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Health Care Transitions

Developing a transition workshop for adolescents with sickle cell disease

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ABSTRACT

Background: The transfer from paediatric to adult care presents a significant challenge for adolescents and young adults (AYA) with sickle cell disease (SCD). Disease self-management skills have been recognized as important mediators of poor health outcomes, but transition-related skills such as scheduling appointments and understanding the shift in health care responsibilities remain under taught in the healthcare system. The purpose of this quality improvement (QI) study was to (1) understand the areas of disease self-management that AYA patients felt underprepared for, and (2) design and evaluate an educational program addressing the top unmet skills.
Methods: The Plan-Do-Study-Act (PDSA) model was implemented in a tertiary outpatient clinic between September 2020 and July 2021. Patients were surveyed during regular clinic visits to identify their priorities on disease self-management skills. Based on the results, a virtual workshop was created and administered three separate times. Feedback was collected using an electronic survey.
Results: 'Navigating the adult health care system' was the top self-management skill that AYA patients (n = 39) identified needing more support with. The majority of participants (79%, n = 14) reported that the virtual workshop was excellent, with 'appointment management' being the most useful topic discussed. Participants also reported feeling more confident (71%) and aware (86%) of how to navigate adult care.
Conclusion: This QI study showed that delivering a virtual workshop on transition skills was well received by AYA participants with SCD. The PDSA framework was useful for identifying specific knowledge gaps in transition aged AYA to help improve patient education in a well-established transition program.

1. Introduction

Transition from paediatric to adult care can be challenging for adolescents and young adults (AYA) with sickle cell disease (SCD).[1] Sickle cell disease is an inherited blood disorder that causes red blood cells to change into a rigid sickle shape.[2] Individuals with SCD may experience unpredictable vaso-occlusive pain episodes, tissue and organ damage, and cerebrovascular injury.[2] Due to medical advances and treatment availability, people with SCD are living well into adulthood, however, morbidity and mortality still remain high in the age range immediately following transition from paediatric to adult care (i.e., 20–24 years).[3–6] Some difficulties associated with transition include the change of health care providers, a move towards a decentralized adult care setting, poor preparation for transition, and a shift in responsibilities from caregivers to AYA.[7–10]

Disease self-management skills have been identified as important mitigators of adverse health events and have been strongly linked with improved self-efficacy and transition readiness.[11–15] Health care providers play a key role in supporting AYA with SCD in developing self-management skills by providing disease-specific education, pain management strategies, and promoting self-advocacy skills.[16] Although the development of self-management skills has been recommended as a component of transition preparation,[17] there is a lack of standardized interventions focused on supporting patients in developing these skills. A recent review of transition programs for AYA with SCD recommends further development, evaluation, and dissemination of transition-focused interventions.[18] Given the lack of standardized approaches to transition planning and self-management skill development,

there is an opportunity to further develop and evaluate existing transition programs to address this need.

The purpose of this Quality Improvement (QI) study was to develop an education program targeting common knowledge gaps in the transition-aged population within a well-established SCD transition program. The plan-do-study-act (PDSA) framework was used to conduct this QI study.[19] The PDSA model allows for an iterative approach to implementing change in a clinical setting by formulating and analyzing small changes over time.[19] Use of a PDSA approach can be useful as it is grounded in a local context and can quickly incorporate feedback provided by key stakeholders.[20] Objectives of this QI study included 1) to identify disease self-management skills that transition-aged adolescent patients with SCD felt underprepared for, and 2) to develop, implement, and evaluate the acceptability of an educational program to address these unmet needs. This study built upon an existing transition program with a dedicated Transition Navigator (TN), where patients aged 12–20 with SCD are coached on disease self-management skills and connected to community resources to support their health-related needs.[21]

2. Methods

2.1. Setting

This QI study was conducted in a paediatric outpatient clinic at the Hospital for Sick Children, a tertiary urban hospital in Toronto, Canada. Approximately 40 AYA patients with SCD are transferred from the paediatric to adult haematology clinic each year at the age of 18. The clinical team is composed of haematologists, nurse practitioners, a clinical nurse specialist, a social worker, and a dedicated TN with a background in occupational therapy. The TN meets with patients and families at each clinic visit, starting at age 12 to begin preparation for transition to adult care. The TN role is multifaceted, involving disease knowledge assessment, transition skills education, resource navigation/development, program evaluation, healthcare systems navigation and administrative support.[21] In addition, the TN facilitates a monthly transition clinic attended by the pediatric team members as well as a physician from the adult hematology clinic to provide a seamless transition to the adult care services prior to patients turning 18. The TN is cross appointed as an employee at the pediatric and adult care sites and continues to work with patients from age 18–20 in the adult setting located directly across the street from the pediatric centre. Most patients in this program are transitioned to the same adult clinic, with some exceptions for those moving away from the area for school or relocation reasons. In the Canadian healthcare system, Canadian residents have universal health insurance through a publicly funded provincial healthcare system.[22] The comprehensive transition program was initiated as a pilot project in 2014 and is now a permanent part of the program.

