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**THE FEASIBILITY OF A MEDICAL STUDENT MENTORING PROGRAM TO  
IMPROVE TRANSITION OF CARE AMONG YOUNG ADULTS WITH SICKLE  
CELL DISEASE**

By

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Written under the direction of

Cristine D. Delnevo and Katie A. Devine

And approved by

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## **ABSTRACT OF THE DISSERTATION**

The Feasibility of a Medical Student Mentoring Program to Improve Transition of Care  
Among Young Adults with Sickle Cell Disease

By

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In the United States, sickle cell disease (SCD) affects an estimated 100,000 people. Although advances in treatment have resulted in up to 98% of patients surviving to 18 years, the majority of deaths in this patient population occur after age 18 and after the transfer from a pediatric to an adult provider. Further, the highest rate of acute care encounters and re-hospitalizations for patients with SCD occurs among 18–30 year olds. Patients with SCD require comprehensive care that necessitates patient compliance with primary care appointments, specialty clinical visits, medications, transfusions, and regular health maintenance. As patients transition from pediatric care, they are at risk for lapses in care that can result in serious complications.

Barriers to successful transition from pediatric to adult care include a lack of support, minimal transition planning, providers' lack of time to address transition issues, and disparities in care related to the racial background of the patients. The absence of well-defined programs for the transition from pediatric to adult care results in young adult patients feeling generally unprepared for transition to the adult healthcare system and leads to reduced utilization of necessary preventive treatment and health maintenance.

Unfortunately, there are few published transition programs in the literature to date, with a noticeable gap in using peer support to improve outcomes.

To address this gap, a novel medical student mentor transition intervention was developed following a formative qualitative needs assessment. Guided by patient feedback and the Social-Ecological Model of Young Adult and Adolescent Readiness to Transition, the intervention targeted SCD knowledge, self-management knowledge and skills, healthcare navigation skills, pain management, healthy behaviors, managing expectations for the emergency room, navigating patient-provider relationships, self-advocacy, managing expectations for adult care, and support resources. Feasibility and acceptability of the intervention was assessed through enrollment rates, reasons for refusal, retention rates, engagement with the intervention, satisfaction, and reasons for drop-out. The preliminary efficacy of the intervention among patient participants was assessed for changes in transition readiness, health related quality of life, self-efficacy, SCD knowledge medication adherence, and health literacy. Among medical student mentor participants, changes in attitudes towards chronic illness and SCD knowledge were explored.

The results demonstrated that a medical student mentor intervention for transition was feasible for both patient and mentor participants. Patient participants demonstrated adequate retention (76.4%) and adherence to the intervention (75.0%) and rated the intervention components highly. All medical students who entered the program completed it fully, and rated the program highly. Patient participants demonstrated significant improvements in transition readiness, self-efficacy, and medication adherence. Medical students also demonstrated significant improvements in SCD knowledge.

A medical student mentor intervention for transition from pediatric to adult care for young adults with SCD is both feasible and acceptable to patients and medical students. Preliminary evidence suggests such an intervention may provide dual benefit for both patients and students. This dissertation highlights the need for further research on the efficacy of this transition program, including psychosocial and medical outcomes of care.

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## **CHAPTER 1 INTRODUCTION**

### **Background**

Medicine has evolved over the past decades such that many adolescents with chronic illnesses who were not living past their teenage years are now living into adulthood. In turn, improving the process of transition of care from a pediatric model of healthcare to an adult model of healthcare has become an increasing priority (Castillo & Kitsos, 2017). Transition for adolescents with chronic illness is a rapidly growing health issue, with more than 500,000 adolescents in the United States alone aging into this population each year (Sharma, O'Hare, Antonelli, & Sawicki, 2014). The American Academy of Pediatrics established the goal of transition "to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate healthcare services that continue uninterrupted as the individual moves from adolescence to adulthood" (Cooley & Sagerman, 2011). Transition preparation should include self-management skill development, transfer of care, and strategies for coordinated care between the pediatric and adult healthcare systems (Sharma et al., 2014). Got Transition/The National Center for Health Care Transition has outlined six core elements of healthcare transition in clinical practice, including: (1) establishment of transition policy; (2) transition tracking and monitoring; (3) assessment of transition readiness; (4) transition planning; (5) transfer of care; and (6) transfer completion (White, Cooley, & McAllister, 2015). These elements are guiding principles for transition practice across pediatric chronic illnesses including sickle cell disease (SCD), cystic fibrosis, asthma, diabetes, irritable bowel disease, and others.

Due to improvements in therapies and treatment, SCD has become a lifelong chronic illness rather than a disease of childhood in the United States, with over 95% of children with SCD living beyond 18 years (Quinn et al., 2010). As a result, the transition from pediatric to adult care has

become an increasingly important clinical priority in this population. However, healthcare delivery models have not been adapted in line with the rising adult population with SCD. Inadequate transition care and low transition readiness contribute to poor health outcomes (Hankins et al., 2012; Lanzkron, Carroll, & Haywood, 2013; Sobota, Shah, & Mack, 2017). There are many potential barriers to successful transition from pediatric to adult care in young adults with SCD, including lack of transitional support for patients, minimal transition planning, and providers' lack of time to address transition issues (de Montalembert & Guitton, 2014; Haywood et al., 2013; Kayle, Tanabe, Shah, Baker-Ward, & Docherty, 2016; Sobota et al., 2015; Speller-Brown et al., 2015). Such factors contribute to adolescents' low transition readiness and lack of self-efficacy in managing self-care. As a result, the highest rate of acute care encounters and re-hospitalizations for individuals with SCD occurs among 18–30 year olds (Brousseau et al., 2010). Additionally, the majority of deaths in this patient population occur after 18 years of age and after transfer to an adult provider is initiated.

One major contributor to increased morbidity and mortality from SCD during young adulthood is the absence of well-defined programs for the transition from pediatric to adult healthcare. The literature provides limited evidence of successful transition programs for patients with SCD. Current programs focus on patient barriers to transition including knowledge and transition readiness. Only a handful of published articles have reported on outcomes or feasibility of transition programs for SCD (Allemang et al., 2016; Andemariam et al., 2014; Calhoun et al., 2016; Calhoun et al., 2019; Crosby et al., 2016; Crosby et al., 2017; Hankins et al., 2012; Manwani et al., 2017; Rogers-Melnick et al., 2017; Smith et al., 2011). These approaches included the use of health information technology (Crosby et al., 2016), patient education (Calhoun et al., 2016; Calhoun et al., 2019; Crosby et al., 2017; Rogers-Melnick et al., 2017; Smith et al., 2011), and

patient navigators (Allemang et al., 2016; Manwani et al., 2017), but there is a noticeable gap in the literature in harnessing peer support to improve transition readiness. Peer support meets a developmental need of adolescents and young adults (AYAs) (Bell et al., 2008; Domhardt, et al., 2015) and offers a novel mechanism for targeting individual components of transition readiness.

Peer mentoring harnesses an imposed social network and the benefits of social support. Mentors have been successfully used to promote positive changes for a number of health behaviors (Petosa, 2014). Medical students, in particular, have been utilized as peer mentors for AYA patients with a variety of chronic conditions to invoke positive health behavior change (Conatser & Babcock, 1993; Schaechter & Canning, 1994; Tess et al., 1997). Medical students have a unique combination of being integrated into the healthcare system and being a similar-aged “peer” to the patient, allowing them to provide specialized support. The integration of a peer relationship within the healthcare system offers the opportunity to make complex processes like transition less overwhelming, by providing support and point of contact within the medical system for the patient. Through communication with the patients (mentees) and specific training and communication with the clinical team, the mentors may help patients improve transition readiness, increase patient knowledge, increase rates of attendance at adult visits, and improve medication adherence, all potentially resulting in improved health-related quality of life and health outcomes for these patients.

The American Academy of Pediatrics recommends that all transition programs promote skills in communication, decision-making, assertiveness, and self-management to help adolescents and young adults gain control and independence over their healthcare (Cooley & Sagerman, 2011). Research studies conducted with sickle cell patients, their parents, and providers have echoed these themes, but also outlined a need for disease-specific education, advocacy, and pain management

(Bemrich-Stolz, Halanych, Howard, Hilliard, & Lebensburger, 2015; Sobota, Kavanagh, et al., 2015; Treadwell et al., 2011).

### **Statement of the Problem**

Healthcare transition is the process of changing from a pediatric to an adult model of healthcare (Blum et al., 1993; Castillo & Kitsos, 2017). The goals of healthcare transition are to improve the ability of AYAs to manage their own healthcare and effectively navigate the healthcare system (Blum et al., 1993; Castillo & Kitsos, 2017). The stark differences between pediatric and adult models of healthcare contribute to transition difficulties. While care delivery models vary across adult treatment centers, pediatric facilities often follow the patient-centered medical home model (Cooley & Sagerman, 2011). Typically, children are able to receive all specialist care within one center, get prescriptions for pain medication as well as hydroxyurea or iron chelation from their pediatric hematologist, and have age-appropriate preventive screenings scheduled for them. At the Rutgers Cancer Institute of New Jersey Comprehensive Sickle Cell Center, pediatric patients obtain comprehensive medical services and psychosocial support services, including academic assistance (e.g., getting an individualized education program plan, scholarship) and assistance applying for health insurance or disability. These important social services are often lost when patients transition to the adult healthcare setting, where they also face logistical challenges of coordinating care among multiple primary and specialist providers (e.g., obtaining pain medication prescriptions from a family medicine practitioner rather than from their hematologist, and scheduling multiple specialist appointments [cardiology, pulmonology, ophthalmology among others] for regular preventive screenings).

Patients with SCD who are preparing for transition report insufficient knowledge about their disease and the transition process, fear of leaving their trusted provider, lack of self-

management skills to handle the disease, and increased negative experiences in the adult emergency department (Sobota et al., 2014; Sobota, Umeh, & Mack, 2015; Treadwell et al., 2011). Providers caring for these patients also report that the lack of an established process to assess transition readiness and a lack of written materials about transition prevent “best practices” in transition care. Transition programs offer one possible solution to address these barriers to transition, however, there is a lack of standardized evidence-based programs for transition care among adolescents and young adults with SCD. Current transition programs have primarily focused on patient barriers to transition (e.g., knowledge). However, there still remains a dearth of evidence of efficacious methods or outcome measures.

This dissertation research seeks to address deficits in transition care among young adults with SCD, primarily targeting patient factors, including: self-efficacy for self-management, self-management skills, knowledge, and communication. This study utilized a formative needs assessment to guide the development and subsequent feasibility and acceptability study of a medical student mentor program for young adults with SCD who are transitioning from pediatric to adult care. The formative work aimed to replicate and build upon previous findings of barriers to transition care for young adults with SCD, as well as directly inform the content of the program. The project also includes a theory-driven intervention to investigate the feasibility of using medical student mentors to improve outcomes related to transition for adolescents and young adults with SCD (e.g., transition readiness, health-related quality of life, medication adherence). Guided by the Social Ecological Model of Adolescent and Young Adult Readiness to Transition (SMART) framework (Mulchan et al., 2016; Schwartz et al., 2013; Schwartz et al., 2011), the intervention targets patient self-management skills, knowledge, and confidence in navigating the adult health system through the specialized peer support offered by a medical student mentor familiar with the

pediatric and adult hematology clinics. The use of medical student mentors capitalizes on the specialized support that they can offer as individuals who are integrated into the medical system and as similar-aged peer role models to patients. The results of this project will determine the feasibility of using medical students as “transition mentors” to improve patient transition and enhance medical students’ attitudes towards patients.

