Transition to Adult Care for Pediatric Patients with Sickle Cell Disease: A Quality Improvement Project

Maggie De La Vergne

OHSU School of Nursing

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Dr. Sharon Norman

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Transition Program for Sickle Cell Disease: Proposal Paper

Abstract

The purpose of this quality improvement project was to develop a standardized transition program for pediatric patients with sickle cell disease from pediatric to adult healthcare settings. Patients with sickle cell disease require long-term management strategies to prevent complications and hospitalizations for their disease. Developing a transition program can help patients learn how to manage their disease. Methods for this project included administering a readiness to transition assessment to patients and caregivers; based off results, patients were provided with education. Measurements taken for the project were percentage of families given readiness assessment, results of the transition assessment and percentage of patients who received education during their appointments. Thus far, results have shown that 100% of eligible patients and families received the transition readiness assessment. There were seven youth who completed the readiness assessment and nine caregivers who completed the readiness assessment.

The data from the readiness assessments demonstrated that most patients do not know how to do skills needed for transition and that most caregivers answered, they want their child to learn. Only one-quarter of patients received education as a part of their appointment. Implications to practice include having separate transition appointments or longer appointments, so there is time to provide education.

Introduction

Sickle cell disease affects around 100,000 Americans (Centers for Disease Control, 2019). With advances in treatment, including Hydroxyurea and the pneumococcal vaccine, patients are now expected to live well past childhood. Given that patients now live well into adulthood, there is a need for an effective transition from pediatric to adult care due to the chronic nature of the disease and increased rate of complications once patients leave a pediatric healthcare setting. Patients who enter into adult healthcare, have an increased acute healthcare utilization (Saulsberry et al., 2019). Young adults, in the age range of 22-24 years old, have the highest rate of mortality for patients with sickle cell disease (Porter et al., 2017). An effective transition process from pediatric to adult care is crucial for patients with sickle cell disease. Effective transition programs can provide them with the education and tools to manage their disease as they enter into adult care. In a systematic review looking at transition programs for sickle cell disease, two-thirds of the studies with structured transition programs, reported significant positive outcomes. These outcomes include adherence to making adult healthcare appointments, decreased hospitalizations, decreased emergency room visits, and increased quality of life (White & Cooley, 2018). Prior to this project, Doernbecher Children's Hospital, did not have transition program to adult care for pediatric patients. This quality improvement project created a standardized plan for pediatric patients with sickle cell disease to transition to adult care. Aspects of the quality improvement project included developing a tool to use in the electronic medical record (EMR). Specifically, this portion of the project developed a readiness to transition assessment, education and post-transition evaluation.

Literature Review

Sickle Cell Disease is a chronic autosomal recessive disease that results in red blood cells getting occluded in the vasculature (DeRanieri, 2019). In the past, patients with sickle cell disease were not expected to live past childhood. However, with current advances in treatment, patients with sickle cell disease have an average life expectancy of fifty-four years old (Lubeck et al., 2019). As patients with sickle cell disease now have much longer life spans and sickle cell disease is a life-long disease, it is necessary for patients to effectively transition to adult healthcare

Porter et al. found that having an effective transition process from pediatric to adult care is crucial for patients with sickle cell disease. Amongst a focus group with young adults with sickle cell disease, they discussed how to make the transition process more effective. The most cited topics patients wanted addressed in transition were finding an adult care provider, seeking emergency care, medication management, complications of disease, and coping skills. Patients reported that they would also like to learn practical skills, such as scheduling appointments (Porter et al., 2017).

In a cohort study, a validated tool, the Transition Intervention Program-Readiness for Transition (TIP-RFT) was developed, which is a survey that monitors progress in readiness to transition to adult care. It is an assessment based off a literature review, as well as patient and provider consensus. This assessment tool evaluates social support, independent living skills and educational or vocational plans. The results showed that many patients had adequate independent living skills, but did not know enough about their health and many were anxious about the transition process. Other results demonstrated 75% of patients said they knew how to manage money and make their own doctor's appointments. Only 50% of patients knew anything about

hydroxyurea and 37% knew their hemoglobin level (Smith et al., 2019). Assessment questionnaires are important to include in a transition program to be able to address gaps in knowledge.

