



Contents lists available at ScienceDirect

The Journal for Nurse Practitioners

journal homepage: www.npjjournal.org

Brief Report

Improving Transition Readiness in Young Adults With Sickle Cell Disease

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A B S T R A C T

Keywords:
measurement tools
sickle cell disease
sickle cell disease and transition
transition readiness
young adults

Transition of young adults with sickle cell disease is essential. This project examined the effectiveness of an educational intervention at a pediatric hematology practice to improve transition readiness in young adults with sickle cell disease. Interventions used were 2 *Stepping Up* videos and 5 questions from “Incorporating Health Care Transition Services Into Preventive Care for Adolescents and Young Adult.” Data was collected and results were analyzed preintervention, immediately postintervention, and at return office visit. Non–high school graduates showed greater improvement in total and subscale mean scores after the intervention at the return office visit.

Published by Elsevier Inc.

Introduction

In the United States, approximately 500,000 young adults with special health care needs reach age 18 years of age annually, and these individuals are expected to transition from pediatric to adult health care.¹ Inadequate preparation for adult health care services can lead to increased mortality and morbidity rates. Inadequate transition preparation from pediatric to adult care services can lead to increased mortality and morbidity rates in patients with SCD aged 18 years and older.² Centers for Disease Control and Prevention statistics reveal that SCD affects approximately 100,000 Americans.³ Currently, 90% of children with SCD, a chronic hematologic condition, are living into adulthood. Young adults often lack essential self-management and health care utilization skills and are inadequately prepared to transition into adult care services.¹ The purpose of this brief report is to discuss methods used to increase transition readiness among young adults aged 18 years and older with SCD who are at risk for inadequate transitional preparation from pediatric to adult-oriented health care services.

Background and Significance

Historically, patients with SCD had a high mortality rate before 18 years of age. Due to continuing medical advances, such as early screening protocols, medications, and blood transfusion therapy, young adults with SCD now require a transition plan to prepare for adult-oriented services.² Transition includes purposeful activities for young adults switching from pediatric to adult-centered health care systems.² Readiness consists of parents and providers, specifically to prepare, initiate, continue, and complete the transition process.² The planned transition should begin in early adolescence (12–14 years of age).⁴ Transition activities should be conducted

during routine primary and specialty care visits and reinforced in subsequent visits. To provide consistent transitional preparedness, the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians developed a set of guidelines recognized for transitional care titled *Got Transition*.⁴ *Got Transition* is a process to increase the transitional readiness from pediatric to adult care services with the use of advanced and innovative strategies for health care professionals, patients, and their families.⁵

Survival improvements are less evident for young adults aged 20–24 years because this is the time immediately after the transition from pediatric to adult health care. Furthermore, transfer of care from pediatric to adult health care services is often poorly executed and results in noncompliance and an increased rate of hospitalization.⁶ Approximately \$25 to \$45 billion health care dollars have been lost due to inept transitional care methods, including unnecessary health complications, frequent emergency department visits, and hospital admissions.⁷

Design

This evidence-based project used a preintervention–postintervention design to evaluate improvement in readiness to transition from pediatric to adult care services. The university institutional review board approved the project. Informed consent was obtained, and ethical guidelines were followed throughout the study. Patients at a pediatric hematology clinic diagnosed with SCD who were 18 years of age or older, spoke English, and were able to read at an 8th-grade level were invited to participate. Patients with other self-reported inherited hematologic disorders were excluded.

Table 1
Mean, Standard Deviation, and Range for Total TRAQ and Subscale Scores Based on Gender