### **Theoretical Framework**

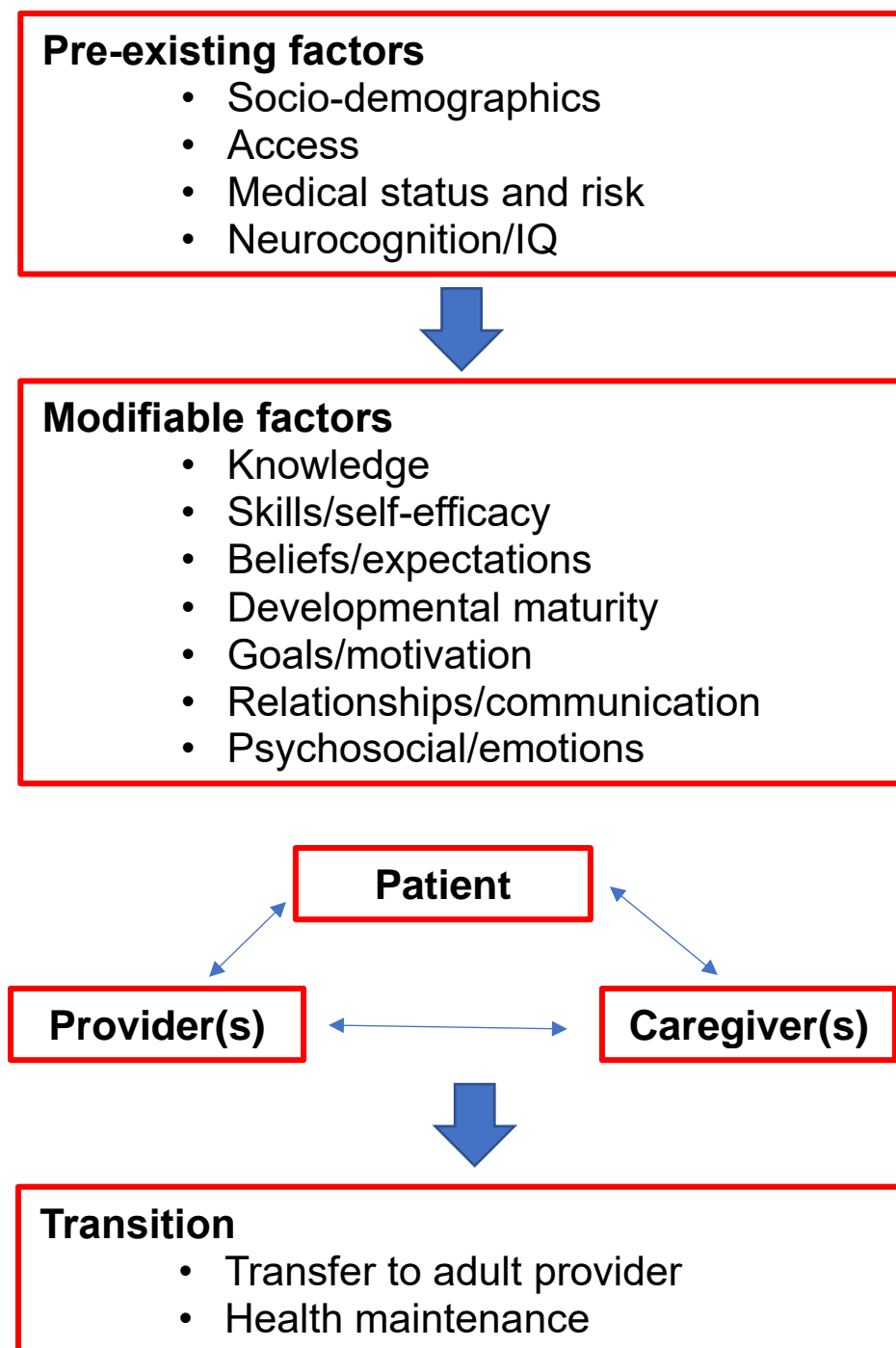
Treadwell and colleagues (Treadwell, Telfair, Gibson, Johnson, & Osunkwo, 2011) highlighted the need for conceptual frameworks and consistent measurement of outcomes to evaluate transition programming in SCD. Transition is a multi-component process that includes the medical, psychosocial, and educational/vocational needs of adolescents. It includes the adolescent, the patient’s family, the pediatric clinical team, and the adult clinical team. Transition is an individualized process that needs specific tailoring to the person undergoing the transition. The SMART framework highlights modifiable factors that contribute to a young adult’s readiness to transition to adult care (Figure 1). These variables include: knowledge of health history and future risks; self-management skills and self-efficacy for self-management; beliefs and expectations about adult care; health transition goals; relationships/communication with parents and providers; and the psychosocial functioning of patients and parents (Schwartz, Tuchman, Hobbie, & Ginsberg, 2011). The SMART model provides an appropriate framework to identify targets for intervention. It has been utilized by researchers in a number of different disease populations to evaluate transition readiness, including survivors of pediatric cancer, cystic fibrosis, and most recently, SCD. Mulchan and colleagues (2016) demonstrated that the SMART model was appropriate in SCD and could be adapted to meet the disease-specific needs of these patients.



The SMART framework guided the needs assessment conducted with the patient population as well as the feasibility mentor-led intervention.

**Figure 1**

*The Social-ecological Model of Adolescent and Young Adult Readiness to Transition*



## **Purpose of the Study**

This dissertation both identifies *and* addresses deficits in transition care among AYAs with SCD. The absence of well-defined programs for the transition from pediatric to adult care for patients with SCD results in young adult patients feeling generally unprepared for transition to the adult healthcare system and leads to reduced utilization of necessary preventive and health maintenance treatments. This project addressed this gap by developing and evaluating a novel transition mentoring program to improve the transition readiness and health outcomes of adolescents and young adults with SCD.

### ***Specific Aim 1: Identify Unmet Needs and Barriers to Transition***

Aim 1 is to identify transition-related patient unmet needs and barriers that could be alleviated by a medical student mentor intervention. This needs assessment provides insight into the patient experience to gain perspective on transition barriers and to identify targets for intervention. The specific needs of this population informed the development of the mentor program. The following research questions were addressed in Aim 1:

**Research Question 1.** What are the barriers, challenges, and deficits in transition readiness associated with the transition to adult care from the perspective of young adults with SCD?

**Research Question 2.** What modifiable transition care needs can be targeted by a medical student mentor intervention?

***Specific Aim 2 (A & B): To evaluate the feasibility and acceptability of a medical student mentor transition intervention among medical students (2A) and patients (2B).***

The results of the qualitative interviews (Aim 1), as well as the SMART framework, guided the development of the mentor training materials and the structure for the mentee educational sessions. Development included creating mentor training materials, a mentor and mentee

handbook, establishing the parameters of the program, and pre-testing all materials with relevant stakeholders.

Feasibility was determined through enrollment rates, reasons for refusal, retention rates, engagement with the intervention, satisfaction, and reasons for dropout. Survey data was used to evaluate intervention utility, impact, and adherence for all participants. The quality of the relationship between the mentee and the mentor was also assessed.

Research questions generated by **Specific Aim 2A** included:

**Research Question 1.** Will medical students enroll and participate as mentors for adolescents and young adults transitioning from pediatric to adult care?

**Research Question 2.** Will medical students complete all program requirements?

**Research Question 3.** How do medical student mentor participants rate their satisfaction with the program?

**Research Question 4.** How do medical student mentor participants rate their relationship quality with their mentees?

Research questions generated by **Specific Aim 2B** included:

**Research Question 1.** Will adolescents with SCD enroll in a transition program utilizing medical student mentors?

**Research Question 2.** To what extent will adolescents with SCD complete a transition program utilizing medical student mentors?

**Research Question 3.** How will patient participants rate their satisfaction with the program?

**Research Question 4.** How do patient (mentee) participants rate their relationship quality with their mentor?

***Exploratory Aim 3 (A&B): To examine the preliminary effects of the intervention on medical student mentor (3A) and patient (3B) outcomes.***

This aim examined the potential impact of the mentor program on medical student mentor outcomes including changes in SCD knowledge and attitudes towards chronic illness (3A). The aim also addresses the impact on psychosocial outcomes for the mentee participants including: transition readiness, health-related quality of life, medication adherence, self-efficacy, SCD knowledge, and health literacy (3B). Relationships between patient age, sex, working alliance, and number of sessions completed were assessed with all of the psychosocial outcomes.

The results generated by this feasibility and acceptability study were not statistically powered to determine a significant change in health outcomes among patients or knowledge and attitude outcomes among medical students. As such, this aim and corresponding research questions were exploratory in nature. Among medical student mentors, we hypothesized improvements in SCD knowledge and attitudes towards chronic illness. Among patients with SCD, we hypothesized improvements in transition readiness, health-related quality of life, medication adherence, self-efficacy, SCD knowledge, and health literacy.

Questions generated by **Aim 3A** included:

**Research Question 1.** Among medical student mentors, are there improvements in SCD knowledge?

**Research Question 2.** Among medical student mentors, are there improvements in attitudes towards chronic illness?

Questions generated by **Aim 3B** included:

**Research Question 1.** Among patients, are there improvements in transition readiness from baseline to intervention completion?

**Research Question 2.** Among patients, are there improvements in health-related quality of life from baseline to intervention completion?

**Research Question 3.** Among patients, are there improvements in medication adherence from baseline to intervention completion?

**Research Question 4.** Among patients, are there improvements in self-efficacy from baseline to intervention completion?

**Research Question 5.** Among patients, are there improvements in SCD knowledge from baseline to intervention completion?

**Research Question 6.** Among patients, are there improvements in health literacy from baseline to intervention completion?

**Research Question 7.** Is age associated with change in any of the psychosocial outcomes (transition readiness, health-related quality of life, medication adherence, self-efficacy, SCD knowledge, health literacy)?

**Research Question 8.** Is sex associated with change in any of the psychosocial outcomes (transition readiness, health-related quality of life, medication adherence, self-efficacy, SCD knowledge, health literacy)?

**Research Question 9.** Is working alliance between the mentor and mentee associated with change in any of the psychosocial outcomes (transition readiness, health-related quality of life, medication adherence, self-efficacy, SCD knowledge, health literacy)?

**Research Question 10.** Was completion of sessions associated with changes in any of the psychosocial outcomes (transition readiness, health-related quality of life, medication adherence, self-efficacy, SCD knowledge, health literacy)?