Differences in pediatric and adult healthcare, make the transition process challenging. The cohort study by Smith et al., demonstrated one such difference is that adult care providers are used to only working with the patient, whereas pediatricians are used to working with the whole family. It is recommended for the first few years after transition, adult providers encourage patients to bring their families with them to appointments (Smith et al., 2019).

Another crucial aspect to effective transition is providing patients with proper education on disease management and functional daily activities. The education modalities that can be used are electronic modules and/or educational handouts. In a cross-sectional study, patients completed an assessment on managing sickle cell disease and based on the responses they were given educational handouts on identified knowledge gaps. Post education their scores in the assessment and knowledge on management of sickle cell improved (Calhoun et al., 2019). Another educational tool is utilizing technology to teach patients about management of sickle cell disease. In a systematic review of patients with sickle cell disease, patients who completed electronic teaching modules were shown to have improvement in knowledge of disease management (Tam et al., 2019) Education can help improve readiness for patients with sickle cell to transition to adult care. Social workers and transition educators can help patients prepare for the process of transition (Smith et al., 2019). In a cohort study, education was most effective when it was done early and also in the moment. For example, pain management strategies should be addressed both early on in the transition process, but also when a patient is having an acute crisis (Smith et al., 2019).

Havelock's Theory was the model used for implementing this quality improvement project. This theory is a way to organize implementation of change and moves through six steps (Polit & Beck, 2017). There was not a transition program at DCH for sickle cell patients, so the first step was having awareness of the problem of an ineffective transition process. Then the second step, was diagnose the problem, would be ineffective transition between pediatric and adult care. Then, the third and fourth stage were to utilize resources to develop a solution, such as how to assess readiness for transition to adult care and how to educate patients. Monitoring the progress was the next step, in which patients and families could be surveyed about how they think the process of transition is going. The last step would be to stabilize the change, where the whole transition process would become a permanent process at DCH for sickle cell patients.

The purpose of this paper is to discuss the transition project that was implemented at Doernbecher Children's Hospital Hematology Clinic. This project was based off interventions from the national guidelines that include the six-core elements of transition. The Social-ecological Model of AYA Readiness for Transition or SMART model was used provide a more effective transition program. The elements to this model included developing a policy and process for transition, tracking progress in EMR, assessing transition readiness, planning for transition with patients and families, transfer care to adult provider with transition package, and follow-up with patient six months after transition (Mcmanus, 2020). Developing a policy and process for transition included informing patients and families of the purpose and process of transition. Tracking progress in the EMR included recording topics have were reviewed. Assessments of transition readiness was asking patients and families questions and assessing knowledge of transition. Planning for transition with patients and families involves an individualized plan as to how patients will become ready to transition to adult care. Transferring

to the adult provider involves providing adult providers with a transfer packet that includes medical information about the patient and their transition process. The last step is confirming follow-up with an adult care provider within three-six months after leaving pediatric care. This transition program was developed at Doernbecher, included all of the core elements of transition. The goal of this quality improvement project was to better prepare patients with sickle cell disease to transition to adult care, ideally leading them to manage their disease and decrease mortality and morbidity. To achieve this goal, patients were given a policy on the transition program, annual readiness assessments and education based off areas of weakness on assessments.

Methods

Setting

The setting of this quality improvement project was at Doernbecher Children's Hospital in the pediatric sickle cell clinic. The clinic provides preventative care and manages complications of sickle cell disease. These patients are seen in a pediatric setting, from birth until 22 years of age. There are currently 51 total patients that are followed for sickle cell disease, of those 10 patients are eligible for the transition program.