2.2. Study design

Adolescent patients were surveyed on their perceptions of unmet disease self-management skills and preferred information delivery methods as part of PDSA cycle 1. This information was then used to design and implement a virtual workshop (VW) addressing the highest ranked theme identified by patients (cycle 2). Subsequently, the VW was administered two more times (cycle 3 and 4). In total, four PDSA cycles were conducted (Table 1).

2.3. Understanding the needs of AYA patients (PDSA Cycle 1)

A literature review was conducted on disease self-management needs in AYA with chronic health conditions. This information was reviewed and consolidated by clinical experts in sickle cell disease including hematology, psychology, social work, and nursing. The survey had a total of 38 items encompassing topics of disease knowledge, symptom

Table 1
Overview of PDSA cycles and study timeline.

	Cycle 1 – Identify Needs	Cycle 2 – Develop and Implement VW	Cycle 3,4 – Modify and Deliver VW
Time	October – December 2020	June – July 2021	July 2021
Plan	·Review concept of disease self-management in literature ·Design patient survey based on literature review and feedback from clinical team	·Evaluate current state of disease self-management interventions ·Interview YA patients ·Consult paediatric and adult care providers ·Develop VW presentation and handouts ·Create electronic feedback survey (REDCap) ·Recruit participants	·Modify VW presentation content and delivery ·Recruit participants
Do	·Administer paper survey during regular clinic visits	·Implement VW over Zoom Healthcare ·Administer electronic feedback survey	·Deliver VW over Zoom Healthcare ·Administer electronic feedback survey
Study	·Analyze survey results	·Analyze participant feedback	·Analyze participant feedback
Act	·Plan intervention focused on top need - 'Navigating the adult health care system'	·Apply feedback to next VW administration	·Apply feedback to next VW administration ·Adopt VW into standard care

management, impact on school/work, healthcare navigation, emotional impact of the disease and communication skills. (Appendix A). A convenience sample was used, with patients being approached from a member of the clinical team they were familiar with during regular clinic visits. The survey was designed to be anonymous and take under 10 minutes to complete. Patients aged 15–18 years old were administered the paper survey during their regular clinic visits. Survey scores were tallied, and the results informed the theme of the VW for the remaining PDSA cycles.

2.4. Designing the VW (PDSA Cycle 2)

Short, semi-structured phone interviews were conducted with two young adult patients (19 years old) who had recently transferred to adult care to share their experiences of the transition process. Quotes and case examples from the young adult patients were included in the workshop to incorporate peer experience. The paediatric and adult clinical team were also consulted on their experience facilitating online youth groups and common knowledge gaps among newly transitioned patients. A PowerPoint presentation was created for the VW with a focus on visual information and case examples to promote participant engagement (Appendix B).

2.5. Implementing and evaluating the VW (PDSA Cycles 2, 3, and 4)

Patients nearing the age of transition and recently transitioned patients (age 17–19) were recruited by the TN via regular care appointments and phone calls. The VW was hosted on Zoom Healthcare and facilitated by the TN. The workshop was one-hour long and administered to three separate groups over a four-week period. Following the workshop, participants completed an electronic survey to evaluate the content and delivery of the group, which helped improve subsequent administrations aligning with the PDSA approach. Digital handouts summarizing each topic were also distributed to all participants by

email.

2.6. Ethical considerations

The study was approved by the paediatric and adult institutions' QI review board, which included ethical oversight. All staff and patients interviewed were informed that their participation was voluntary and would not impact the clinical care they receive. Written consent was received upon completing the survey in PDSA cycle 1, and verbal informed consent was received prior to VW participation in cycles 2–4. Participants were made aware they would be joined by other clinic patients during the VW's and that they could choose to use a real name, alias, and have their camera on or off during the VW. Paper survey responses remained anonymous and were stored in a double-locked secure location. Electronic survey data were secured in a hospital-based electronic storage service (REDCap). No unique patient identifiers were collected on the paper survey during PDSA cycle 1, or the electronic surveys administered during PDSA cycles 2–4.