## **Summary of Introduction**

Advances in the treatment of SCD have resulted in up to 98% of patients living to age 18, however, the majority of deaths in this patient population occur after age 18 and after the transfer from a pediatric to an adult provider. Further, the highest rate of acute care encounters and re-hospitalizations for patients with SCD occurs among 18–30 year olds. Patients with sickle cell require comprehensive care including treatment with hydroxyurea, pain management, and frequent blood transfusions, in addition to ongoing monitoring of renal function, cardio-respiratory function, and vision as potential complications of the disease. This requires patient compliance with primary care appointments, specialty clinical visits, medications, transfusions, and regular health maintenance. As patients transition from pediatric care (which typically involves multidisciplinary clinics that coordinate various specialty visits) to adult care (which typically requires more active coordination by the patient), they are at risk for lapses in care that can result in serious complications. Thus, efforts are needed to help AYA patients more successfully transition to adult care.

Barriers to successful transition from pediatric to adult care include a lack of support, minimal transition planning, providers' lack of time to address transition issues, and disparities in care related to the racial background of the patients. The absence of well-defined programs for the transition from pediatric to adult care results in young adult patients feeling generally unprepared for transition to the adult healthcare system and leads to reduced utilization of necessary preventive treatment and health maintenance. Unfortunately, there are few effective transition programs in the literature to date; the few published reports have focused on the feasibility of specific transition program models (e.g., one-time education sessions, pre-transition meetings with adult physicians), with a noticeable gap in using peer support to improve outcomes.

This dissertation addressed these gaps by assessing relevant barriers to transition for patients with SCD at Rutgers Cancer Institute of New Jersey and then evaluating a novel transition mentoring program to improve the transition readiness and health outcomes of AYA with SCD. Guided by the SMART framework, the intervention targeted patient self-management skills, knowledge, and confidence in navigating the adult health system through the specialized peer support offered by a medical student mentor familiar with the pediatric and adult hematology clinics. The results of this dissertation provide data to a) provide insights into barriers and challenges associated with transition; b) demonstrate the feasibility, acceptability and preliminary effectiveness of a medical student mentor program for AYA with SCD; and c) inform the development of future transition programs.

### **Organization of the Dissertation**

This dissertation is comprised of 5 chapters. Chapter 1, which this section concludes, provided a brief summary of relevant background literature and a problem statement. It also stated the aims of the research and a set of research questions that guide the analyses. Chapter 2 provides a more detailed review of the literature on the relevant research that informed this dissertation. This includes reviews of the literature on SCD, transition (including a review of key clinical guidelines and consensus statements on transition care), transition specific to patients with SCD (highlighting barriers and challenges related to transition including patient, caregiver, and healthcare provider and system factors), existing transition programs for patients with SCD, mentoring adolescents with chronic disease, and using medical students as patient mentors. Chapter 3 describes the study methodology of each phase of the research as well as the planned analyses. Chapter 4 presents the results of the analyses by aim and research questions. Finally, Chapter 5 provides a discussion of the findings as it relates to the published literature. This section

also provides recommendations for further study and a general conclusion. An appendix that includes supplemental information concludes the dissertation.



## **DEFINITIONS OF KEY TERMS AND ACRONYMS**

AYA- an acronym for adolescent and young adult

Adolescent and young adult- Refers to the developmental periods of adolescence (ages 10–17 years) and young adulthood (ages 18–25 years)

AAP- American Academy of Pediatrics

AAFP- American Academy of Family Physicians

ACP- American College of Physicians

APHON- Association of Pediatric Hematology/Oncology Nurses

ASCQ-Me- Adult Sickle Cell Quality of Life Measurement

ASPHO- American Society of Pediatric Hematology Oncology

HBSS- Sickle Cell Anemia- Homozygous Sickle Cell Anemia

HBSC- Sickle C Disease

HbS  $\beta$  Thal- Sickle Cell Beta Thalassemia

HRQOL- an acronym for health-related quality of life

Health-related quality of life- a multi-dimensional concept that includes domains related to physical, mental, emotional, and social functioning

IRB- Institutional Review Board

MMAS- 8- Morisky Medication Adherence Scale – 8 Items

SCD- an acronym for sickle cell disease

SPSS- Statistical Package for the Social Sciences

TIP-RFT- Transition Intervention Program Readiness for Transition Instrument

Transition- in this dissertation transition refers to the transition from a pediatric care provider to an adult care provider

## **CHAPTER 2**

### **LITERATURE REVIEW**

#### **Introduction**

The focus of this dissertation was to identify and address deficits in transition care among young adults with SCD by implementing a medical student mentor intervention. The feasibility, acceptability, and preliminary effectiveness of such a program were explored for both patient-participants as well as the medical student mentors. Disparities in care (e.g., frequency of transfusions, emergency room utilization, iron chelation) during the transition period for AYA with SCD have been well documented (Blinder et al., 2013; Bundy et al., 2012; de Montalembert & Guitton, 2014), and despite some evidence of the feasibility and effectiveness of transition programs, no gold standard currently exists (Allemang et al., 2016; Calhoun et al., 2016; Crosby et al., 2013; Frost et al., 2016; Hankins et al., 2012; Manwani, et al., 2017; Smith et al., 2011; Williams et al., 2015). The aims for this dissertation, namely to identify the unmet needs and barriers to transition care for young adults with SCD and to assess the feasibility of a medical student mentor intervention, were informed by the research on SCD transition and the benefits of mentoring for patients with chronic illness, and are guided by the Social-ecological Model of Adolescent and Young Adult Readiness to Transition (SMART) framework (Schwartz et al., 2011).

This chapter focuses on the relevant literature that informed this research. Key topics reviewed include: (1) an overview of SCD, which provides important background on the complications and severity of this disease; (2) the literature on transition for youth with chronic health conditions, which includes a review of key clinical guidelines and consensus statements on transition care; (3) theoretical approaches to transition; (4) the literature about transition specific to patients with SCD, which highlights the severity of this medically vulnerable period as well as

barriers and challenges related to transition; (5) a review of the literature on transition programs for patients with SCD; and (6) a review of the literature on mentoring adolescents with chronic disease, including the use of medical students to act as patient mentors. A summary of the literature reviewed concludes this chapter.

## **SCD Overview**

Worldwide, an estimated 300,000 infants are born with SCD each year. SCD is the most common monogenic (controlled by one gene) disorder (others include cystic fibrosis, Tay-Sachs, and polycystic kidney disease; Piel, Steinberg, & Rees, 2017). In the United States, population estimates indicate that around 100,000 people are living with SCD, with an incidence of 15.5 per 1,000 births each year (Piel et al., 2017). The term SCD encompasses a group of inherited red blood cell disorders. People with SCD have abnormal hemoglobin, a protein that red blood cells use to carry oxygen. The SCD hemoglobin (HbS) has a mutation that causes red blood cells to become rigid and shaped like sickles or crescent moons. These irregular red blood cells can get stuck in small blood vessels, blocking blood flow and oxygen transfer to other parts of the body.

The severity of the illness depends on the number and types of mutated alleles. Individuals with two mutated hemoglobin alleles are considered to have sickle cell anemia, the more severe form of SCD. Characteristics of the disease include anemia (shortage of red blood cells), severe episodes of pain, painful swelling of hands and feet, frequent infections, delayed growth, vision problems, risk of stroke, and acute chest syndrome. The chronic complications of SCD include neurocognitive effects, chronic kidney disease, avascular necrosis in the bones and joints, gallstones, and iron overload from transfusions. Currently, there is no definitive cure for SCD. However, there are three primary SCD therapies: hydroxycarbamide (hydroxyurea), blood transfusion, and hematopoietic stem cell transplantation (Kato et al., 2018; Yawn & John-Sowah,

2015). Hydroxyurea increases the presence of fetal hemoglobin (thus limiting the amount of HbS or the “sickle” hemoglobin present in the blood) and significantly reduces the risk of vaso-occlusive crises and hospitalizations (Kato et al., 2018). Blood transfusions limit the amount of circulating “sickle red blood cells” and have been shown to reduce inflammatory damage in the blood vessels (Kato et al., 2018). Hematopoietic stem cell transplantation is the only potentially curative treatment available for patients. Hematopoietic stem cell transplantation requires that patients have a human leukocyte antigen-matched family donor. Because of the significant risks associated with transplant, this has not been considered a universal option for all patients (Kato et al., 2018). Scientists have also been studying gene therapy as another possible curative treatment for SCD (Hoban, Orkin, & Bauer, 2016).

Care for a patient with SCD is lifelong and requires routine preventive care. Children are at increased risk for pneumococcal disease, requiring prophylactic penicillin in addition to the pneumococcal vaccine. All adolescents with SCD patients require screening for vascular complications each year using transcranial Doppler ultrasonography. Other preventive treatments and screenings include annual screening for ischemic retinopathy, treatment with B vitamins, complete blood count and iron level monitoring, and routine cardiopulmonary exams (Humphreys, 2012). Certain comorbidities of SCD increase as patients age, including renal disease, hypertension, cardiac disease, pulmonary hypertension, avascular necrosis of joints, chronic pain, and transfusional iron overload. Adult patients with SCD require extensive routine care including blood pressure screening, pulmonary evaluation, and renal chemistry analysis up to 6 times per year (Treadwell et al., 2019).

### **Transition from Pediatric to Adult Care for Youth with Chronic Illness**

Advances in medical technology have increased the number of adolescents with special healthcare needs who are living into adulthood. Transition is the “purposeful, coordinated and comprehensive” transfer from pediatric to adult care, with the goal of providing continuity of care and preparing young adults for greater independence (Blum et al., 1993; Castillo & Kitsos, 2017). Transition has become a medical priority in many disease populations, including SCD, juvenile diabetes, juvenile irritable bowel disease, juvenile arthritis, cystic fibrosis and congenital heart disease (Davis, Brown, Taylor, Epstein, & McPheeters, 2014; Sharma et al., 2014). There is a growing body of evidence that AYAs have decreased access to healthcare during the transitional period and that this is associated with poorer health outcomes (Chu et al., 2015; Davis et al., 2014; Sharma et al., 2014). The cause of this decrease has been attributed to loss or change of insurance, a suboptimal transfer from a pediatric to an adult physician, patient self-management practices, and other provider- and family-related barriers (Chu et al., 2015; Davis et al., 2014; Sharma et al., 2014).

In the last two decades, leading healthcare organizations have published numerous consensus statements and guidelines to improve transition care. In 2002, a joint consensus statement by the American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP), and the American College of Physicians (ACP) highlighted the need for a comprehensive and efficient transition to adult care for AYAs with chronic conditions (American Academy of Pediatrics, 2002). A position paper published the following year by the Society of Adolescent Medicine (Rosen et al., 2003) made several recommendations for transition care, including collaboration and partnership between physicians, patients and families, ongoing education for patients and their families, adequate preparation for adult healthcare providers, and the development of best practices for the management of adults with diseases of childhood. In

2011, the AAP clinical report established the goal of transition “to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate healthcare services that continue uninterrupted as the individual moves from adolescence to adulthood” (Cooley & Sagerman, 2011). The report provided best practice guidelines to facilitate a developmentally appropriate and safe transition for patients. It also includes specific recommendations for physician training and continuing education to better implement best practices in transition care. In 2015, the Association of Pediatric Hematology/Oncology Nurses (APHON) and the American Society of Pediatric Hematology/Oncology (ASPHO) issued a consensus statement that recommended written transition plans for all patients, annual transition preparation, and coordination of transfer of care by both the pediatric and adult healthcare providers (Bryant et al., 2015). Most recently, in 2018, the AAP published an updated clinical report that emphasized the infrastructure needs and gaps in transition care. This report emphasized the importance of physician education, care coordination support, and quality improvement processes (White & Cooley, 2018).

