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Pilot of the Chronic Disease Self-Management Program (CDSMP) for Adolescents and Young Adults with Sickle Cell Disease

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Abstract

Purpose—This study evaluated the feasibility of a group self-management intervention, the well-established Stanford Chronic Disease Self-Management Program (CDSMP), for adolescents and young adults (AYA) with sickle cell disease (SCD).

Methods—A total of 22 AYA participants with SCD, ages 16 to 24 years, completed self-efficacy and quality of life (HRQOL) measures before the CDSMP, after, and 3 and 6 months later.

Results—This AYA cohort showed significant improvements in self-efficacy (primary outcome) after the intervention. Analyses of follow-up data revealed a medium effect of the CDSMP on patient activation 3 months post although this was not sustained. Participants were highly satisfied, but only 64% completed the program.

Conclusions—This study demonstrates that the CDSMP is acceptable, and has the ability to improve self-efficacy. Additional research is needed to determine feasibility and evaluate health outcomes for AYA with SCD.

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Implications and Contribution

Adolescents and young adults with sickle cell disease suffer from disease complications and can benefit from self-management. This study reports that the Stanford Chronic Disease Self-Management Program is acceptable and improves self-efficacy, but future studies should evaluate feasibility and impact on outcomes such as patient activation and quality of life.

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Keywords

sickle cell disease; adolescents; young adults; pediatric hematology; chronic illness; self-management; intervention

Introduction

Sickle cell disease (SCD) causes significant morbidity and mortality, particularly during adolescence and young adulthood (AYA) [1]. Disease manifestations worsen in adolescence, impairing functioning and lowering health-related quality of life. The chronic nature of SCD increases the risk of impaired academics and social isolation [2]. Behavioral interventions exist for disease knowledge and managing physical symptoms (e.g. pain), but few interventions have targeted broader SCD management skills such as avoiding triggers and receiving yearly screenings (e.g. MRI), managing complications (e.g. stroke, bone damage) and for some, monthly blood transfusions.

Chronic disease self-management interventions focus on equipping patients with skills to manage their health. One widely used intervention is the Stanford Chronic Disease Self-Management Program (CDSMP), a six-week group-based intervention led by lay leaders with a chronic health condition. The program helps patients understand acute and chronic disease, and teaches skills (e.g., action planning and problem-solving) to manage health conditions, symptoms, and resulting emotions. CDSMP is associated with improvements in self-reported health, exercise, symptom management, patient-provider communication, functioning and long-term improvements in health behaviors [3].

Initially implemented with Caucasian and older populations, CDSMP may also improve self-efficacy and self-management skills in racially and ethnically diverse patients [4]. A Cochrane Review recommended that CDSMP be explored with pediatric populations [5]. CDSMP has the potential to improve self-management in AYA with chronic diseases [6], but no data exist for AYA with SCD. Accordingly, we investigated whether CDSMP would be feasible and acceptable, improve self-efficacy and self-management behaviors, and decrease emergency room visits for this population. We also explored the relationship between CDSMP and patient activation, the skills, knowledge, and confidence to manage health, as this has been associated with improved self-management [7].

Methods

Participants

AYA were eligible if they had SCD, were between 16–24, and received care at a pediatric or adult SCD clinic in the Midwest. Providers did not refer AYA with additional health complications or known cognitive limitations that would interfere with completion of the CDSMP or measures. With IRB approval, AYA were recruited between March 2013 and June 2014.

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Procedure

AYA (and caregivers for 16–17 year olds) consented and completed baseline measures (T1: 1–3 weeks before intervention). CDSMP was conducted as designed with no tailoring for SCD and consisted of six 2.5 hour weekly sessions (see Table 1). Two trained leaders facilitated four cohort groups of 4–8 participants. Completion was defined per CDSMP guidelines as attending ≥ 4 sessions. After the last session, AYA completed measures (T2), and then returned for study follow-ups 3 months ±30 days (T3) and 6 months ± 30 days later (T4). AYA received transportation support ($10) and incentives for each session ($35) and assessment ($35 – $50).