3. Results

3.1. Survey results

A total of 39 patients completed the survey in PDSA cycle 1 over a three-month period. In total 62 patients were scheduled during this time. Total participation was limited by patients not attending clinic appointments, and some not being approached due to other clinical priorities on the day of appointments (Table 2). Each section had 10–15 themes to select from and was scored using a 3-point Likert scale (1 = 'I don't need any help on this,' 2 = 'I need *some* help with this,' 3 = 'I need *a lot* of help with this'; Appendix A). 'Future with SCD' and 'Navigating adult care', were the highest ranked knowledge gaps, while 'In-Person by clinic staff' was the highest ranked method for information delivery (Table 3).

3.2. Participation and workshop content

There were 15 participants (Male = 67%, aged 17–19) in total who attended the workshop, with four to seven participants per session. Fourteen patients were unable to participate in the VW due to scheduling conflicts, and six declined interest (Table 2). Based on the input of the AYA patients and clinical team, the topics chosen for the theme of 'Navigating adult care' included: 1) shift in treatment approach, 2) video introductions of the adult care team, and 3) scheduling and managing

Table 2
Patient Participation in PDSA Cycles.

Cycle 1 (October – December 2020)	n	Percentage out of Possible Patient Encounters (n = 62)
Scheduled for Clinic Visit	62	100%
Attended Clinic	51	82%
Did Not Attend Clinic	11	18%
Approached to Participate	46	74%
Declined Participation	7	11%
Completed Survey	39	63%
Cycle 2–4 (June – July 2021)	**n**	**Percentage out of Possible Patient Encounters (n = 43)**
Scheduled for Clinic Visit	43	100%
Attended Clinic	35	81%
Did Not Attend Clinic	8	19%
Unable to Attend VW	14	33%
Declined VW Participation	6	14%
Attended VW	15	35%

Table 3
Highest-ranked themes in the patient survey (n = 39).

Disease Knowledge		Disease Self-Management Skills		Information Delivery Method	
Theme	Score	Theme	Score	Theme	Score
Future with SCD	41	Navigating Adult Care	43	In-Person by Clinic Staff	61
Sexual Health and SCD	35	Managing Relationships	28	Website/While Waiting for the Doctor[*]	48
Healthy Living with SCD	27	Communication Skills	26	Peer with SCD	47

[*] Note: Result had equal responses.

medical appointments (Appendix B). Although patients expressed a desire for in-person education, this was not possible due to the ongoing COVID-19 pandemic so a VW was utilized as an alternative approach whereby participants would still be familiar with TN as part of their clinical team.

3.3. Workshop feedback

Participants responded to an electronic survey immediately after attending the workshop. Responses were combined from all three workshop deliveries. Most participants found the overall content 'Excellent' and the length 'Just right' (Table 4). 'Managing appointments' was the most valuable topic presented. The majority also agreed that the workshop helped them feel more confident and aware of how to navigate care in the adult setting. Overall, the feedback from the VW was highly positive.

4. Discussion

There is a well-established need to support patients with SCD during their transition to adult care as they face many knowledge and skill-based challenges.[7,23] We found that 'Navigating adult care' was the top unmet self-management skill identified by patients and that a VW was a feasible way of delivering health care navigation information. A key strength of this study was its patient-centred approach.[24] From the initial survey to VW delivery, patient input was continuously assessed to meet patient needs and optimize impact. In addition, the small group setting of the VW promoted many opportunities for shared learning and support among participants. Another major strength of the study was the contextualization of transition-related information into location-specific examples. This included integrating clinic-specific details and video introductions from the adult providers into the workshop content, which was made possible because of the highly coordinated care system in place.

Table 4
Electronic Survey Results (n = 14[*]).

Question		Response
1.	Overall, I would rate the content of this session as:	Excellent (79%) Good (14%) Neutral (7%)
2.	I would rate the length of this session as:	Just right (100%)
3.	After completing this group, I feel **more confident** with how to navigate care in the adult setting:	Agree (71%) Somewhat Agree (29%)
4.	After completing this group, I feel **more aware** of how to navigate care in the adult setting:	Agree (86%) Somewhat Agree (14%)
5.	Please rate each workshop topic out of 10 (1 – Poor, 10 – Excellent):	Shift in Treatment Approach (7.5) Meet the Team (7.93) Managing Appointments (9.5)

[*] Note: One participant did not respond to the survey.