As a result of these reports, Got Transition: The National Center for Health Care Transition Improvement was founded to guide the development of transition programs for clinical practices. Got Transition/The National Center for Health Care Transition Improvement enumerated six core elements of healthcare transition in clinical practice that serve as best-practice guidelines to improve transition practices and programs for AYA with chronic conditions (White et al., 2015). The six core elements define the key components of a model transition program that include: (1) establishment of transition policy; (2) transition tracking and monitoring; (3) assessment of transition readiness; (4) transition planning; (5) transfer of care; and (6) transfer completion (White et al., 2015). Got Transition has published numerous resources and self-assessment tools including

transition readiness assessments, transfer checklists, post-transfer feedback surveys, among others that can be accessed on their website. These core elements of healthcare transition primarily focus on provider and system factors of healthcare transition and are applicable for interventions targeting the primary and specialty care settings.

### ***Summary of Transition Literature***

Transition care has increasingly become a priority in many AYA chronic disease populations. Transition is a multi-component process that includes the medical, psychosocial, and educational/vocational needs of adolescents. It includes the adolescent, the patient's family, the pediatric clinical team, and the adult clinical team. Transition is an individualized process that needs tailoring to the person undergoing the transition. To address these complexities, relevant medical organizations have created consensus statements and clinical practice guidelines illustrating best practices in transition care. The transition literature provides a plethora of practice recommendations including the six core elements of a successful transition that can aid medical professionals and researchers in developing transition programming. Healthcare organizations have endorsed the need for transition programs for AYA with chronic illness, particularly highlighting the need for coordinated care between pediatric and adult providers and ongoing education for patients and providers alike.

### **Theoretical Approach to Transition, the Social-ecological Model of Adolescent and Young Adult Readiness to Transition**

Multiple theoretical frameworks have been developed to improve the medical transition from pediatric to adult care (Griffin et al., 2013; Hislop et al., 2016; Schwartz et al., 2014). These frameworks recognize that transition is a multi-component process that includes the medical, psychosocial, and educational/vocational needs of adolescents (Blum et al., 1993; Treadwell et al.,

2011; White & Cooley, 2018). Transition involves a number of stakeholders including the AYA, the patient's family, the pediatric clinical team, and the adult clinical team. Previous care frameworks were limited in scope and did not address the multi-component and multi-stakeholder nature of the transition process (Betz, 2009; Schwartz et al., 2011). Thus, a novel theoretical framework that applies a social-ecological framework to transition readiness, including multiple stakeholders as well as multiple factors, was developed by Schwartz and colleagues (2011).

The Social-ecological Model of Adolescent and Young Adult Readiness to Transition (SMART) framework includes four pre-existing objective factors (less amenable to change), six modifiable subjective factors, and one factor specific to the patient (developmental maturity). The pre-existing objective factors include: sociodemographics/culture, access/insurance, medical status/risk, and neurocognitive functioning/IQ. The modifiable subjective factors include knowledge of health history and future risks, self-management skills and self-efficacy for self-management, beliefs and expectations about adult care, health transition goals, relationships/communication with parents and providers, and psychosocial functioning/emotions.

The SMART framework expands the focus of transitional care from disease knowledge and skills to a broader scope of targets for intervention. Schwartz and colleagues propose that addressing the modifiable domains will improve transition readiness and success in adult healthcare settings (Schwartz et al., 2011). SMART was originally validated with a sample of 100 AYA cancer survivors (Schwartz et al., 2011; Schwartz et al., 2013). Mulchan and colleagues (2016) demonstrated that the SMART framework applied to youth with SCD and could be adapted to meet the disease-specific needs of these patients. A qualitative study of young adults with SCD who had already transitioned to adult care confirmed that the SMART framework was compatible with patients' desired transition programming topics and could be used to help develop transition



programming for adolescents and young adults with SCD (Porter, Wesley, Zhao, Rupff & Hankins, 2017).

### **Transition for Young Adults with SCD**

The transition period has been characterized as a “medically vulnerable” time period for AYAs with SCD, as it is associated with a sharp increase in disease-related complications (Blinder et al., 2013; Bundy et al., 2012; de Montalembert & Guitton, 2014). For individuals with SCD, the transition period has shown significant increases in healthcare resource utilization, including the number of patient encounters per year, hospitalizations, and emergency room use (Brousseau, Owens, Mosso, Panepinto, & Steiner, 2010). There is a sharp increase in mortality rates from 0.6/100,000 between ages 15 and 19 years to 1.4/100,000 between ages 20 to 24 years, which coincides with the transition period when a patient must transfer from pediatric to adult care (Hamideh & Alvarez, 2013).

In a large cohort study of 940 adolescents who were diagnosed with SCD at birth and followed through age 18 (8857 patient-years of follow-up), researchers found that the only deaths in the cohort occurred in the two years following the transition from pediatric to adult care (Quinn et al., 2010). In a review of Medicaid data from 3,208 child and AYA patients with SCD, healthcare costs and complications rose significantly for patients ages 16 years and older, while use of hydroxyurea (an oral medication shown to reduce or prevent SCD complications) decreased after age 18 (Blinder et al., 2013). Results from a review of data from the Pediatric Health Information System over a nine-year period showed that healthcare costs for young adults (18–22 years) were significantly higher than that of adolescents (13–17 years) who were hospitalized in pediatric settings (Dickerson et al., 2011). In this study, complications of SCD including nephropathy and pulmonary hypertension were also found to be higher in older patients ( $p = 0.001$ ; Dickerson et

al., 2011). Most recently, a longitudinal analysis of medical record data for 339 AYA with SCD ages 12 to 27 years found that disease severity increased with age for a quarter of the patients. Fourteen patients died during the study period, with ten of the fourteen dying after the age of transition (Kayle et al., 2019).

Many AYA with SCD experience gaps in care during the transition period resulting in significant morbidity and mortality. Efforts are needed to address the barriers and challenges experienced by AYA with SCD to help them successfully transition to adult care.

### ***Challenges and barriers to transition in SCD***

There are many potential barriers to successful transition from pediatric to adult care, including lack of transitional support for patients, minimal transition planning, and providers' lack of time to address transition issues (de Montalembert & Guitton, 2014; Haywood et al., 2013; Kayle, Tanabe, Shah, Baker-Ward, & Docherty, 2016; Sobota et al., 2015; Speller-Brown et al., 2015). Such factors contribute to adolescents' low transition readiness and lack of self-efficacy in managing self-care. Factors can be organized into three main categories: patient, family, and system factors.

#### **Patient Factors.**

***Lack of Knowledge and Preparation.*** The literature consistently shows that AYAs feel unprepared to transition due to lack of perceived knowledge and lack of skills (Jordan et al., 2013; McPherson, et al., 2009; Porter et al., 2017a; Sobota et al., 2014; Sobota et al., 2015; Speller-Brown et al., 2015; Williams et al., 2014). Studies using validated transition readiness assessments indicate an inadequate level of preparation for transition to adult care (McPherson et al., 2009). Physicians acknowledge the level of complexity of the skills necessary for successful self-management as a significant barrier to transition (Stollon et al., 2015). AYAs with SCD are

required to navigate the healthcare system, communicate effectively with physicians (in the emergency room (ER) or in outpatient settings), educate others (including healthcare providers) about SCD, schedule and coordinate healthcare appointments, refill prescriptions, and adhere to medications. AYAs report that transition-related skills such as communicating with healthcare providers, tracking medical records, scheduling appointments, and having independent living skills are important for a successful transition (Porter et al., 2017).

Reported lack of knowledge comprises several different areas. For example, Sobota et al. (2014) conducted a pilot study to assess knowledge and readiness for transition among AYA with SCD ages 18 to 22 years. The researchers assessed five knowledge skill sets (medical, educational, health benefits, social support, and independent living) and found pervasive deficits among the sample. For example, nearly three-quarters of the sample (73%) did not know their baseline hemoglobin level, 52% did not know about SCD community resources available, 36% did not understand the different types of health insurance, and 15% did not know how to schedule an appointment with a provider (Sobota et al., 2014).

When surveyed about knowledge of transition, only 21% of patients ( $n = 8$ ) at one academic center reported having received transition education, and 91% were interested in receiving transition education (Williams et al., 2014). Patients report wanting more information about SCD-specific health knowledge, about what to expect after transfer, about adult facilities and the differences between the adult and pediatric providers, and about best practices for self-management (Porter et al., 2017a; Sobota et al., 2015, Williams et al., 2014).

Additionally, many caregivers share concerns about their child's skills and knowledge to manage his or her disease and navigate the healthcare system (Hauser & Dorn, 1999; Porter et al., 2014, Porter et al., 2017b; Telfair et al., 1994). Using qualitative interviews, Porter et al. (2014),

examined the perspectives of 12 families (12 caregivers, 11 siblings, and 11 patients) on the transition from pediatric to adult care. In this study, the authors found that caregivers were concerned about their child's increased self-management responsibility that would be required once their child transferred to adult care, including tasks like medication adherence. Caregivers also felt that they were unprepared and lacked knowledge about the transition process. They expressed concerns about whether the adult providers would be knowledgeable about SCD. Siblings echoed these concerns about the increased self-management demands placed on their affected sibling, also particularly noting concerns about medication adherence. Telfair et al. (2004), found similar results in an earlier cross-sectional study of adolescents ( $n = 36$ ), young adults ( $n = 60$ ), and caregivers ( $n = 25$ ). In this study, caregivers reported being most concerned about their AYA's ability to manage their own care. They also expressed concerns about an adult provider's lack of knowledge about SCD, adult provider's lack of belief in AYA report of pain severity, and leaving a familiar pediatric practice. Similar findings were again found by Porter and colleagues (2017b) in a qualitative study of adolescents ( $n = 14$ ) and their caregivers ( $n = 20$ ). Caregivers reported concerns about their child's ability to manage their own care and about the availability of appropriate and knowledgeable adult providers.

The perceived lack of adequate knowledge and skills for assuming self-management responsibilities reflects an important need of AYAs with SCD. Education, while not sufficient, is clearly a necessary component of transition programming.

***Emotional Response to the Transition.*** Unsurprisingly, AYAs report a reluctance to leave trusted pediatric providers due to a mistrust of the healthcare system and fears about adult providers and adult healthcare settings (Bemrich-Stolz et al., 2016; de Montelambert et al., 2014; Porter et al., 2017b). In a qualitative study of adults who had recently transitioned from pediatric

to adult care, Bemrich-Stolz and colleagues (2016) found that a large number of the participants felt “surprised” and “abandoned” when they were approached about transition. In another qualitative study of 14 adolescents, participants expressed concerns and fear about finding a competent adult provider and being able to communicate effectively with a new provider (Porter et al., 2017b). Many patients reported that they were transferred within weeks of being initially told about transition, contributing to the high levels of anxiety and uncertainty regarding the transition process. Patients also fear being misunderstood by their new provider or being perceived as “drug-seeking” during a pain crisis (de Montelambert et al., 2014, Telfair et al., 2004).

