort using this measure is needed to support our preliminary findings. Finally, some of the measures have not been normed for the SCD population (e.g. PAM-13, UNC TRxANSITION), but have been widely used across chronic conditions, and the PAM-13 has now shown good internal consistency in two studies.[50]

Conclusion

In summary, we evaluated the impact of SCThrive, a group-based, technology-enhanced on disease knowledge, self-efficacy, motivation and self-management skills in AYA with SCD. Our preliminary results showed clinically significant improvement in patient activation or self-efficacy and statistically significant improvement in one self-management skill, tracking health, and supporting the potential of SCThrive to improve self-management in this population. These results support interventions that build AYA confidence/self-efficacy through practicing self-

management skills (e.g., tracking symptoms, calling to schedule a medical appointment) as this approach might motivate them to take a more active role in managing their SCD.

Acknowledgements

We would like to acknowledge Naomi Joffe, Ph.D. and Emily McTate, Ph.D. for their contributions to the SCThrive Intervention. The study reported was supported in part by Eunice Kennedy Shriver National Institute of Child Health & Human Development of the National Institutes of Health under Award Number R21HD084810 (LEC). Anna Hood was supported in part by a grant from the National Heart, Lung, and Blood Institute (1F32HL143915). Data available on request due to privacy/ethical restrictions.

Conflict of Interest Statement

Authors have no financial conflicts of interest other than the funding listed above.

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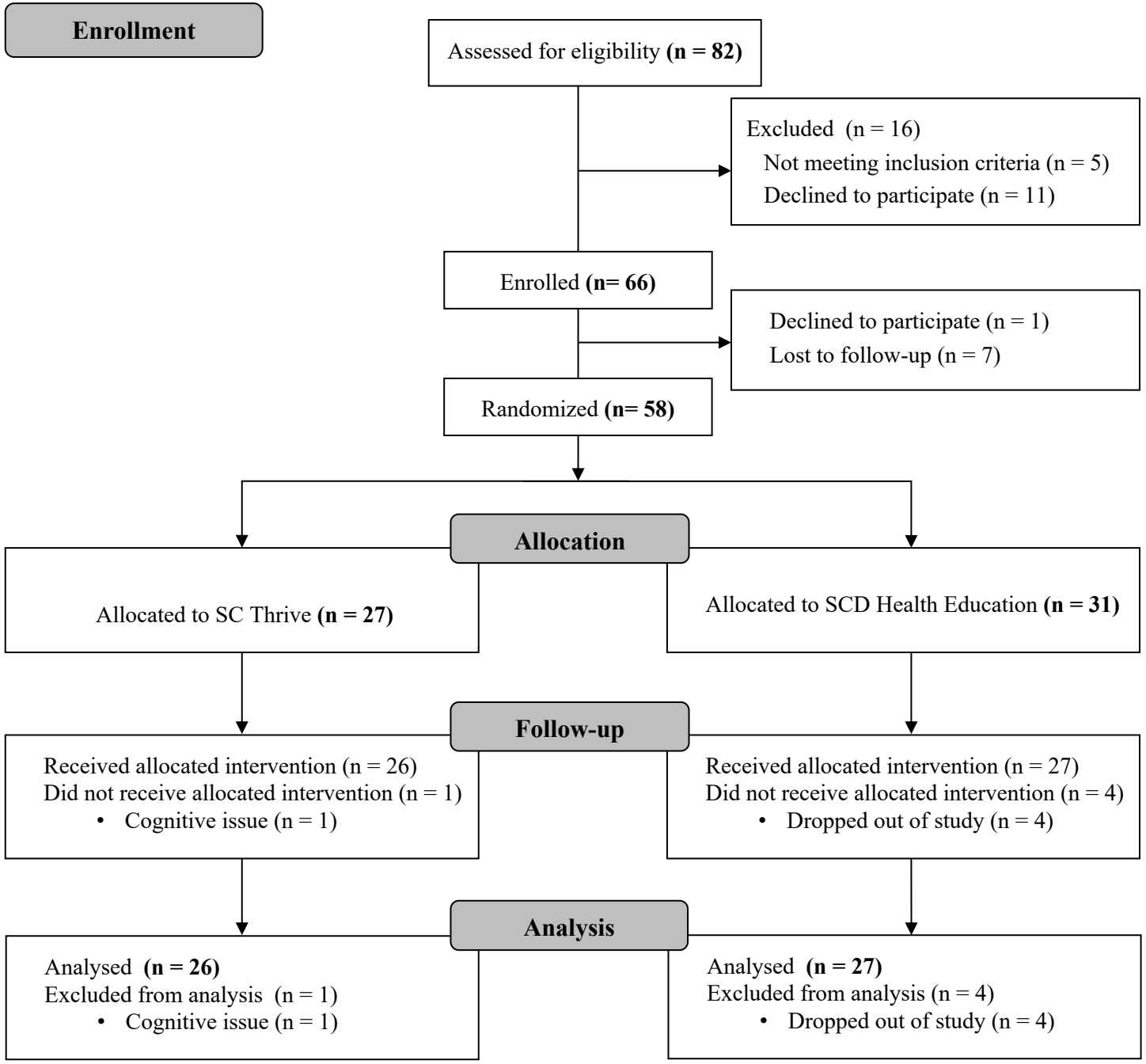
Figure Legends