Prior to this project, there was no process to transition these patients to an adult hematologist or primary care provider. The hematology team at Doernbecher had a strong desire to develop a transition program, making this project a priority to be completed. As an organization, there was readiness to change and the hematology team as a whole was invested in the transition program. A barrier was that part of the project required support from informatics to

build tools in the EMR and this request will be competing with other organizational priorities thus delaying the implementation of the transition program.

Sample Population

Participants for this project were pediatric patients with sickle cell disease, who receive care at Doernbecher Children's Hospital hematology clinic. Inclusion criteria was patients with sickle cell disease, who are between the ages of 12-21 years. Exclusion criteria would be patients who do not have sickle cell disease and who are less than 12 years old and older than 21 years old. In the timeframe of the project, there were seven youth and nine caregivers who participated in the project. There was not necessarily recruitment for this project, but starting at 12 years of age, patients and their families were given a policy and timeline for the transition process. This project has been approved by IRB for non-human research. Identities of the patients will remain de-identified and following HIPAA rules.

Implementation

This project utilized the Social Ecological Model of AYA Readiness for Transition (SMART) theoretical framework, which is tested and validated as an effective model for transition. Team members included in the implementation of this project are: hematologists, social worker, information technology support, and hematology clinic RNs. A pediatric transition policy and timeline was developed for children 12-21 years old with sickle cell disease seen in the hematology/oncology clinic; this was handed out by the front desk workers when patients and their families checked into the clinic for their appointment. The policy and timeline that utilized was based off the examples from the Got Transition website. The policy reviewed what exactly a transition program entails and benefits of a transition program **(Appendix A)**. A

timeline that was handed out when patients check into appointments, was used as a guideline as to what transition topics should be addressed at annual hematology visits starting at age 12 **(Appendix B)**.

The transition readiness assessment utilized was a validated and studied tool from the Got Transition website (Smith et al., 2019). Each patient completed a readiness survey via a tablet that syncs to RedCap **(Appendix C)**. Providers then copied results from RedCap into the EMR. Based off weakness areas, such as knowledge of disease management, how to schedule doctor's appointments, etc. shown from readiness assessments and appointments, patients received access to a collection of educational modules. These educational modules were from St. Jude's Children's Hospital; they included interactive modules that utilize videos and quizzes. There was also a resource folder, divided into age ranges and subdivided into topics of medical, psychosocial, that patients can utilize to obtain more knowledge on a subject area of weakness. The providers and social workers provided verbal education during appointments. After transition is completed, patients and families will be given an evaluation survey on the transition process **(Appendix D)**.

Measures

For the policy and timeline, the percentages of patients who received policy and timeline given at their first transition appointment was calculated. The percentage of eligible patients who filled out transition readiness assessment was also be measured. The answers to the transition readiness assessment were measured, analyzing the percentage of patients who answered no, yes, or want to learn. Upon completion of transition, when patients are transferring to adult care, between ages eighteen to twenty-one years old, results from patient and family surveys about transition process will be reviewed. These measurements utilized EMR, so chart

reviews were done in patient's medical record, to evaluate if they were asked transition questions and if they had filled out readiness assessment survey. Accuracy of data collection was ensured by using a reliable source; the EMR is a legal document, thus the transition notes and tool would be accurate. Independent chart reviews were performed to verify data. The costs included labor from the Epic support team building the transition tool and the RedCap team assisting with edits of survey. Additional costs were minimal, such as the printing of timelines and policies. There was not a cost for use of tablets as they were available from within Doernbecher Children's Hospital.