In studies of caregiver perspectives of the transition from pediatric to adult care, researchers have identified that caregivers share similar fears about their child being treated by a new provider who may not be familiar or comfortable managing a patient with SCD (Hauser & Dorn, 1999, Telfair et al., 1994, Porter et al., 2014).

***Sociodemographic Factors.*** Sociodemographic factors such as poverty, patient and parent education level, challenges at home, and competing work demands have been found to contribute to transition outcomes (Stollon et al., 2015; Mulchan et al., 2016). Normative developmental milestones such as attending college, starting romantic relationships, or obtaining employment also present competing demands to transition (Mulchan et al., 2016). In one study of physicians who care for AYA with SCD, physicians reported that patients experience challenges that impact their ability to access adequate healthcare and force them to prioritize other immediate needs (finding stable income, finding a stable living situation) over taking care of their disease. These sociodemographic variables may also contribute to poor psychological functioning, which is also related to poor transition outcomes (Stollon et al., 2015).

African American youth with SCD may be disproportionately affected by health disparities in transition support (Stollon et al., 2015). SCD has been described as a “microcosm of how issues of race, ethnicity, and identity come into conflict with issues of healthcare.” Recent estimates indicate that SCD occurs in 1 out of every 365 Black/African American births ("Data and Statistics," 2017). It is well established that African Americans and other racial/ethnic minorities in the United States experience disparities in healthcare ("African American Health," 2017). Compared with other genetic disorders diagnosed in US newborns, there are disparities in access to disease-specific treatment, medication assistance, and federal research funding directed towards individuals with SCD (Smith, Oyeku, Homer, & Zuckerman, 2006; Stollon et al., 2015). African American patients with SCD experience lower quality of care than African Americans with other diseases and conditions (Haywood, Tanabe, Naik, Beach, & Lanzkron, 2013).

In a recent study, it was found that patients with SCD experience wait times longer than general patient samples, explained both by their African American race and their disease status (Sobota, Shah, & Mack, 2017). For example, patients with SCD experienced up to 25% longer wait times to see a physician after arrival in the emergency department despite elevated pain levels and high priority triage ratings (Haywood et al., 2013). This finding was consistent with other research demonstrating longer wait times for black versus white patients (Todd, et al., 2000; Wilper et al., 2008). Despite no evidence of higher rates of opioid addiction in this population, patients with SCD presenting with pain are often viewed as drug seekers, with providers either limiting access or increasing time to treatment (Ballas, Kanter, Agodoa, Howard, Wade, Nozon, & Dampier, 2018). Race-based and disease-based discrimination has been found to contribute to a higher burden of pain experienced by patients, as well as higher rates of morbidity and mortality outcomes (Ballas, Kanter, Agodoa, Howard, Noxon, & Dampier, 2018).

### **Parent, Family, and Caregiver Factors.**

***Inability to “Let Go.”*** Many caregivers have reported an inability to “let go” or to let their child assume more responsibility in their care management. Telfair et al. (2004) found that nearly half of caregivers (44%) reported concerns about their child taking over their healthcare responsibilities independent of the caregiver. Speller Brown et al. (2015) conducted a descriptive study of AYA and parent dyads to examine perceptions of transition readiness and to assess the relationship between transition readiness (decisions made and actions taken for building the capacity of the AYAs, parents, and the providers to prepare for, begin, continue, and finish the process of transition) with readiness to transfer from pediatric to adult care. Parents reported being “often” responsible for their child’s care, also reporting that the AYAs were not at all responsible for scheduling specialty or primary care appointments or refilling prescriptions. The researchers found that parental involvement was negatively correlated with perceived readiness to transfer to adult care. The authors called for interventions directed at decreasing parental involvement and increasing AYA’s responsibility for self-management (Speller Brown et al., 2015).

In an interview study conducted by Kayle and colleagues (2016), researchers sought to assess the challenges in shifting management from parents to adolescents with SCD. Parents reported that their biggest challenges were as follows: (1) giving over the complex management, (2) communicating management with their adolescent, (3) balancing protection against risk with fostering independence, (4) changing a comfortable rhythm, and (5) releasing the adolescent into a “SCD naïve” world. The authors acknowledged that shifting management responsibility is an adaptive process that requires the young adult to feel ready and competent to take on the new challenges. Transition programs need to provide AYAs not only with the skills for self-

management, but with the capacity to communicate effectively with their parents about taking over new roles.

***Benefits of Caregiver Support.*** Parent support has been attributed as a positive facilitator of a successful transition. Parental involvement in healthcare and confidence in their child's preparation for the transition showed a high correlation to AYA transition readiness (Speller Brown et al., 2015). Parents who emphasize self-management and autonomy as a priority were found to contribute to successful transition outcomes for their child (Stollon et al., 2015). Many caregivers recognize that they must modify their own behavior to help prepare their child for transition (Porter et al., 2017b) and many create plans with steps towards increasing their AYA's responsibility for tasks like communicating with doctors or taking their medication (Porter et al., 2017b). Caregivers provide an important support system for AYAs throughout their development and through the transition process. They contribute to the success of AYAs increasing their own self-management skills and thus their influence on the transition process must be considered.

#### **Healthcare Provider and System Factors.**

***Lack of Training and Availability of Adult Providers.*** Consistent evidence has shown that many adult healthcare providers feel ill-equipped to manage the care of patients with SCD. A large number (66%) were found to be unaware of existing SCD guidelines (Lunyera et al., 2017). A survey of pediatric providers found that only 60% of those surveyed transfer their patients to an adult hematologist specializing in SCD, and ten percent of the centers surveyed transfer patients to an internist versus a hematologist (Sobota et al., 2011). Similarly, other reports found providers were uncomfortable managing SCD and related complications (Mainous et al., 2015; Telfair et al., 2004). Despite a need for training and education, there are very few opportunities to receive it. The



American Academy of Pediatrics (AAP) has identified training and clinical learning experiences in care transition as key gaps to be addressed (American Academy of Pediatrics, 2011).

***Lack of Care Coordination.*** There is no standard practice for transition care in the United States, and most comprehensive sickle cell centers do not have established transition programs (Andemariam et al., 2014; Bemrich-Stolz et al., 2015; Williams et al., 2015). Particularly in rural areas, many AYA with SCD lack access to appropriate medical and psychosocial support services (de Montelambert et al., 2011; Treadwell et al., 2011). A survey of pediatric providers found that most providers identified a need for “transition programs and materials,” and a “formal/written/checklist/documentation of steps and readiness to transition,” indicating the lack of support for transition services. Only about half (54%) of the transition programs surveyed evaluated their transition program at least annually, with even fewer (39%) assessing patient satisfaction, following patient outcomes (33%), or healthcare utilization measures (17%;obota et al., 2011). Despite calls for coordination and collaborative efforts between pediatric and adult healthcare providers, few centers caring for patients with SCD have programs to foster self-management or assess patient readiness prior to transition (Sobota et al., 2011; Telfair et al., 2004). While many pediatric centers communicate with adult providers prior to transfer, very few assess if patients are able to independently schedule a clinic visit or contact providers. Providers acknowledge a need for transition programs that both assess and improve transition readiness and self-management skills (Sobota et al., 2011).

### ***Summary of SCD Transition***

Due to improvements in therapies and treatment, SCD has become a lifelong illness instead of a disease of childhood. As a result, the transition from pediatric to adult care has become an increasingly important clinical priority. The highest rate of acute care encounters and re-

hospitalizations among individuals with SCD occurs among 18–30 year olds. Additionally, the majority of deaths in this patient population occur after 18 years of age and after transfer to an adult provider is initiated. Unfortunately, many barriers to transition still exist for the rising adult SCD population.

Young adults who have SCD feel generally unprepared for the transition to the adult healthcare system. This includes a lack of knowledge about SCD and obtaining care from an adult provider, fear of unfamiliar clinicians and procedures, physician mistrust, and low self-efficacy to manage their care. Other factors that contribute to adolescents' low transition readiness and lack of self-efficacy in managing self-care include lack of transitional support, minimal transition planning, and providers' lack of time or training to address transition issues. All of these barriers are potentially modifiable targets that can ultimately improve transition quality indicators as well as patient health-related outcomes and quality of life

### **Transition and Self-Management Programs**

Transition programs have been hypothesized to improve disease control, decrease hospital or emergency admissions, improve better quality of life, and increase patient satisfaction with care (de Montalembert et al., 2014; Treadwell, et al., 2011). Historically, transition preparation has varied in delivery, methods, content, and personnel involvement from center to center. Many hospitals and sickle cell centers have transition programming, but few have rigorously measured and assessed the outcomes of such programs. While some studies have investigated transition education and programming preferences of adolescents, there is limited evidence of successful transition programs or program components for patients with SCD. Patients report wanting more information and education about the transition process, particularly using technology-based health education platforms (Allemang et al., 2016; Calhoun et al., 2016; Crosby et al., 2013; Frost et al.,

2016; Hankins et al., 2012; Manwani, et al., 2017; Smith et al., 2011; Williams et al., 2015). Thus far, transition programs have focused on increasing preparation, through facility tours (Andemariam et al., 2014; Hankins et al., 2012), education-based interventions (Calhoun et al., 2016; Calhoun et al., 2019; Crosby et al., 2017; Rogers-Melnick et al., 2017; Smith et al., 2011), technology-based interventions (Crosby et al., 2016; Kidwell et al., 2019), and patient navigators (Allemang et al., 2016; Manwani et al., 2017).

Andemariam et al. (2014) evaluated a transition program that included attending at least four transition clinics where the patient was educated about SCD and had an opportunity to communicate with pediatric and adult providers. A patient navigator also attended all clinic appointments and provided tours of the adult SCD center. Through a retrospective review of 47 patients, they found that 68% of the participants who attended the combined transition clinic successfully transferred to adult care (defined as attending one adult care appointment within twelve months of their last pediatric appointment). Factors attributed to loss to follow-up (unsuccessful transition) included: (1) hemoglobinopathy status associated with milder disease severity; (2) age greater than 21 at the time of transition; and (3) distance from the hospital to home greater than 20 to 30 miles. Transition success was not influenced by sex ( $p = 0.38$ ), race ( $p = 0.67$ ), or type of insurance ( $p = 0.33$ ).

Another comprehensive intervention included a tour of adult SCD programs, a lunch discussion with pediatric staff, and assistance scheduling the first appointment with an adult provider. It demonstrated initial success, as nearly three-quarters of participants scheduled their adult visit within three months of leaving the pediatric SCD program (Hankins et al., 2012). The results of this study were limited as adolescents who participated first self-selected into the transition program (41% of eligible patients). Of those who did not opt into the one-day transition

program, only 33% completed the transfer to adult care ( $p = 0.002$ ). All of the study participants who completed the one-day transition program rated the program as helpful or very helpful.