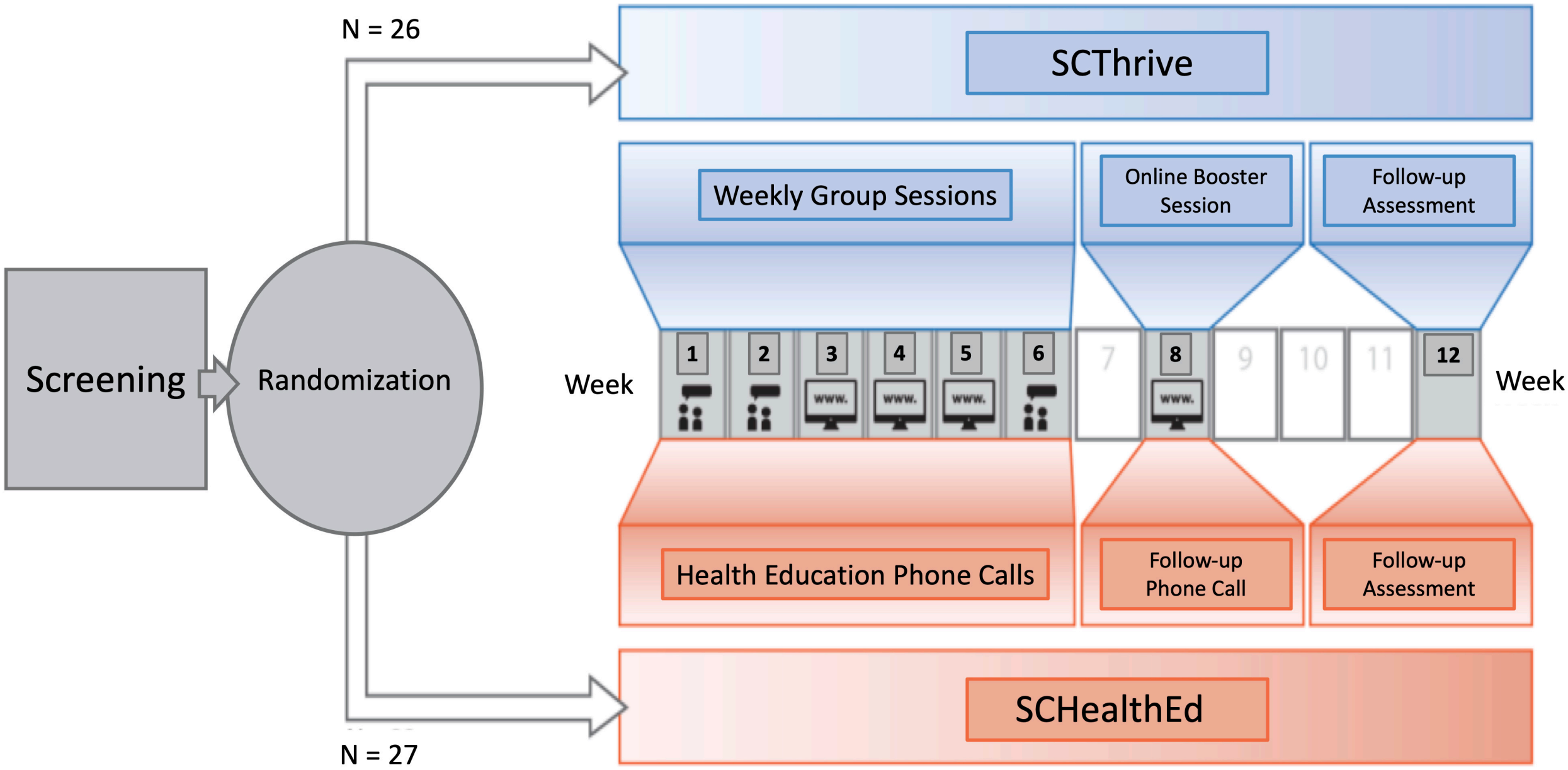
Figure 1. Study CONSORT diagram

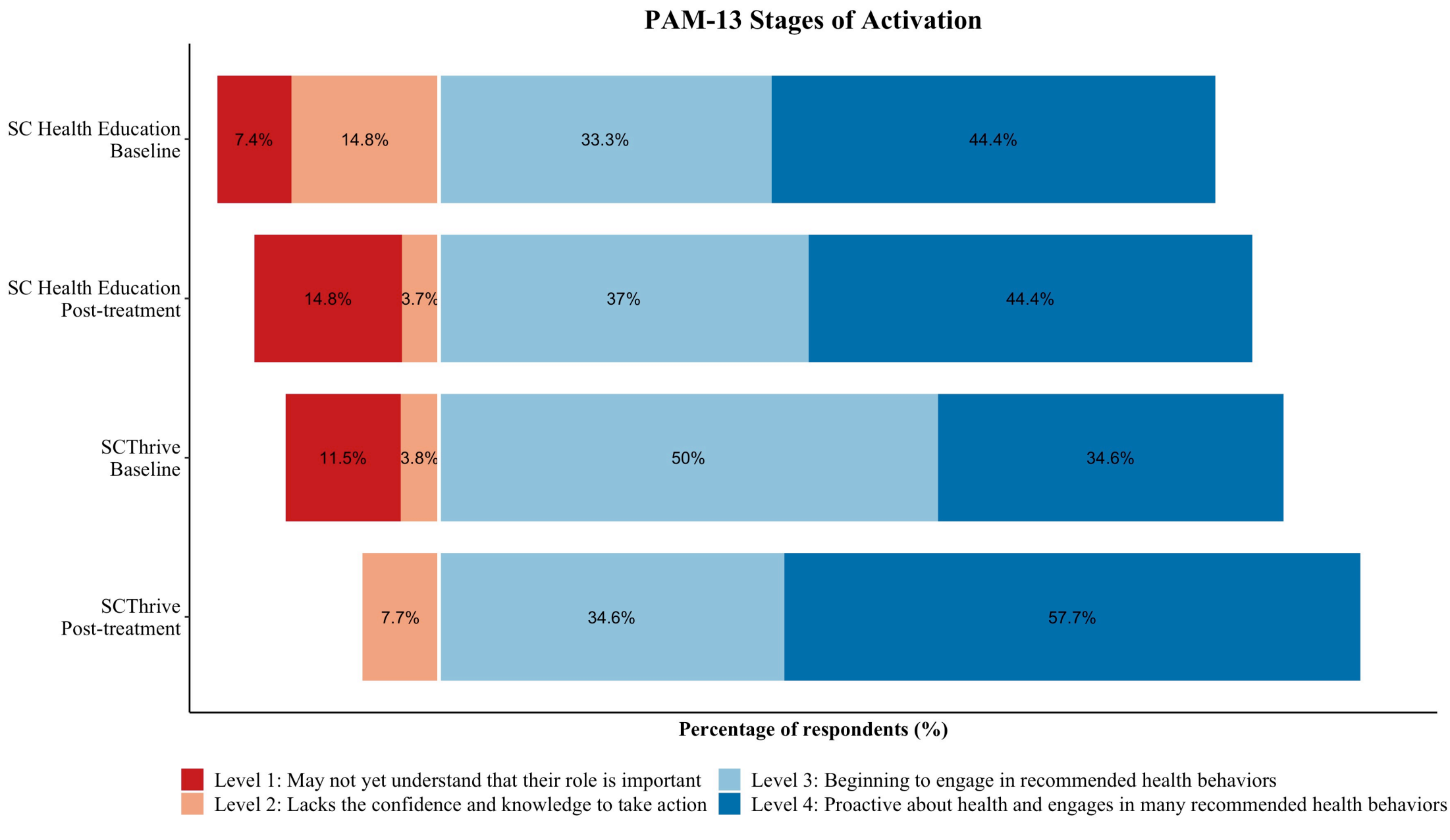
Figure 2. Study Design and Timeline

Figure 3. Likert scale of change in PAM-13 activation scores for groups at baseline and post SCThrive intervention or SCHealthEd education

Figure 3. UNC TRxANSITION total and subscale scores for AYA in the SCThrive Intervention Group. *represents a significant difference between subscales from baseline to post intervention ($p < .05$).


Enrollment
Assessed for eligibility (n = 82)
Excluded (n = 16)
Not meeting inclusion criteria (n = 5)
Declined to participate (n = 11)
Enrolled (n= 66)