Ethics

There are key ethic issues that must be addressed in the process of transitioning pediatric patients to adult care. One such ethical issue is helping patients develop autonomy over their health. In a transition program, this includes providing patients information about their disease and slowly giving them more decision making capacity. Children transitioning to adult care need to be taught how to manage their health and chronic disease. There are some specific equity issues related to pediatric sickle cell disease that affect the care patients receive. The majority of patients who have sickle cell disease are African American. A survey of adolescents with sickle cell disease was done on their perception and experience of racial bias in the healthcare setting. The majority of patients reported experiencing racial bias and feeling stigmatized by healthcare providers. These stigmas towards patients can lead to patients delaying seeking healthcare due to fear of feeling stigmatized (Wakefield et al., 2017). If patients delay seeking care, they are more likely to face increase in complications of their illness. This relates to the transition program project because there may be issues transitioning if patients feel they are being stigmatized by the adult provider and thus may not want to go to appointments. Another equity issue that was

addressed, such as gaining access to care. The issues surrounding access to care is that there are not enough adult hematology specialists and as patients transition to adult care, they may not have insurance. As patients are moving to adult care, they need to be informed about their disease and the care they are being provided (Paul et al., 2018). Patient rights will be protected de-identifying them and storing data on encrypted computers.

Ethics in relation to participant protection were that the project received IRB approval for non-human research. The data was stored on RedCap, which deidentifies patient and caregiver information. Other patient information was stored in the EMR, which is an encrypted device. HIPPA compliance was maintained throughout the project.

Implementation and Outcomes

Implementation of Project

Over the course of ten months, this DNP project evolved and changed in a few ways. With regards to the policy, the first change was the logo. Initially, on the policy the Doernbecher doll was the logo and was changed to the Doernbecher fire log. Initially, the transition readiness assessment was completed on paper and providers would type results in the EMR. Eventually, the readiness assessment was entered into RedCap. The hematology team had access to the survey and would administer it to patients and their families on a tablet device. The providers would then copy the results from RedCap and enter it into the EMR. Changes made to the readiness assessment included starting with a question as to whether the survey respondent is a patient or caregiver, in order to allow both surveys to work. Other changes including adding examples to a few questions, as some of the patients and families were confused about the meaning. Additionally, demographic questions were added to the survey, including age, gender,

and ethnicity. The last change that was made was dividing the survey into subsections, related to the subject, such as medication, insurance, with a subtitle above the topic area **(Appendix E)**

Outcomes

Due to the time constraints of the project, missing data is the evaluation surveys post transition completion. The annual results of transition readiness assessment were missing to compare improvements in scores, as this was only a ten-month project. Demographic data includes that one-third of patients were Hispanic and two-thirds were African American. The average age of youth who completed the survey was 13.8 years old. Half of the patients were female and half were male. For first appointment transition visits 100% of patients were given the policy on the transition program. Other key results were that seven youth patient participants thus far have completed the readiness assessment survey. All of the seven who attempted the surveys answered 100% of the questions. Patient participants answered yes, they know how to do the transition skill 30.8% of the time, they want to learn 24% of the time, and no they don't know how 44.4% of the time. Of the Caregiver respondents, they answered yes, their child can complete the skill 37.3% of the time, no they can't 24.6%, and they want to learn how 38% of the time. The scores for each question ranged from 0-2 (0 being no they don't know, 1 being they want to learn and 2 being Yes); adding all the questions together, there is a total of 52 points to be earned **(Appendix F)**. The average score on the youth patient assessments was a score of 36.6 and a mean score on each question of 1.4. For the caregiver readiness assessments, the average score was 30.6 and the mean score on each question was 1.17. Education was only charted as being done at two of the transition appointments. Results were comparable to the literature, in that with the implementation of a transition program, there was an increase in discussing the transition process. One result that was different than literature was results from

readiness assessment that patients in the literature seemed to have higher scores compared to the actual results. However, this could be related to the patients in the actual results being on the lower age range of eligible patients, compared to the literature.