In response to patient informational needs about the transition process (Frost et al., 2016; Williams et al., 2015), education-based interventions have also been developed (Calhoun et al., 2016; Calhoun et al., 2019; Crosby et al., 2017a; Rogers-Melnick et al., 2017; Smith et al., 2011). In one intervention, participants were given access to structured online modules and completed a 2.5 hour group session (Crosby et al., 2017a) designed to improve chronic disease self-management in young adults. This study examined the impact of the modules on patient activation, skills, knowledge, and confidence to manage their own health. AYAs ages 16–24 years ( $n = 22$ ) who completed the program showed a significant improvement in self-efficacy, but not disease-specific self-efficacy nor self-reported self-management behaviors. The AYA did find the program acceptable and beneficial for managing their disease; however, only 64% completed the entire program. The authors noted that the in-person format of the intervention may have limited uptake and that in the future a web-based program could decrease attrition.

Another transition program tested the use of educational handouts (Calhoun et al., 2016; Calhoun et al., 2019). This feasibility trial included 122 patients, half of whom transitioned their clinical care during the intervention period and were not included in the follow-up survey. The educational fact sheets were created using the Adolescent Autonomy Checklist (AAC) modified for SCD and includes domains such as nutrition, emergency management, personal skills, healthcare skills, and money management. One fact sheet was designed to correspond with each of the 100 items on the AAC-SCD. Participants took the AAC-SCD at their clinic appointment and then randomly received five fact sheets based on items designated as “needs practice.” Significant improvements were seen post-intervention for domains including laundry,

housekeeping, healthcare, and sexual development ( $p < 0.05$ ). This low-cost intervention was found to be acceptable to the study population and low-burden to clinical staff.

One study investigated the impacts of a music therapy program in conjunction with educational sessions on patients' self-efficacy, trust, and SCD knowledge (Rogers-Melnick et al., 2017). Participants ( $n = 28$ ) who attended *Bridge Clinic* (a multidisciplinary clinic designed to help patients who had recently transitioned from pediatric care) were invited to participate in 1-hour BEATS music therapy sessions following their regular clinic visit. The music therapy included group drumming sessions with other AYA with SCD. Following group drumming, educational sessions with an adult SCD team member occurred. Sessions included information about medication management, SCD knowledge, and pain management. Participants demonstrated a significant improvement in SCD knowledge ( $p < 0.001$ ) compared to baseline, an increase in acute care clinic, but not emergency department, utilization ( $p = 0.01$ ), and a non-significant improvement in clinic attendance ( $p = 0.19$ ). Participants' subjective evaluations revealed a positive response to BEATS. There were no significant changes in self-efficacy, trust, hospital admissions, or blood transfusion adherence.

In a descriptive clinical investigation, Smith et al. (2011), investigated the initial impact of a transition program on participant's SCD knowledge, concerns, and emotions about transition. In this program, participants listened to lectures given by trained undergraduates in addition to receiving supplementary written educational materials (Smith et al., 2011). The program was intended to be implemented within the context of regular comprehensive sickle cell visits. The researchers recruited thirty-three AYA ages 15–18 years old. Overall SCD knowledge increased from baseline by 8% ( $p = 0.07$ ). Smith et al. (2011) hypothesized that knowledge would demonstrate a greater increase if participants began the program at an earlier age and completed

more educational sessions. The authors also noted that emotions and concerns related to the transition varied both at baseline and follow-up. They attributed this to the fact that AYA who had previously thought about the transition may feel more relieved after getting more information, but that those who had not previously thought about the transition may exhibit an initial increase in negative emotions after beginning a transition program.

In response to patient preferences for technology-based health education platforms, Crosby et al. (2017b), developed and evaluated a mobile app to address barriers to successful self-management in AYAs with SCD. AYAs were involved in the co-creation and evaluation of the self-management app. Only five AYAs tested the app for usability, but found it to be beneficial for tracking their SCD symptoms, and liked that it allowed them to set their own self-management goals and communicate with others about self-management strategies. AYAs had reported that self-management was a low priority because they did not feel confident that it would lead to health benefits. They felt that they would be more motivated by receiving support from peers outside of their family and their healthcare system. Further testing with a larger range of participants is necessary to establish the feasibility and impact of this app on health outcomes. In another study, Kidwell et al. (2019), sought to assess the feasibility of a web-based portal for AYA with SCD and to evaluate its impact on medical decision-making, patient-provider communication, and patient-provider relationships. The results of the study indicated high acceptability of the portal. Patients used the portal to check their appointments, learn more about SCD, use the messaging system and check laboratory values. The portal was perceived as a tool that could facilitate easier self-management and may be an effective tool for improving the delivery of care for patients with SCD.

Transition programs have utilized patient navigators to improve disease knowledge and transition readiness (Manwani et al., 2017), as well as loss to follow-up and medication adherence

(Allemang et al., 2016). In an abstract by Manwani et al. (2017), the authors described the results of a protocolized intervention for young adults aged 17–20 years who were preparing to transition to an adult care provider. A patient navigator was acceptable to young adults with SCD at their urban medical center. Participation in the program was associated with improved transition readiness and disease knowledge, though the abstract did not include effect size or statistical significance. Allemang et al. (2016) conducted a retrospective cohort study to compare AYA with hemoglobinopathies (not limited to SCD) who turned 18 one year prior to ( $n = 51$ ) and one year after ( $n = 61$ ) the initiation of a transition program. The transition program with the transition navigator reduced loss to follow-up from 29% to 7% ( $p = 0.034$ ). Medication adherence also improved to greater than four days per week ( $p = 0.047$ ).

Additional transition programs are being developed. For example Melita et al. (2019) developed a problem-solving education intervention tailored to meet the needs of AYA with SCD. The authors conducted focus groups with adolescents with SCD and their caregivers to identify barriers to transition as well as questions about the problem-solving intervention. Seventeen adolescents and 15 caregivers participated in the focus groups. The authors found that “fitting in” was a central theme discussed by the participants. AYAs reported that fitting in often competes with properly taking care of their disease and leads to worry about how their peers will view them. The AYAs also reported that they felt that it was important that an intervention is delivered by someone who was familiar or connected with SCD, but that age of the interventionist was less important. The young adults also indicated that convenience would be a factor such that having to go to the clinic to participate in the intervention could be a barrier. They concluded that the young adults demonstrated motivation for improving their self-management and that problem-solving may help improve self-management and transition readiness.

### *Summary of Existing Programs*

Although several transition programs have been published, few utilized a formative and theory-driven approach to intervention development, and there was significant inconsistency in the measurement of outcomes related to transition (e.g., transfer and knowledge) as well as format and targets of the programs. Major limitations of existing programs include small and convenience samples (range: 3–61 participants), lack of comparison groups or within-group comparisons, and evidence of selection bias.

Transition programs have focused on increasing preparation and knowledge through a variety of formats. These include transition clinics and facility tours (Andemariam et al., 2014; Hankins et al., 2012), education-based interventions (Calhoun et al., 2016; Calhoun et al., 2019; Crosby et al., 2016; Crosby et al., 2017; Rogers-Melnick et al., 2017; Smith et al., 2011), and patient navigators (Allemang et al., 2016; Manwani et al., 2017). None so far have harnessed peer social support, a developmentally advantageous approach, to improve transition readiness.

The inconsistency in the measurement of disease-specific and non-disease-specific outcomes presents an additional challenge to evaluating these and other transition programs (Coyne, Hallowell, & Thompson, 2017). There is no established consensus on appropriate benchmarks for a successful transition in SCD, though researchers are working to identify the most important quality indicators (Sobota et al., 2016).

Despite these limitations, there is evidence that transition programs are a viable strategy to improve transition care and health outcomes. Many features of existing programs have been found acceptable to AYAs with SCD. Program components such as facility tours, tailored education, and peer support were found to be favorable to AYAS. Interventions that did not require patient attendance at the clinic or hospital also seemed more feasible than interventions or programs that



required extra clinic attendance. The body of research provides rich information to inform future intervention development and provides insight into strategies for recruitment, retention, and content development for other transition programs.

### **Mentoring Young Adults with Chronic Illness**

Mentoring and peer-led interventions for adolescents with chronic health conditions is a growing area of interest and research. Mentoring harnesses an imposed social network and the benefits of social support. Mentoring allows for “the incorporation of skill-building activities; reinforcement of self-regulation activities; engagement in individual and group activities; and social support to meet personal health goals” (Petosa et al., 2014). Studies of youth paired with mentors have shown significant improvements in psychological, behavioral, and social outcomes as compared to non-mentored youth (DeWit et al., 2016). Peer mentors and patient navigators have been shown to benefit patient health outcomes by offering practical assistance (logistics, medication) and interpersonal support (Knox et al., 2015; Zelikovsky & Petrongolo, 2013). The social support offered through mentoring meets a developmental need of AYAs (Bell et al., 2008; Domhardt et al., 2015), contributes to increased quality of life (Merianos et al., 2016), and offers a novel mechanism for targeting individual components of transition readiness and self-management.

Mentors have successfully promoted positive changes for a number of health behaviors among adolescents such as reduced drug use, increased physical activity, and improved birth control use (Petosa, 2014). Similarly, a review of mentoring relationships among AYAs with chronic health conditions showed that mentoring relationships improved transition planning, transition awareness, social connectedness, self-management, goal attainment, and quality of life, as well as decreased school absenteeism (Merianos et al., 2016). Youth with chronic illnesses have

benefited from relationships with peer mentors, or other adolescents currently living with the same disease (Zelikovsky & Petrongolo, 2013; Merianos et al., 2016), as well as community members (such as through a Big Brothers Big Sisters Program; Lipman et al., 2018).

Two randomized controlled trials have been conducted to examine the efficacy of mentoring programs for youth with juvenile idiopathic arthritis and chronic pain. In the first study, iPeer2Peer, trained peer mentors (aged 16–25 years) were paired with adolescent participants ( $n = 16$ , aged 12–18 years) and were expected to complete ten video calls over an eight-week period. Half of the pairings completed the total number of expected calls over the eight-week period (Stinson et al., 2016). Participants were satisfied with the program and reported they would recommend it to their peers. Participants in the intervention group also showed an increased perceived ability to manage their disease as compared to control participants ( $p < 0.04$ ; Stinson et al., 2016). The second study, by the same research group, demonstrated the feasibility and acceptability of the same mentoring program for adolescents with chronic pain (Ahola Kohut et al., 2016). Twenty-eight adolescents ( $n = 12$  in the intervention group) participated in the trial. Compared with controls, adolescents who completed the mentoring program showed increased self-management and coping skills (Ahola Kohut et al., 2016). Qualitative research has been done with AYA patients who have hemophilia (Breakey et al., 2018) as well as patients who have irritable bowel disease (Mackner, Ruff, & Vannatta, 2014) that shows that these patient groups also demonstrate an interest in participating in one-on-one mentoring relationships.