Declined to participate (n = 1)
Lost to follow-up (n = 7)
Randomized (n= 58)
Allocation
Allocated to SC Thrive (n = 27)
Allocated to SCD Health Education (n = 31)
Follow-up
Received allocated intervention (n = 26)
Did not receive allocated intervention (n = 1)
• Cognitive issue (n = 1)
Received allocated intervention (n = 27)
Did not receive allocated intervention (n = 4)
• Dropped out of study (n = 4)
Analysis
Analysed (n = 26)
Excluded from analysis (n = 1)
• Cognitive issue (n = 1)
Analysed (n = 27)
Excluded from analysis (n = 4)
• Dropped out of study (n = 4)


N = 26
SCThrive
Screening
Randomization
Weekly Group Sessions
Online Booster Session
Follow-up Assessment
Week
1
2
3
4
5
6
7
8
9
10
11
12
Week
Health Education Phone Calls
Follow-up Phone Call
Follow-up Assessment
SCHealthEd
N = 27


PAM-13 Stages of Activation
SC Health Education Baseline
7.4%
14.8%
33.3%
44.4%
SC Health Education Post-treatment
14.8%
3.7%
37%
44.4%
SCThrive Baseline
11.5%
3.8%
50%
34.6%
SCThrive Post-treatment
7.7%
34.6%
57.7%
Percentage of respondents (%)
Level 1: May not yet understand that their role is important
Level 2: Lacks the confidence and knowledge to take action
Level 3: Beginning to engage in recommended health behaviors
Level 4: Proactive about health and engages in many recommended health behaviors