'Navigating adult care', which can also be referred to as 'health-care navigation skills', is a broad theme that has been identified as an essential component of transition readiness.[25] The topics chosen in the VW thus serve to encompass some key self-management skills necessary for AYA patients to feel prepared and confident while using the adult healthcare system.[8,26] Notably, 'managing appointments' was rated the most useful topic, while understanding the 'shift in treatment approach' was deemed less useful, though still rated highly. We found that the former covered information that was not previously known to participants, such as education on adult clinic policies, problem-solving conflicting schedules, and how to book medical appointments. Conversely, most participants were already aware of the 'shift in treatment approach', from family-centered to patient-centered care, as this topic is routinely discussed by the TN during regular clinic appointments. Although it was not as pertinent for our specific patient population, reviewing the shift in treatment approach is still critical to include for emerging transition programs as it highlights key differences in patient-physician interactions.

Implementation of a VW within a long-standing transition program was a novel approach in our clinic. PDSA models have been reported as a useful way for programs to create new or modify existing educational materials while remaining relevant to the needs of the specific patient population.[27] Use of a QI approach with multiple PDSA cycles allowed our team to quickly identify areas that transition-aged AYA felt underprepared for and create focused content to address their needs. In addition, participants appeared to value the contextual information provided such as clinic and location-specific details. This QI study showcases how the PDSA approach serves as a feasible method to identify educational opportunities that are of high importance to AYA with SCD. Overall, PDSA assisted in refining clinic educational tools in a well-established transition program to better support patients in their preparation to transferring into adult care. This QI model could be adopted in other clinics as an iterative way of improving transition or disease management skills for AYA living with a chronic disease.

5. Limitations

There were several limitations in this study. First, our small sample size limits the generalizability of the findings. This may be due to use of a convenience sample across all PDSA cycles, which failed to account for patients who do not attend clinic appointments regularly or did not attend their scheduled appointment. For PDSA cycles 2–4, although we attempted to increase the number of VWs conducted during the study period, we faced difficulty recruiting patients due to their conflicting work and personal schedules. Second, in-person delivery was not possible during the ongoing COVID-19 pandemic despite being the top-rated delivery method identified by AYA patients. As an alternative, the VW format still enabled two-way clinician-patient interactions that would have been present during an in-person delivery. Third, standardized psychometric assessments were not used during the study as we could not find a survey that suited our proposed scope. The measurement of increased confidence and awareness during PDSA cycles 2–4 were also not thoroughly defined or assessed in this preliminary study; rather, it was used as an indicator of perceived usefulness for the information provided. Given these limitations, a longitudinal study that

incorporates standardized psychometric assessments to measure the application of health care navigation skills following the intervention is warranted. Additionally, collecting feedback from a larger group of clinic patients including those who do not attend clinic appointments as regularly would provide a more thorough view of patient needs.

6. Conclusion

This QI study highlights how clinicians aiming to improve their educational materials for AYA with chronic health conditions can utilize PDSA methodology. Through four PDSA cycles, we identified the top unmet self-management skill and developed a program addressing this gap. Our study demonstrated that a single, one-hour VW was well-received and can offer a space for AYA patients to feel empowered by having discussions about transition and engaging with their peers. Given the acceptability and success of the intervention, it has now been integrated as part of the clinic's regular transition programming. Future directions will include additional administrations of the workshop to increase our sample feedback and further tailoring of the content to best fit the needs of AYA patients as they evolve.

Ethics statement

This manuscript has been read and approved for submission to Health Care Transitions by all authors. None of the authors have any conflicts of interest to declare. This submission is original work that has not previously been published in any part, substantial or otherwise, elsewhere, nor is it under consideration for publication elsewhere. The study was approved by the paediatric and adult institutions' QI review board, which included ethical oversight.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Data availability

Data will be made available on request.

Appendix A. – Patient disease self management survey and consent form

Study Title: Utilizing Quality Improvement to Develop a Transition Skills Workshop for Adolescents with Sickle Cell Disease.

Disease self-management is a term used to describe a person's ability to manage the medical, physical, and emotional aspects of a chronic or life-long health condition. Although the term "self" management makes it seem like you are managing things alone, this term actually means learning to rely on all of your supports to navigate through your life while living with a chronic condition. This including parents, family, friends, and also your healthcare team!.

Patients that have transitioned from SickKids to adult care have been surveyed and they feel that learning disease self-management skills is the

most important thing they want to learn more about. Now we are asking for your feedback to help us figure out what parts of self-management are the most important to you.

Participation or non-participation in this survey will not affect the care you receive. All information collected in this survey will be anonymous and not linked to your care in any way. Whether you choose to complete this survey is completely your decision.

If you choose to participate in this study, please complete the survey below and hand to any member of your health care team in the Sickle Cell clinic at SickKids. The survey should take about 10 minutes to complete.

I provide my consent to complete this survey Yes ☐ No ☐.