Practice Related Implications

Implications from this project would be to continue with the sickle cell transition project to at least see post-transition evaluations as well as results from annual transition readiness assessments. Other implications would be to continue to work on developing a standardized EMR tool for the hematology team to utilize to make the process more straightforward. After the project has been proven effective, in having all eligible patients being asked about transition, education being completed and results from evaluation, in the sickle cell department, consideration should be given for expansion to other pediatric departments that manage the care of patients with chronic conditions. Given that only two patients were able to receive education during transition visits, one implication is to have longer appointments or to have separate transition appointments from the regular sickle-cell visit. By having a separate visit or at least a longer visit, this would give providers more time to review the results of the readiness assessment and provide patients with education. Other options include having educational visits with a registered nurse or social worker.

A limitation of this project was the small sample size, which limits the validity of the project. An additional limitation is the project only included patients with sickle cell disease, so the results are not necessarily generalizable to other populations. This project is sustainable given the hematology teams desire to continue the project and investment in the project. The readiness assessment and transition toolkit has not been able to be built into the EMR yet, which was a limitation for ease and accessibility of tool for providers.

Summary and Next Steps

Sickle Cell Disease is a chronic hematological disease that requires life-long management to prevent complications and hospitalizations. Those patients in the 22-24 years of age, have the highest rates of mortality amongst patients with sickle cell disease. Transition programs from pediatric to adult healthcare can be effective in assessing readiness for transition and providing patients and their families with education to manage their SCD diagnosis. This DNP project utilized a transition readiness assessment to assess patient's readiness to transition to adult care by inquiring about patient's knowledge of disease and medication management. Through this tool, the team tracked patients' progress and knowledge and provided education based off readiness assessment results. This project demonstrated that 100% of the time patients were asked to answer the survey, they completed it fully. These results demonstrated engagement of participants and providers in the transition program It also demonstrated that almost half of patients answered "no" they don't know an aspect of their disease management.

Next steps for this project would be to develop the Epic Transition tool, so providers can link the transition readiness assessment to the EMR automatically, instead of copying from RedCap. The Epic tool will also allow for increased utilization of education, by attaching educational materials to patient's chart or after visit summary. A specific job position for transition visits could be developed to increase the amount of time of appointments and education patients receive. Another option would be to have transition specific appointments that are virtual, to increase the amount of transition education patients and caregivers receive.

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Appendix A

Transition Policy

THE SIX CORE ELEMENTS OF HEALTH CARE TRANSITION™ 3.0

Doernbecher Children's Hospital Transition and Care Policy/Guide

OHSU

[Pediatric Practice Name] cares about you.

We will help you move smoothly from pediatric to adult health care. This means working with you, starting at ages 12 to 14, and your parent/caregiver to prepare for the change from a pediatric model of care to an adult model of care. A pediatric model of care is where parents/caregivers make most choices. An adult model of care is where you will make your own choices. We will spend time during visits without your parent/caregiver in the room to help you set health goals and take control of your own health care.

By law, you are an adult at age 18. We will only discuss your health information with others if you agree. Some young adults choose to still involve their parents/caregivers or others in their health care choices. To allow your doctor to share information with them, consent is required. We have these forms at our practice. For young adults who have a condition that limits them from making health care choices, our office will share with parents/caregivers options for how to support decision-making. For young adults who are not able to consent, we will need a legal document that describes the person's decision-making needs.

We will work with you to decide the age for moving to an adult doctor. We suggest that this move take place before age 22. Our office policy is to prepare you to move to an adult doctor. This includes helping you find an adult doctor, sending medical records, and talking about any special needs with the adult doctor. We will help you find community resources and specialty care, if needed.

Your health matters to us. As always, if you have any questions, please feel free to contact us at 503-346-0640.

Transitioning Youth to an Adult Health Care Clinician
Six Core Elements of Health Care Transition™ 3.0

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got transition.

Appendix B

Transition Timeline

Please note this is an example guideline for a timeline and doesn't include the age of 12 years old, as the DCH transition program will be starting transition at 12 years old., not 13 years old.