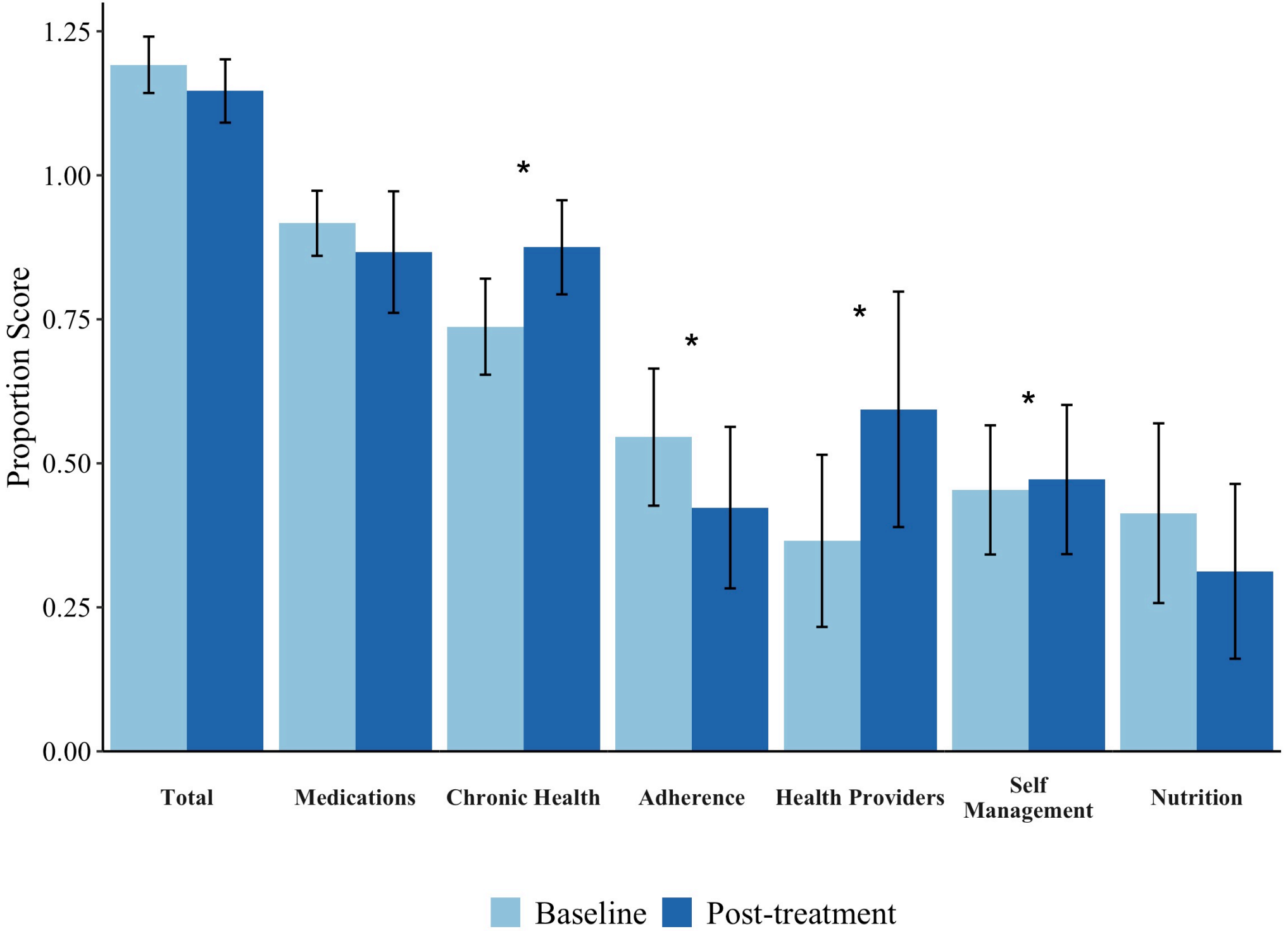

1.25
1.00
0.75
0.50
0.25
0.00
Proportion Score
*
*
*
*
Total
Medications
Chronic Health
Adherence
Health Providers
Self Management
Nutrition
Baseline
Post-treatment