### ***Medical Student Mentors***

Medical students have been utilized as mentors for both healthy AYAs as well as AYA patients with different chronic conditions to invoke positive health behavior change (Bernhardt et al., 2000; Conatser & Babcock, 1993; Schaechter & Canning, 1994; Tess et al., 1997; Towle et al.,

2006). In the intervention described by Bernhardt et al. (2000), medical students were paired with healthy adolescents to act as mentors and health educators. The medical students engaged in email communication with adolescents to discuss tobacco prevention strategies. Medical students felt the intervention helped them to communicate effectively, particularly with pediatric patients. Adolescent participants appreciated the opportunity to ask difficult and personal questions to someone outside of their friends and family, and additionally to someone connected to the medical system. In another intervention by Towle et al. (2006), medical students delivered workshops to high school students to teach them the importance of good doctor-patient relationships and how to communicate effectively with their physicians. More than half of student participants who participated in the workshops noticed a difference in their communication with their providers compared to previous encounters. The teachers reported that the medical students were effective role models and mentors for the students. The medical students also reported that the experience provided them with skills to talk to adolescents (their future patients).

Three programs used the Big Brothers/Big Sisters model of mentoring to match medical students with patient mentees. One program matched patients with medical student “pals” who visit with one another weekly for various activities (Schaecter et al., 1994). Medical students were required to attend bi-monthly educational seminars on child development, chronic illness, and family dynamics. Medical students felt they were able to benefit the patient’s illness experience while also learning about the social issues associated with chronic illness. Patient perspectives were not offered in this publication. Tess and colleagues (1997) sought to assess the impact of the Big Brothers/Big Sisters mentor program on the psychosocial and emotional needs of adolescents infected with human immunodeficiency virus (HIV). First-year medical students attended the pediatric outpatient HIV clinic to meet and interact with the adolescent patients. They were then

paired with an adolescent and their family and interacted with their mentee at least once a week for a 2-year period. All students felt that this experience helped them develop an understanding of patients living with chronic illnesses that they were unable to get from their didactic education. Finally, Conaster et al. (1993) examined the impact of a tailored Big Brothers/Big Sisters mentoring program on both medical students and adolescents with cancer and other chronic illnesses. Parents reported that the program was useful for their children, but also reported that the student appeared to have learned from the experience. Older patients echoed this sentiment, reporting that they believed that they had influenced the attitudes of these future doctors towards patients by telling the students what they liked and disliked about the ways their doctors treated them.

The mentoring relationship provides an opportunity for medical student education and growth. The Institute of Medicine has recommended increased training at the undergraduate medical education level to familiarize students with the challenges faced by youth with lifelong health conditions (Lawrence et al., 2009). The AAP joint consensus statement recommended educating providers and medical students about pediatric-onset chronic illnesses and transitioning patients from adolescent to adult care (Bryant et al., 2015; Cooley & Sagerman, 2011). Physicians report inadequate training in dealing with chronic illness (Montenegro et al., 2014) and pediatric and internal medicine/pediatric residents report a lack of specific training in treating adolescents with chronic illnesses during the transition from pediatric care to adult care (Patel & O'Hare, 2010). Some medical schools have utilized medical students as peer mentors and educators for AYA patients with different chronic conditions (Towle et al., 2006). Results of these studies indicate that medical students believe these experiences teach them how to communicate more effectively

(Towle et al., 2006), deepen their understanding of barriers to health (George et al., 2015), and improve quality of care delivery and medical education (Vijn et al., 2017).

### ***Summary of Mentoring and Medical Student Mentors***

Mentoring provides developmentally appropriate social support for AYA with chronic health conditions (Bell et al., 2008; Domhardt et al., 2015). Mentors can provide many types of support including emotional, appraisal and informational support that can be beneficial for AYA preparing for healthcare transitions. Mentoring has been associated with positive health outcomes and behavior change and has demonstrated success in other chronic illness populations (Ahola Kohut et al., 2016; Stinson et al., 2016).

Medical students have a unique combination of being integrated into the healthcare system and being similarly aged to the patient, allowing them to provide specialized support. The integration of a peer relationship within the healthcare system offers the opportunity to make complex processes like transition less overwhelming by providing support and a point of contact within the medical system for the patient. Through communication with patients (mentees) and specific training and communication with the clinical team, mentors may help patients improve transition readiness, increase patient knowledge, increase rates of attendance at adult visits, and improve medication adherence. These changes may result in improved quality of life and health outcomes for these patients. The literature is limited by the lack of results of patient-reported outcomes of medical student mentoring interventions. More research is warranted to get feedback on the acceptability of this type of program as well as the effectiveness of medical student mentoring on health outcomes.

### **Chapter Summary**

Improvements in treating SCD complications in recent years have resulted in nearly 95%

of SCD patients reaching 18 years of age (Quinn et al., 2010). Due to the increased aging population of SCD patients, the transition from pediatric to adult care has become an important element of patient care for this population. The transition period (18–30 years of age) has been characterized as a “medically vulnerable” time for adolescents and young adults with SCD, as it is associated with a sharp increase in disease-related complications (Blinder et al., 2013; de Montalembert & Guitton, 2014). It is also associated with greater healthcare resource utilization, including an increased number of patient encounters per year, hospitalizations, and emergency room use (Brousseau et al., 2010).

Given the high risk of medical complications, it is critical that young adults with SCD continue to get regular care as they move from a pediatric to an adult provider. However, there are many barriers to successful transition from pediatric to adult care, including lack of transitional support for patients, minimal transition planning, and providers’ lack of time to address transition issues (de Montalembert & Guitton, 2014; Haywood et al., 2013; Sobota et al., 2015; Speller-Brown et al., 2015). Inadequate transition care and low transition readiness contribute to poor health outcomes (Hankins et al., 2012; Lanzkron, Carroll, & Haywood, 2013; Sobota, Shah, & Mack, 2017). There is a lack of standardized evidence-based programs for transition care for young adults with SCD. Thus far, transition programs have focused on increasing preparation, through facility tours (Andemariam et al., 2014; Hankins et al., 2012), education-based interventions (Calhoun et al., 2016; Calhoun et al., 2019; Crosby et al., 2016; Crosby et al., 2017; Rogers-Melnick et al., 2017; Smith et al., 2011), and patient navigators (Allemang et al., 2016; Manwani et al., 2017). However, such programs have not utilized a theory-driven approach to intervention development, and have not utilized a social support approach like mentoring to address transition preparation.

There has been a demonstrated need for conceptual frameworks and consistent measurement of outcomes to evaluate transition programming in SCD (Treadwell et al., 2011). Transition is a multi-component process that includes the medical, psychosocial, and educational/vocational needs of adolescents. The Social-Ecological Model of Adolescent and Young Adult Readiness to Transition (SMART) framework highlights pre-existing and modifiable factors that contribute to young adults' readiness to transition to adult healthcare (Schwartz et al., 2011). Pre-existing factors include a patient's sociodemographic characteristics, medical status, and health risks. Modifiable factors include knowledge of health history and future risks, self-management skills, self-efficacy for self-management, beliefs and expectations about adult care, health transition goals, relationships and communication with parents and providers, and the psychosocial functioning of patients and parents. Mentors can directly address these barriers with patients, offering strategies for rapport building and tips for communicating effectively with new providers, teaching patients about their disease and offering advice for how to navigate the complex adult healthcare system. Most significantly, mentors can provide social and emotional support for patients during the time of preparation for transfer.

Studies of healthy youth paired with mentors have shown significant improvements in psychological, behavioral, and social outcomes as compared to non-mentored youth (DeWit et al., 2016). Social support meets a developmental need of adolescents and young adults (Bell et al., 2008; Domhardt et al., 2015), contributes to increased quality of life (Merianos et al., 2016), and offers a novel mechanism for targeting transition readiness. Medical students have been utilized as mentors for AYAs with different chronic conditions to promote positive health behavior change and provide support (Conatser & Babcock, 1993; Schaechter & Canning, 1994; Tess et al., 1997). Medical students have a unique combination of being integrated into the healthcare system and

similarly aged to the patient, allowing them to provide specialized support. The integration of a peer relationship within the healthcare system offers patients a supportive contact to potentially make complex processes like transition less overwhelming. To date, medical students have not been utilized as patient mentors to help with the transition process.

The proposed research seeks to address deficits in transition care among young adults with SCD. The results of this project will provide evidence of the feasibility of using medical students as “transition mentors” to improve patient transition.



## CHAPTER 3 METHODOLOGY

### Study Overview

There are only a small number of published interventions for young adults with SCD who are preparing to transition from pediatric to adult care. Among these, few have used theory-driven or user-guided approaches to intervention development. This dissertation aims to fill that gap by developing a theory-based (SMART framework) and user-focused intervention to help young adults prepare to transition to an adult hematology practice. The research was conducted in two phases: (1) a qualitative study of AYA perspectives on the barriers and challenges related to transition as well as direct feedback about a mentoring program; and (2) a feasibility and acceptability study of a medical student mentoring transition intervention. The study was primarily designed to examine feasibility and usability outcomes. A secondary (exploratory) aim evaluated changes in psychosocial outcomes for patients and mentors. All research was conducted following IRB approval (See Appendix A and Appendix B for the IRB protocols).

### Review of the Specific Aims and Research Questions

#### *Specific Aim 1*

Specific Aim 1 was to identify unmet needs and barriers to transition for young adults with SCD. We aimed to gather feedback and preferences from young adults about what they would want from a medical student mentor program to help them with their transition from pediatric to adult care to inform intervention development. There were two research questions:

**Research Question 1.** What are the barriers, challenges, and deficits in transition readiness associated with the transition to adult care from the perspective of young adults with SCD?

**Research Question 2.** What modifiable transition care needs can be targeted by an intervention?

Informed by the results of Specific Aim 1, as well as the SMART framework for transition, a medical student mentor intervention for young adults with SCD preparing to transition to adult care was developed. Development included establishing the parameters of the program, creating mentor and mentee handbooks, designing and in-person training for mentors, and pre-testing all materials with relevant stakeholders.

### ***Specific Aim 2 A and B***

The goal of **Specific Aim 2 (A and B)** was to assess the feasibility and acceptability of the transition mentor program. **Specific Aim 2A** addressed feasibility and acceptability among medical students. **Specific Aim 2B** addressed feasibility and acceptability among patient participants.

Research questions generated by **Specific Aim 2A** include:

**Research Question 1.** Will medical students enroll and participate as mentors for adolescents and young adults transitioning from pediatric to adult care?

**Research Question 2.** Will medical students **complete** all program requirements?

**Research Question 3.** How do medical student mentor participants rate their satisfaction with the program?

**Research Question 4.** How do medical student mentor participants rate their working with their mentees?

Research questions generated by **Specific Aim 2B** include:

**Research Question 1.** Will young adults with SCD **enroll** in a transition program utilizing medical student mentors?