Characteristic	Pre-intervention			Post-intervention			Return Office Visit		
	M	SD	Range	M	SD	Range	M	SD	Range
Total TRAQ Score									
Females	3.46	1.00	1.85–4.5	3.46	1.00	1.85–4.5	4.31	.35	3.9–4.5
Males	3.19	1.03	2.10–4.8	3.16	1.03	2.10–4.8	3.28	1.02	2.1–4.8
Managing medications									
Females	3.45	1.23	1.50–4.5	3.45	1.23	1.50–4.5	4.31	.77	3.3–5.0
Males	3.55	1.28	2.00–5.0	3.55	1.28	2.00–5.0	3.65	1.32	2.0–5.0
Appointment Keeping									
Females	3.00	1.18	1.43–4.1	3.00	1.18	1.43–4.1	3.75	.88	2.4–4.3
Males	2.74	1.14	1.86–4.7	2.74	1.14	1.86–4.7	2.77	1.13	1.9–4.7
Tracking health issues									
Females	3.50	1.52	1.50–4.8	3.50	1.52	1.50–4.8	4.56	.43	4.0–5.0
Males	2.50	1.21	1.50–4.5	2.50	1.21	1.50–4.5	2.80	1.11	1.8–4.5
Talking with Providers									
Females	3.70	1.79	1.50–5.0	.70	1.79	1.50–5.0	5.00	.00	5.0–5.0
Males	4.00	.79	3.00–5.0	4.00	.79	3.00–5.0	4.00	.79	3.0–5.0
Managing daily activities									
Females	4.33	.62	3.67–5.0	4.33	.62	3.67–5.0	4.83	.33	4.3–5.0
Males	4.13	1.10	2.33–5.0	4.13	1.10	2.33–5.0	4.13	1.10	2.3–5.0

TRAQ = Transition Readiness Assessment Questionnaire.

Intervention

The intervention comprised 2 components and addressed transition readiness assessment, instructions for taking prescribed medications, guidelines for preventing pain crises, guidelines for managing personal care and health care, adult care coping strategies, and self-advocacy. First, the *Stepping Up* videos, a 2-part series designed to help teens and young adults with SCD transitioning from pediatric to adult care services, were shown to participants.³ The 4-minute videos help teens and young adults prepare to take responsibility for their health and self-care behaviors during the transition. Second, the participants joined a 15-minute question-and-answer session using 4 scripted questions from “Incorporating Health Care Transition Services Into Preventive Care for Adolescents and Young Adults: A Toolkit for Clinicians.”⁵ The questions were as follows (p. 11):

1. How comfortable do you feel managing your own health, such as explaining your medical condition to others and knowing your allergies?
2. Tell me about when you need to see your primary care and, if needed, specialist clinicians.
3. How important is it to manage your own health care, such as filling a prescription, taking your own medications, carrying around an insurance card, and scheduling appointments?
4. What questions or concerns, if any, do you have as you transfer to a clinician who cares for adults?

Measurement Tool

The Transition Readiness Assessment Questionnaire (TRAQ) was used to measure transition readiness to adult health care services in primary care or specialty health care areas. The TRAQ is a 20-item scale with 5 subscales: Managing Medications, Appointment Keeping, Tracking Health Issues, Talking With Providers, and Managing Daily Activities. Each item received a score ranging from 1 to 5, with 1 = “No, I do not know how” and 5 = “Yes, I always do

this when I need to.”⁸ The TRAQ scoring produces an average total score and subscale scores. Participants completed the TRAQ survey tool before and immediately after watching the videos and joining the question-and-answer session. A third TRAQ was completed at 4 weeks, 6 weeks, or 8 weeks during a regularly scheduled return to office visit (ROV). Developed by Sawicki et al² and refined by Wood et al,⁸ the TRAQ is a validated, patient-centered questionnaire that can be used to cultivate necessary skills for transition to adult care efficiently.

Data Analysis

Preintervention, postintervention, and ROV data were compiled in IBM SPSS Statistics Version 25. The total and subscale TRAQ scores were analyzed.

Results and Discussion

The sample included 10 participants who consented to participate in the study. The participants were equally divided between males and females. Seventy percent of participants were high school graduates.

Mean TRAQ scores differed for females and males (Table 1). Higher mean scores for the females indicated greater improvement in transitional readiness. Total mean scores for females improved from 3.46 to 4.31 at ROV, whereas males improved slightly from 3.19 pre- and postintervention to 3.28 at ROV. Females showed improvement in transitional readiness for managing medications, tracking health issues, talking with providers, and managing daily activities. The greatest area for improvement was talking with providers with a mean of 5.00 at ROV. Females were more likely to respond as “No, but I’m learning to do this” in the pre- and post-intervention testing to “Yes, I have started doing this” or “Yes, I always do this when I need to” in the ROV. Males showed slight improvements in managing medications, appointment keeping, and tracking health issues from pre- and postintervention to ROV testing. Males were likely to respond “No, but I’m learning to do this” across all data collection time frames.