Sickle Cell Transition Curriculum

13-15

Medical	Psychosocial	Academic
☐ Intro to SCD ☐ Genetics ☐ Fever & SCD ☐ Anemia ☐ Pain triggers ☐ Hydration ☐ Meaning of lab values ☐ Good nutritional habits ☐ Disease complications ☐ Importance of physical activity ☐ Periods ☐ Priapism ☐ Risk of drugs/alcohol here	☐ Sexuality ☐ High risk pregnancy ☐ Self-advocacy ☐ Sharing diagnosis w/ others ☐ Identifying support networks ☐ Stress reduction ☐ Peer pressure ☐ Behavioral pain management, gate control theory of pain, etc. ☐ Starting to increase independence and manage your own medications/healthcare	☐ Short- / Long- term goals High school prep ☐ IB program ☐ HS Magnet Programs ☐ Section 504 ☐ IEP ☐ Applying for scholarships/loans ☐ Interventions to improve motivation and self-efficacy for higher education and/or trade school

16-18

16-18

Medical	Psychosocial	Academic
☐ Living well with SCD ☐ Periods ☐ Priapism ☐ Anemia & SCD ☐ When to call Doctor ☐ Meaning of own laboratory values ☐ Pain triggers/treatment ☐ Adherence strategies ☐ Risk of alcohol and drugs ☐ Current medications ☐ Immunizations ☐ Genetics	☐ Sexuality/ high risk pregnancy ☐ Romantic relationships, recognizing dating violence, healthy communication ☐ Available government benefits ☐ Stress reduction ☐ Intro to insurance ☐ Power of Attorney (If necessary) ☐ Options for adult care in community ☐ Managing stress/confidence/self-efficacy around going to an adult provider ☐ Increasing personal agency/responsibility for medical care, medications, etc. ☐ MyHealth Portal App ☐ Behavioral pain management	☐ Short- / Long- term goals Dual enrollment ☐ SAT/ ACT Prep ☐ 504 Plan ☐ Vocational careers ☐ Job/ career interest ☐ College Prep ☐ Applying for scholarships/loans ☐ Interventions to improve motivation and self-efficacy for higher education and/or trade school

Sickle Cell Transition Curriculum

	☐ Sharing diagnosis w/ others ☐ Identifying support networks	

19-21

Medical	Psychosocial	Academic
☐ Growing, aging, and maturing with SCD ☐ Eyes & CSD ☐ Kidneys &SCD ☐ Blood pressure ☐ Pregnancy ☐ Knowledge of genotype ☐ Disease complications ☐ Transfusion indications/risks	☐ Medical system navigation ☐ Stress Management ☐ Support networks ☐ Insurance Coverage ☐ Medicaid ☐ Power of Attorney (If necessary) ☐ Options for adult care in community ☐ Independence ☐ Sexuality/ pregnancy ☐ Romantic relationships, recognizing dating violence, healthy communication ☐ Pain triggers and behavioral pain management ☐ Employment ☐ Adherence strategies	☐ Short- / Long- term goals ☐ 504 Plan ☐ Job/ career interest ☐ College Admission/ Prep ☐ Registering with student disabilities center in college ☐ Vocational careers ☐ Special programs ☐ Applying for scholarships/loans ☐ Interventions to improve motivation and self-efficacy for higher education and/or trade school

Appendix C

Transition Readiness Assessment

Transition Readiness Assessment for Youth

OHSU

Please fill out this form to help us see what you already know about your health, how to use health care, and the areas you want to learn more about. If you need help with this form, please ask your parent/caregiver or doctor.

Preferred name	Legal name	Date of birth	Today's date

TRANSITION IMPORTANCE & CONFIDENCE *Please circle the number that best describes how you feel now.*

The transfer to adult health care usually takes place between the ages of 18 and 22.