Table 1. SC Thrive Intervention Target by Treatment Sessions

Week (Location)	Completion Rate n (%)	Objectives	Topics	Behavioral Activation Target
1 (in-person)	24 (92)	Describe role in managing SCD Identify at least two SCD problems Name at least 2 self-management strategies (e.g., self-monitoring and action planning) Make a weekly action plan	Introduction to SC Thrive Provide SCD knowledge Introduction to self-monitoring and action planning Introduction to iManage and The Patient Profile *Homework: Encourage reading Chapter 1 in Hope & Destiny Jr book; Set up section of patient profile at home; Chart pain and/or mood*	Knowledge, Self-Efficacy, Readiness for Change, Family/Social Support
2 (in-person)	26 (100)	Discuss ways to communicate about SCD to others Describe the steps to problem solving Make a weekly action plan	Fill out My Team section of Patient Profile Introduce and practice communication skills Introduce and practice problem solving Action planning *Homework: Come up with 3 questions to ask provider at next visit OR tell someone about sickle cell disease*	Skills, Self-Efficacy, Family/Social Support
3 (online)	25 (96)	Introduce gate control theory of pain Describe ways to manage pain and fatigue Describe ways to manage strong emotions Make a weekly action plan	Discuss gate control theory of pain Fill out My Pain section of the Patient Profile Pain management – Progressive Muscle Relaxation (PMR) and abdominal breathing Introduce pain diary Mood management – (i.e., pleasant activities and imagery) *Homework: Practice diaphragmatic breathing once a day for 5-minutes each; Set reminders to get 5 mini relaxations in every day*	Mood, Self-Efficacy, Skills, Family/Social Support
4 (online)	24 (92)	Discuss the gate control theory of pain Describe ways to manage pain and fatigue Describe ways to manage strong emotions Make a weekly action plan	Fill out Daily Life section of Patient Profile Distraction techniques Guided imagery Positive thinking *Homework: Keep track of thoughts using a thought log*	Self-Efficacy, Skills, Family/Social Support
5 (online)	26 (100)	Discuss SCD symptoms Describe ways to manage SCD symptoms Explain how to manage a health emergency Define treatment adherence Describe strategies for managing medications or treatments Make a weekly action plan	Fill out Self- Management section of Patient Profile Describing and managing SCD symptoms Managing emergencies and treatments Action planning *Homework: Print medications and upcoming appointments in MyChart; Encourage setting up an action plan and using the iManage app for reminders and to get support from group members if taking medications*	Knowledge, Skills, Self-Efficacy, Resources, Family/Social Support

6 (in-person)	25 (96)	Describe the steps to decision making Discuss how much water s/he should drink each day Discuss different types of exercise Discuss ways to improve sleep Discuss healthy eating guidelines Make a weekly action plan	Fill out Future Vision section of Patient Profile Decision making Healthy lifestyle habits (e.g., water, exercise, sleep, healthy eating) Action planning Course review	Skills, Knowledge, Self-Efficacy, Resources, Family/Social Support
Booster (in-person /online)	25 (96)	Describe at least 3 self-management tools Discuss how to manage SCD Ways to maintain changes Make a weekly action plan	Fill out the Transition section of the Patient Profile Planning for healthcare transition SCD Review (Jeopardy Game) Planning to maintain changes Action planning	Self-Efficacy, Readiness to Change, Family/Social Support