Table 2
Mean, Standard Deviation, and Range for Total TRAQ and Subscale Scores Based on Education Status

Characteristic	Pre-intervention			Post-intervention			Return Office Visit		
	M	SD	Range	M	SD	Range	M	SD	Range
Total TRAQ Score									
HS grad	3.78	.72	2.7–4.8	3.78	.72	2.7–4.8	3.98	.75	2.7–4.44
Not HS grad	2.27	.52	1.85–2.9	2.27	.52	1.85–2.9	3.27	1.23	2.1–4.55
Managing medications									
HS grad	4.07	.80	3.00–5.0	4.07	.80	.0–5.00	4.21	.89	3.0–5.00
Not HS grad	2.17	.76	1.50–3.0	2.17	.76	1.5–5.00	3.42	1.51	2.0–5.00
Appointment Keeping									
HS grad	3.33	.99	2.1–4.7	3.33	.99	2.1–4.71	3.40	1.05	2.3–4.71
Not HS grad	1.81	.81	1.43–2.1	1.81	.81	1.43–2.1	2.81	1.30	1.9–4.29
Tracking health issues									
HS grad	3.61	1.22	2.0–4.75	3.61	1.22	2.0–4.75	4.00	1.51	2.0–5.00
Not HS grad	1.58	.14	1.5–1.75	1.58	.14	1.5–1.75	4.00	1.15	2.0–5.00
Talking with Providers									
HS Grad	4.14	1.21	.0–5.00	4.14	1.21	2.0–5.00	4.50	.84	3.0–5.00
Not HS Grad	3.17	1.53	1.5–4.50	3.17	1.53	1.5–4.50	4.33	.76	3.5–5.00
Managing Daily activities									
HS grad	4.43	.57	3.67–5.0	4.43	.57	3.67–5.0	4.61	.44	4.0–5.00
Not HS grad	3.75	1.35	2.33–5.0	3.75	1.35	2.33–5.0	4.11	1.53	2.3–5.00

HS = high school; grad = graduate; TRAQ = Transition Readiness Assessment Questionnaire.

Table 2 shows the ROV scores for the TRAQ total and subscales based on high school graduate status, indicating a clinically significant difference between the groups. Non-high school graduates showed greater improvement in total and subscale mean scores after the intervention at the ROV. Responses in the pre- and post-intervention periods were consistently rated at “No, I do not know how” or “No, but I want to learn” for the total score and the subscales managing medications, appointment keeping, and tracking health issues. At the time of the ROV, all scores improved to “No, but I’m learning to do this” response or higher, with the exception of appointment keeping.

A transparent and simplistic transitional program may decrease preventable mortality and morbidity in adolescents and young adults with chronic illnesses. The importance of sustainability for a formal transition educational program is due to the increased failure of transition in this vulnerable population caused by inadequate preparation.⁷

Limitations

The primary limitation of this study is its small sample size, with project implementation in a single clinic in the southeast United States, which limits generalization of findings. A larger sample size would further demonstrate the clinical utility of the TRAQ tool. Another limitation is the short period of follow-up after intervention, which may not be sufficient to yield a true assessment of change in transition readiness. Further, data collection was limited to 12 weeks due to the university’s institutional review board established timeline.

Conclusion

Advanced Practice Nurses who are competent in transitioning adolescents SCD patients into adult services may decrease health care costs and negative patient outcomes.

The TRAQ tool is a validated and consistent measurement tool that addresses 2 essential important transitional topics: disease self-management and self-advocacy skills. Advance practice nurses

who are knowledgeable of the physical, emotional, psychological, and psychosocial needs of patients with SCD can provide high-quality and holistic care, improving health care outcomes.

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In compliance with national ethical guidelines, the authors report no relationships with business or industry that would pose a conflict of interest.