Measures

At baseline, AYA completed a demographics form and measure of psychosocial risk (PAT2.0_GEN AYA) [8]. Self-efficacy (primary outcome) was assessed via the Sickle Cell Self-Efficacy and Self-Efficacy for Managing Chronic Disease Scales. The Transition Readiness Assessment Questionnaire (TRAQ-5) measured self-reported self-management behaviors (primary outcome) and assessed the perceived ability to manage medications, keep appointments, track health issues, manage daily activities and talk with providers. For secondary outcomes, the National Health Interview Survey measured self-reported health status, the Patient Activation Measure (PAM-13) assessed patient activation, the Pediatric Quality of Life Inventory (PedsQL) assessed health-related quality of life, and the electronic medical record provided emergency visit data. Six questions evaluated feasibility and acceptability.

Analysis

Descriptive statistics summarized demographic data and outcome measures using SPSS Version 22. Emergency visits were tracked for six months before and after intervention. Repeated measures ANOVA analyses examined pre-post-follow-up changes for self-efficacy, self-management behaviors, patient activation, health status and healthcare utilization, including effect sizes. Small, medium, and large partial eta-squared values are defined as 0.02, 0.06, & 0.14, respectively.

Results

AYA ranged from 16 to 23 years ($M = 18.8$, $SD = 2.2$). The sample was 55% male and 100% African American (Table 1). Among 22 AYA, 64% attended all sessions; completers were less likely to have HbSS. Sessions were missed due to disease-related (i.e., hospitalized/ill), transportation, and/or schedule challenges. Most participants were satisfied and would recommend CDSMP (91%). AYA liked interacting with peers with SCD, problem-solving and action planning although two did not enjoy group discussions (see Table 1).

At T2, AYA showed significant improvements in general self-efficacy but not disease-specific self-efficacy (Table 2). There were no significant improvements in self-reported self-management behaviors, health status, quality of life or emergency room visits over time (Table 2). A medium effect size was noted for patient activation.

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Discussion

We evaluated the CDSMP, a low-resource and low-cost program that uses a group, skill-based and interactive format with potential appeal for AYA with SCD. Participants found the CDSMP very acceptable (high satisfaction), rating it as relevant and beneficial for managing SCD. Only 64% of AYA completed all sessions raising questions about feasibility; this completion rate is lower than Black CDSMP participants in other studies (78.5%) [9]. Retention may have been impacted by disease-related factors. Shorter interventions or those using a combination of web-based (group video chat) and in-person sessions could improve attendance while maintaining engagement.

Consistent with previous studies [3,4], we found significant improvements in disease self-efficacy post CDSMP. This is important since self-efficacy has been associated with reduced health care use and improved health outcomes [3]. No improvements in disease-specific self-efficacy were found which may reflect the broad CDSMP curriculum; inclusion of disease-specific content should be evaluated. AYA did not show improvements in perceived self-management behaviors; a medium effect size supports the CDSMP’s potential for improving patient activation 3 months post. However, effects were not sustained suggesting the benefits of a booster session should be evaluated.

Limitations include lack of a control group and single site recruitment. Sample size limited ability to predict responders or the number of sessions (dose) necessary for improved self-efficacy. This study used a convenience sample; targeted recruitment strategies may be needed to reach AYA with the greatest self-management needs. Future studies should evaluate primary outcomes to determine long-term effects. If CDSMP increases self-efficacy, then it has potential for significant health impact in SCD.

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Abbreviations

AYA	adolescents and young adults
ANOVA	analysis of variance
CDSMP	Chronic Disease Self-Management Program
PAT2.0_GEN AYA	Psychosocial Assessment Tool 2.0 General – Adolescent and Young Adult Version
PAM-13	Patient Activation Measure - 13
PedsQL	Pediatric Quality of Live Inventory
SCD	sickle cell disease

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SPSS	Statistical Program for the Social Sciences
T1	Time 1
T2	Time 2
T3	Time 3
T4	Time 4
TRAQ-5	Transition Readiness Assessment Questionnaire – 5th version

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Table 1

Baseline characteristics, recruitment and acceptability data for CDSMP participants ($N = 22$)