How important is it to you to move to a doctor who cares for adults before age 22?

| 0 not | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 very |

How confident do you feel about your ability to move to a doctor who cares for adults before age 22?

| 0 not | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 very |

MY HEALTH & HEALTH CARE *Please check the answer that best applies now.*	NO	I WANT TO LEARN	YES
I can explain my health needs to others.	☐	☐	☐
I know how to ask questions when I do not understand what my doctor says.	☐	☐	☐
I know my allergies to medicines.	☐	☐	☐
I know my family medical history.	☐	☐	☐
I talk to the doctor instead of my parent/caregiver talking for me.	☐	☐	☐
I see the doctor on my own during an appointment.	☐	☐	☐
I know when and how to get emergency care.	☐	☐	☐
I know where to get medical care when the doctor's office is closed.	☐	☐	☐
I carry important health information with me every day (e.g., insurance card, emergency contact information).	☐	☐	☐
I know that when I turn 18, I have full privacy in my health care.	☐	☐	☐
I know at least one other person who will support me with my health needs.	☐	☐	☐
I know how to find my doctor's phone number.	☐	☐	☐
I know how to make and cancel my own doctor appointments.	☐	☐	☐
I have a way to get to my doctor's office.	☐	☐	☐
I know how to get a summary of my medical information (e.g., online portal).	☐	☐	☐
I know how to fill out medical forms.	☐	☐	☐
I know how to get a referral if I need it.	☐	☐	☐
I know what health insurance I have.	☐	☐	☐
I know what I need to do to keep my health insurance.	☐	☐	☐
I talk with my parent/caregiver about the health care transition process.	☐	☐	☐
I know what type of sickle cell disease I have.	☐	☐	☐
I know what a hematologist is and why I see one.	☐	☐	☐
I understand what causes a pain episode.	☐	☐	☐
I have friends I can talk to about sickle cell disease.	☐	☐	☐
I know about necessary screen exams.	☐	☐	☐
I know how to get blood work and x-rays.	☐	☐	☐
I understand how drugs, alcohol and tobacco affect sickle cell disease.	☐	☐	☐
MY MEDICINES *If you do not take any medicines, please skip this section.*			
I know my own medicines.	☐	☐	☐
I know when I need to take my medicines without someone telling me.	☐	☐	☐

Appendix D

Transition Evaluation Survey

Sample Health Care Transition Feedback Survey for Youth/Young Adults

This is a survey about what it was like for you to move from pediatric to adult health care. Your answers will help us improve our health care transition process. Your name will not be linked to your answers.

DID YOUR PAST DOCTOR OR OTHER HEALTH CARE PROVIDER... Please check the answer that best fits at this time.	YES	NO
Explain the transition process in a way that you could understand?	☐	☐
Give you guidance about the age you would need to move to a new adult doctor or other health care provider?	☐	☐
Give you a chance to speak with them alone during visits?	☐	☐
Explain the changes that happen in health care starting at age 18 (e.g., changes in privacy, consent, access to health records, or making decisions)?	☐	☐
Help you gain skills to manage your own health and health care (e.g., understanding current health needs, knowing what to do in a medical emergency, taking medicines)?	☐	☐
Help you make a plan to meet your transition and health goals?	☐	☐
Create and share your medical summary with you?	☐	☐
Explain how to reach the office online or by phone for medical information, test results, medical records, or appointment information?	☐	☐
Advise you to keep your emergency contact and medical information with you at all times (e.g., in your phone or wallet)?	☐	☐
Help you find a new adult doctor or other health care provider to move to?	☐	☐

Appendix E

RedCap Survey

Transition Readiness Assessment for Patient

Please fill out this form to help us see what you already know about your health, how to use health care, and the areas you want to learn more about. If you need help with this form, please ask your parent/caregiver or doctor.

Thank You!

1) **What is your name?**

2) **_____ what is your email address?**

3) **_____ how important is it to you to move to a doctor who cares for adults before age 22?**

4) **_____ how confident do you feel about your ability to move to a doctor who cares for adults before age 22?**

Knowledge of Disease (tell us what you know and who you talk to about sickle cell).