Age:

Gender:

Sickle Cell Disease Self-Management Skill Survey – please place an X in the boxes below to indicate if you need help in leaning these skills

Section 1. Disease Knowledge

Topic	I don't need any help with this	I need *some* help with this	I need *a lot* of help with this
1. What is sickle cell disease?			
2. Managing my sickle cell pain.			
3. Managing other symptoms of sickle cell disease.			
4. How to deal with stress.			
5. Living with sickle cell disease.			
6. What sickle cell disease will bring in the future.			
7. Managing the uncertainty of sickle cell disease on my day to day life.			
8. Modifying my lifestyle to adapt to sickle cell disease.			
9. Community resources and youth groups for people with sickle cell disease.			
10. Managing sickle cell disease at school.			
11. Managing sickle cell disease at work.			
12. The Impact of sickle cell disease on puberty, sexual health, and having children.			
13. Healthy living tips for people with sickle cell disease.			
14. Impact of emotions and stress on sickle cell disease.			
15. Knowing the purpose of my medications.			

Please review the list above, and circle your TOP 3 most important topics for disease self-management skills

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Do you have any other comments on topics you would like to learn about sickle cell disease?

Sickle Cell Disease Management Skills- please place an X in the boxes below to indicate if you need help in leaning these skills

Section 2. Self-Management Skills

	I don't need any help with this	I need *some* help with this	I need *a lot* of help with this
16. Setting and achieving health-related goals.			
17. Identifying a support network (people who I can talk to when I need support or help).			
18. Managing my medication on my own (taking medication, filling prescriptions).			
19. Navigating the adult health care system after I turn 18.			
20. Speaking up for myself and my needs ("self-advocacy").			
21. Balancing my health needs with my personal needs (other important things in my life).			
22. Improving communication skills (i.e. How to talk to healthcare providers, teachers, employers and friends about my needs).			
23. Other life skills (i.e. money management, laundry, cooking, public transport etc.).			
24. Problem-solving when health issues arise.			
25. Sharing my health condition with other people.			
26. Meeting others my age or slightly older (peers) with sickle cell disease.			
27. Sickle cell disease and relationships.			

Please review the list above, and circle your TOP 3 most important topics for disease self-management skills

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Do you have any other comments on topics you would like to learn about sickle cell disease?

Section 3 . Information Delivery.

How would you like to receive this information? Circle all that apply:	**Circle One Option**		
1. In-person by clinic staff.	No	Maybe	Yes
2. A group setting online (login from home computer).	No	Maybe	Yes
3. A group setting at the hospital.	No	Maybe	Yes
4. From a young adult living with sickle cell disease.	No	Maybe	Yes
5. Educational websites or videos that I can review at home or in the clinic.	No	Maybe	Yes
6. Having a member of the health care team follow-up by telephone in between my clinic appointments to check in on my goals and provide guidance.	No	Maybe	Yes
7. Paper educational handouts or pamphlets from clinic.	No	Maybe	Yes
8. Interactive media (i.e. Using A computer or iPad during a clinic visit to review information).	No	Maybe	Yes
9. Reviewing information on my own while I wait to see the doctor at my clinic visit.	No	Maybe	Yes
10. By using an App on my phone.	No	Maybe	Yes
Please review the list above, and circle your TOP 3 options for receiving information			

Do you have any other comments on how you would like information and / or education to be provided to you?

Appendix B. – VW slide outline

INTRODUCTION.

1. Introduction
2. Group guidelines
3. Icebreaker activity
4. Agenda
5. Patient quote for discussion – feeling nervous about transition
6. Feelings about transition – group discussion
7. Patient quote for discussion – taking charge of health
8. Agenda – goals for today
   SHIFT IN TREATMENT APPROACH
9. Shift in treatment pediatric vs. adult approaches
   MEET THE TEAM
10. Meet adult care team – allied / support staff
11. Meet adult care team – physicians
12. Clinic contact details
    MANAGING APPOINTMENTS
13. How and why to contact clinic nurse practitioner
14. Scheduling appointments – paediatric vs. adult
15. Clinic, specialist and other test locations
16. Managing appointments – group discussion
17. Tracking medical appointments - group discussion
18. Transportation to clinic
19. Adult clinic policies
20. Making appointments
21. Using the patient portal
22. Importance of primary care physician
23. Finding a primary care physician
    SCENARIOS FOR GROUP DISCUSSION
24. Scenario for group discussion – post-secondary school
25. Scenario for group discussion – problem solving in adult care
26. Scenario for group discussion – managing appointments
27. Summary of discussions
28. Booking appointments – example and group critique
    CLOSING
29. Summary of session
30. Final group discussion – successful transition
31. Wrap-up / questions
32. Feedback survey

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