Table 2. Characteristics of Participants at Baseline

	SCHealthEd	SCThrive
Mean (SD)		
Age (years)	16.3 (2.5)	16.7 (2.3)
Range	13 – 21	13 – 21
Hospitalizations	1.81 (4.0)	1.73 (3.5)
Emergency room visits	2.1 (3.0)	2.1 (2.3)
HRQOL*	52.0 (12.3)	65.1 (14.2)
N (%)	27 (51)	26 (49)
Gender		
Female	14 (52)	14 (54)
Male	13 (48)	12 (46)
Race/ethnicity		
African-American	27 (100)	26 (100)
SCD genotype		
HbSS	17 (63)	12 (46)
HbSC	5 (18)	10 (38)
HbSβ + thalassemia	3 (11)	3 (12)
HbSβ 0 thalassemia	1 (4)	0 (0)
HbSD	1 (4)	1 (4)
Acute Chest Syndrome		
Yes	14 (48)	17 (65)
No	13 (52)	9 (35)
Stroke		
Yes	2 (7)	0 (0)
No	25 (93)	26 (100)
Pain episode		
Yes	14 (52)	14 (54)
No	13 (48)	12 (46)
Insurance		
Public	13 (48)	10 (38)
Private	7 (26)	8 (31)
Both	0 (0)	1 (4)
None	3 (11)	3 (12)
Unknown	4 (15)	4 (15)
Mother's Education		
7th – 9th grade or less	1 (3)	1 (4)
9th – 12th grade or less	3 (11)	3 (12)
High School Graduate	10 (37)	4 (15)
Some College or Certification	5 (19)	6 (23)
College Graduate	4 (15)	8 (31)
Graduate or Professional Degree	4 (15)	4 (15)

Notes. 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). * HRQOL data were only available for 19 participants in the SCThrive intervention and 16 participants in the SCHealthEd group. Hospitalizations/emergency room visits = 3 or more hospitalizations/emergency room within the past year for pain; Pain episode = Vaso-occlusive pain episode within the past 12 months; HRQOL = health-related quality of life; HbSS = hemoglobin genotype SS; HbSC = hemoglobin genotype SC; HbSβ thalassemia = hemoglobin genotype sickle beta; SD = standard deviation; SCD = sickle cell disease

Table 3. Changes in outcome measures from baseline to posttest for SC Thrive intervention and SC Health Education Groups

Measures	SCHealthEd		SCThrive		Posttest Difference between Groups	*F*	*p*	η^2
	Baseline (n = 27)	Posttreatment (n = 27)	Baseline (n = 26)	Posttreatment (n = 26)				
	Mean (± SD)	Mean (± SD)	Mean (± SD)	Mean (± SD)				
Behavioral Activation								
PAM-13 total	69.13 (20.75)	68.82 (18.18)	68.48 (15.47)	76.57 (15.04)	8.32	3.04	.09†	.06
Self-Management								
TRAQ-5 total	3.54(.81)	3.53 (.79)	3.46 (.83)	3.68 (.81)	.15	1.22	.28	.02
Managing Medications	3.61(.96)	3.64 (1.00)	3.72 (1.03)	3.88 (.87)	.24	.28	.60	.01
Appointment Keeping	3.02(1.13)	3.01(1.13)	2.87 (1.07)	3.19 (1.28)	.18	1.05	.31	.03
Tracking Health	3.24 (.99)	3.04 (1.05)	2.93 (1.16)	3.29 (1.05)	.25	4.47	.04*	.08
Talking with Providers	4.61 (.80)	4.67 (.55)	4.69 (.58)	4.65 (.56)	.02	.15	.71	.003
Managing Daily Activities	4.37 (.85)	4.51 (.57)	4.38 (.79)	4.46 (.60)	.05	.08	.79	.001
Motivation								
TSRQ RAI	-.20 (1.09)	-.06 (1.04)	.06 (1.12)	-.12 (1.02)	.06	1.85	.18	.02
Autonomous Motivation	5.69 (1.22)	5.89 (1.09)	5.81 (1.12)	5.69 (1.00)	.20	1.41	.24	.01
Externally Controlled Motivation	5.89 (1.56)	5.83 (1.30)	5.87 (1.35)	5.81 (1.26)	.02	.003	.95	.00

Notes: PAM-13 = Patient Activation Measure; TRAQ-5 = Transition Readiness Assessment Questionnaire; TSRQ = Treatment Self-Regulation Questionnaire