	No	They Want To Learn	Yes
5) **I know my family medical history.**	○	○	○
			reset
6) **I talk with my parent/caregiver about the health care transition process.**	○	○	○
			reset
7) **I have friends I can talk to about sickle cell disease.**	○	○	○
			reset
8) **I know what a hematologist is and**	○	○	○

	No	They Want To Learn	Yes	
9) I understand what causes a pain episode.	○	○	○	
				reset
10) I know what type of sickle cell disease I have.	○	○	○	
				reset
11) I understand how drugs, alcohol and tobacco affect sickle cell disease.	○	○	○	
				reset

Medication Skills/Knowledge (tell us what you know about your medications)

	No	They Want To Learn	Yes	
12) I know my own medicines.	○	○	○	
				reset
13) I know when I need to take my medicines and actually take them, without someone telling me.	○	○	○	
				reset
14) I know how to refill my medicines if and when I need to.	○	○	○	
				reset
15) I know my allergies to medicines.	○	○	○	
				reset

Self Care and Advocacy (tell us how you ask for what you want and how you take care of yourself)

	No	They Want To Learn	Yes	
16) I can explain my health needs to others.	○	○	○	
				reset
17) I know how to ask questions when I do not understand what my doctor says.	○	○	○	
				reset
18) I talk to the doctor instead of my parent/caregiver talking for me.	○	○	○	
				reset

		No	They Want To Learn	Yes	
19)	I see the doctor on my own during an appointment.	◯	◯	◯	
					reset
20)	I know about necessary screenings and exams (tests for strokes, lungs, eye exams, etc).	◯	◯	◯	
					reset
21)	I carry important health information with me every day (e.g., insurance card, emergency contact information).	◯	◯	◯	
					reset
22)	I know at least one other person who will support me with my health needs.	◯	◯	◯	
					reset
23)	I know how to get blood work and x-rays (make lab appointment or schedule imaging).	◯	◯	◯	
					reset

Healthcare Resourcefulness (tell us how well you take care of your own health needs)

		No	They Want To Learn	Yes	
24)	I know when and how to get emergency care.	◯	◯	◯	
					reset
25)	I know where to get medical care when the doctor's office is closed.	◯	◯	◯	
					reset
26)	I know how to find my doctor's phone number.	◯	◯	◯	
					reset
27)	I know how to make and cancel my own doctor appointments.	◯	◯	◯	
					reset
28)	I know how to get a referral (appointment with a medical sub-	◯	◯	◯	

Transfer of Care Skills (tell us if you are ready to start seeing a doctor by yourself)

		No	They Want To Learn	Yes	
29)	I have a way to get to my doctor's office.	◯	◯	◯	
					reset
30)	I know how to fill out medical forms.	◯	◯	◯	
					reset
31)	I know that when I turn 18, I have full privacy in my health care.	◯	◯	◯	
					reset
32)	I know what I need to do, to keep my health insurance.	◯	◯	◯	
					reset
33)	I know what health insurance I have.	◯	◯	◯	
					reset
34)	I know how to get a summary of my medical information (e.g., online portal).	◯	◯	◯	
					reset

37) _____ what is your age?

12
13
14
15
16
17
18
19
20
21
22

reset

38) _____ what sex were you assigned at birth?

Male
Female

reset

39) _____ what gender do you identify with?

Male
Female
Other (please specify in the below question)

reset

40) _____ please specify what gender you identify with.

[   ]

Submit

Save & Return Later

Optional Demographic Questions (tell us about yourself

	I would like to answer the below questions	I do not want to answer the below questions
35)	○	○

reset

36) _____ what is your race/ethnicity?

White

Black or African-American

Hispanic

American Indian or Alaskan Native

Asian

Native Hawaiian or other Pacific islander

From multiple races

Some other race (please specify)

reset

Appendix F

Transition Readiness Assessment Results for Youth and Caregivers

Transition Readiness Assessment Preliminary Results