	***M*[a] (SD)[b]**
Age	18.77 (2.22)
Emergency Room Visits	1 (1.31)
	N (%)
Gender	
Female	10 (45.5)
Male	12 (54.5)
Race/Ethnicity	
African American	22 (100)
SCD Genotype	
HbSS	14 (63.6)
HbSC	6 (27.3)
HbSβ+thalessemia	2 (9.1)
Insurance	
Public	14 (63.6)
Private	4 (18.2)
Both	3 (13.7)
None	1 (4.5)
PAT	
Total score	1.28 (0.78)
Risk category	Targeted
Recruitment	
Total Eligible	81
Total Receiving letter/phone call	81
Total Returned letters	20
Total No response/unable to reach by phone	28
Total Declined	5
Total Enrolled	28
Total Withdrawn	6
Session Completion	
6 sessions	64%
5 sessions	27%
4 sessions	9%
General Session Topics & Ratings	
Action Planning, Problem Solving, Mind Management	4.44 (0.49)
Managing Emotions, Exercise	4.32 (0.61)
Decision Making, Pain & Fatigue Management	4.43 (0.43)
Breathing, Communication, Healthy Eating	4.45 (0.39)
Managing Medications, Treatment Decisions	4.50 (0.42)
Working with the Healthcare Team, Future Plans	4.09 (0.84)

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	M^a (SD)^b
CDSMP Acceptability Ratings	
Learned things to help manage SCD	4.25 (0.17)
Topics were relevant	4.26 (0.14)
Will develop an action plan	4.24 (0.15)
Self-management skills important to manage SCD	4.51 (0.13)
Group leaders were helpful	4.50 (0.18)
Return for another session	4.61 (0.24)

[a] Mean,

[b] Standard deviation,

[c] Psychosocial Assessment Tool (PAT) Total Score takes into account parental education level, income, and number in the household. Targeted risk category means that participants are at elevated risk for difficulties with coping with their illness and in need of intervention.

Note. Sample demographics were consistent with data from the overall clinic sample (N=88) at the time of baseline, including mean age (M=20.18, SD=2.48), gender (53% female; 47% male) and SCD type (66% HbSS; 18% HbSC; 14% HbSβthal).

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Table 2

Changes between pretest, posttest and follow-up means and effect sizes for primary and secondary outcomes

Primary Outcomes	**Baseline $M^a(\pm SD)^b$**	**T2 (Post) $M^a(\pm SD)^b$**	**T3 (3-months) $M^a(\pm SD)^b$**	**T4 (6-months) $M^a(\pm SD)^b$**	**F**	**p**	**Effect size η_p^{2c}**
Chronic Disease Self-Efficacy	7.26 (±1.5)	8.02 (±1.34)	—	—	8.27	.009	.293
Sickle Cell Self-Efficacy Scale	32.6 (±3.7)	33.2 (±5.49)	—	—	0.33	.575	.015
Self-Management TRAQ-5[d]	3.62 (±0.83)	3.40 (±0.62)	—	—	0.45	.516	.039
Managing Medications	3.54 (±1.10)	3.40 (±0.85)	—	—	0.99	.759	.009
Appointment Keeping	3.04 (±1.07)	2.95 (±0.63)	—	—	0.70	.796	.006
Tracking Health Issues	3.44 (±0.95)	2.92 (±0.82)	—	—	1.47	.250	.118
Talking with Providers	4.58 (±0.76)	4.25 (±1.01)	—	—	1.07	.322	.089
Managing Daily Activities	4.63 (±0.64)	4.50 (±0.87)	—	—	0.49	.501	.042

Secondary Outcomes	Baseline $M^a(\pm SD)^b$	T2 (Post) $M^a(\pm SD)^b$	T3 (3-months) $M^a(\pm SD)^b$	T4 (6-months) $M^a(\pm SD)^b$	F	p	Effect size η_p^{2c}
Patient Activation Measure	69.75 (±13.17)	75.36 (±16.03)	74.12 (±14.95)	71.45 (±17.98)	.911	.440	.071
Health Status	2.50 (±1.10)	2.45 (±1.14)	2.24 (±1.25)	2.28 (±1.02)	.427	.662	.030
Pediatric Quality of Life	65.81 (±12.43)	68.28 (±15.08)	70.01 (±14.89)	66.73 (±15.23)	.249	.787	.017
Emergency Room Visits	1.00 (± 1.31)	—	—	1.64 (±2.80)	1.31	.266	.059

Note.

[a] M = Mean.

[b] SD = Standard deviation.

[c] η_p^2 =partial eta squared.

[d] TRAQ-5 = Transition Readiness Assessment Questionnaire; $n = 12$.

[e] Baseline = emergency room visits 6 months prior to baseline.