**Research Question 2.** How much of the program will young adults with SCD complete?

**Research Question 3.** How will patient participants rate their satisfaction with the program?

**Research Question 4.** How do patient participants rate their relationship quality with their mentor?

***Specific Aim 3 A and B***

Finally, an exploratory aim, **Specific Aim 3 (A and B)** sought to investigate the impact of the medical student mentor program on both the mentor (**Aim 3A**) and the mentee (**Aim 3B**) participants. Changes in attitudes towards chronic illness and SCD knowledge were assessed for mentor participants. We evaluated changes in psychosocial outcomes, including transition readiness, sickle cell self-efficacy, sickle cell health-related quality of life, medication adherence, SCD knowledge, and health literacy for mentee participants. We examined if age, sex, working alliance, and the number of sessions completed were associated with changes in the psychosocial outcomes. The research questions generated for **Aim 3A** included:

**Research Question 1.** Among medical student mentors, are there improvements in SCD knowledge?

**Research Question 2.** Among medical student mentors, are there improvements in attitudes towards chronic illness?

Research questions generated for **Aim 3B** included:

**Research Question 1.** Among patients, are there improvements in transition readiness from baseline to intervention completion?

**Research Question 2.** Among patients, are there improvements in health-related quality of life from baseline to intervention completion?

**Research Question 3.** Among patients, are there improvements in medication adherence from baseline to intervention completion?

**Research Question 4.** Among patients, are there improvements in self-efficacy from baseline to intervention completion?

**Research Question 5.** Among patients, are there improvements in SCD knowledge from baseline to intervention completion?

**Research Question 6.** Among patients, are there improvements in health literacy from baseline to intervention completion?

**Research Question 7.** Is age associated with a change in any of the psychosocial outcomes (transition readiness, health-related quality of life, medication adherence, self-efficacy, SCD knowledge, and health literacy)?

**Research Question 8.** Is sex associated with a change in any of the psychosocial outcomes (transition readiness, health-related quality of life, medication adherence, self-efficacy, SCD knowledge, and health literacy)?

**Research Question 9.** Is working alliance associated with a change in any of the psychosocial outcomes (transition readiness, health-related quality of life, medication adherence, self-efficacy, SCD knowledge, and health literacy)?

**Research Question 10.** Was completion of sessions associated with changes in any of the psychosocial outcomes (transition readiness, health-related quality of life, medication adherence, self-efficacy, SCD knowledge, health literacy)?

## **Phase 1. Formative Phase, Qualitative Interviews**

### ***Patient Eligibility and Recruitment***

A criterion, purposeful, convenience sample of participants (Palinkas, et al., 2015; Wu et

al., 2016) was recruited from the pediatric outpatient hematology clinic at Rutgers Cancer Institute of New Jersey Comprehensive Sickle Cell Center, and one the adult outpatient hematology clinic in the Rutgers Robert Wood Johnson University Hospital. Patients who had not yet transitioned to an adult hematology provider were eligible if they had a diagnosis of SCD and were aged 18–25 years. At the Rutgers Cancer Institute of New Jersey Comprehensive Sickle Cell Center, the age of transition is typically between 20 and 23 years. Patients who had transitioned to adult hematology care were eligible if they had a diagnosis of SCD, were aged 18–30 years, and were within 10 years of their first adult provider appointment. Patients were excluded from participating in this study if they had physician- or self-reported cognitive delay or impairment that would affect participation in the interview. A total of 20 eligible participants were recruited (10 pre-transition and 10 post-transition). All patients who were invited to participate in the study agreed to participate and completed an interview.

Recruitment procedures took place within the clinic facilities. The pediatric and adult medical providers, nurses, and patient navigator at the study sites were presented with an overview of the study and inclusion and exclusion criteria. Patients meeting criteria were identified by the clinical team and approached for participation following their clinical visit. If a patient was interested in participating, her/his eligibility was verified and informed consent was obtained. The informed consent process included a full verbal and written disclosure to the study participant (see Appendix C for the informed consent document). After the documents were read in their entirety and all questions were answered, signatures were obtained and a copy of the informed consent document was given to the study participant. The signed original informed consent documents were stored in a locked filing cabinet at Rutgers Cancer Institute of New Jersey.

### ***Participant Interviews***

Interviews lasted approximately 45–60 minutes and were conducted using a semi-structured interview guide informed by the SMART framework. Separate interview guides were created for those who were preparing to transition and those who had completed their transition (see Appendix D for interview guides). Questions for young adults who had already transitioned asked about their experiences with the transition, concerns about transitioning, how much responsibility they took for their care, perceived differences between adult and pediatric care, and competing demands during the transition period. These participants were also asked if/how a medical student mentor could have been helpful in the transition process. Questions for young adults who had not yet made the transition were similar and asked about their concerns for the transition process, expectations for transition, perceived differences between adult and pediatric care, and their emotional response in anticipation of transition. These participants were also asked if/how a medical student mentor might be helpful during the transition process as well as other preferences for a mentor program. Demographic data (i.e., age, sex, race/ethnicity, whether or not the individual had transitioned to adult care, age at transition) was collected to describe the study sample.

### ***Qualitative Data Management***

Interviews were transcribed verbatim from the audio recording. Once completed, the transcripts were read, reviewed, and compared with the audio recordings to ensure the accuracy of the transcripts.

### ***Qualitative Analysis***

Descriptive statistics were used to describe the sample. The data were evaluated to identify patterns based on age or sex (e.g., if some concerns were more common among younger vs. older AYAs or females vs. males). The data from the participants who had already transitioned from

pediatric to adult care and the data from participants who had not yet transitioned were analyzed separately to examine patterns by transition status.

The SMART model was used as the organizing framework for the directed content analysis of the data (Hsieh & Shannon, 2005). Initial coding categories for the data were established using the key concepts of the SMART framework. Prior to data analysis, operational definitions for each of the codes were established. These original codes were used by two independent coders to analyze the first three interviews. Data generated from the interviews that could not be categorized by a predetermined code was discussed to determine if it represented a new code or category. Using the modified code book, an additional five interviews were coded by two independent coders. Again, data generated that was not categorized by a pre-established code was discussed to determine if it represented a new code or category. Coding was thus an iterative process, utilizing continual revision to account for new codes or to remove unneeded codes. After the first ten interviews were coded and discussed, a revised codebook was used to analyze the remaining interviews. Any discrepancies in coding between the two coders were discussed until agreement was reached. All transcripts were checked against the final codebook.

Interviews were analyzed on a continuous basis in order to assess when saturation was achieved. Pooling data across participants, 20 interviews was determined to be adequate to achieve data saturation (i.e., no new themes emerged).

Thematic analysis of the individual interviews was used to determine barriers to transition for these AYAs, and to learn what topics would be most relevant for the mentor intervention. Preferences for the intervention were also assessed, including the frequency of communication and preferences for in-person versus video-chat for first meetings. Descriptive statistics were used to describe responses to these questions (e.g., “how many hours would you prefer to communicate with your mentor per week?”).

## ***Program Development***

The results of Phase 1, as well as the SMART framework, were used to refine relevant topics for the mentor training and education sessions.

Training materials (including a training manual and topics to be covered during mentor training, see Appendix E) were developed to guide the mentor training. A corresponding manual for mentee participants was created (Appendix F). All materials were reviewed by clinicians including Dr. Drachtman (pediatric hematologist/oncologist), Dr. Kaveney (adult hematologist), Beth Savage (Ph.D. and nurse practitioner), and Claudia Junchaya-Jenssen (patient navigator) for feedback. The materials were also reviewed by a Patient Advisory Panel, a group of 4 patients who had already transitioned, for feedback on the relevance of the content and to identify other topics for inclusion.

## **Phase 2. Feasibility Study**

### ***SCD Patient Eligibility and Recruitment***

Patients with SCD who are preparing for transition (as determined by the clinical team) were identified by the clinical team at their regularly scheduled visit. Eligibility included  $\geq 18$  years old, no documented or self-reported cognitive deficits, and English-speaking.

Recruitment procedures took place within the clinic facilities. The pediatric and adult medical providers, nurses, and patient navigator at the study sites were presented with an overview of the study and inclusion and exclusion criteria. Patients meeting criteria were identified by the clinical team and approached for participation following their clinical visit. If a patient was interested in participating, their eligibility was verified and informed consent was obtained. The informed consent process included a full verbal and written disclosure to the study participant (see Appendix G for the informed consent document). After the documents were read in their entirety



and all questions were answered, signatures were obtained and a copy of the informed consent document was given to the study participant. The signed original informed consent documents were stored in a locked filing cabinet at Rutgers Cancer Institute of New Jersey.

For patients who did not have or did not show for an appointment during the recruitment period, recruitment was attempted via mail and phone. Patients were sent a letter that included information about the study, a copy of the informed consent document, and a pre-addressed stamped return envelope. Patients were then called up to three times to initiate contact, answer questions about the study, and to obtain preliminary verbal consent. Patients were required to sign and return an informed consent document.

### ***Procedures for SCD patients***

After providing informed consent, participants completed the baseline survey using Qualtrics, a secure online survey service. The baseline survey included demographic questions as well as the validated measures of transition readiness, self-efficacy, health-related quality of life, medication adherence, and health literacy (Appendix H).

Participation in the peer mentor program was designed to last 6 months. Details of the mentor program are reported in the next section.

All participants were asked to complete a 20–30-minute post-intervention survey after completion of the program (approximately 6 months post-baseline). The follow-up survey included questions about acceptability and satisfaction with the program, as well as the same measures of transition readiness, self-efficacy, health-related quality of life, medication adherence, and health literacy as the baseline survey. Table 1 includes a summary of the measures used and the time points at which each measure was completed.

## **Measures**

### **Sickle Cell Transition Intervention Program- Readiness for Transition (TIP-RFT).**

The TIP-RFT (Treadwell et al., 2015) includes 22 items assessing transition readiness in 4 domains: knowledge and skills in medical self-care (6 items), social support skills (4 items), independent living skills (8 items), and educational/vocational skills (4 items). The instrument assesses healthcare skills (e.g., *I can answer my doctor's questions during my clinic visits*), behaviors in relation to social support systems (e.g., *I have friends that I can talk to about sickle cell disease*), independent living skills (e.g. *I know how to manage money and pay a bill*), and behaviors related to education and future vocation (e.g., *I have a vision for my future*). The response format was a 5-point scale from *strongly agree* to *strongly disagree*. Total scores are obtained by summing responses to the items, with higher scores indicating greater transition readiness. In a study of 113 AYAs with SCD, the TIP-RFT demonstrated high internal consistency, with a Cronbach's alpha of 0.84 for the total scale, and alphas ranging from 0.60 to 0.81 for the subscales (knowledge and skills in medical self-care ( $\alpha = 0.70$ ), social support skills ( $\alpha = 0.60$ ), independent living skills ( $\alpha = 0.81$ ), and educational/vocational skills ( $\alpha = 0.60$ )). Internal consistency in this study was lower than in prior studies, with Cronbach's alpha = 0.30 for the educational/vocational skills set,  $\alpha = 0.53$  for the social support skills set,  $\alpha = 0.63$  for the healthcare knowledge skills set, and  $\alpha = 0.66$  for the independent living skills set. The overall scale demonstrated moderate internal consistency ( $\alpha = 0.60$ ).

**Adult Sickle Cell Quality of Life Measurement System (ASCQ-Me).** The ASCQ-Me measure (Keller et al., 2014) includes 25 items in 5 domains: emotional impact, pain impact, sleep impact, social functioning impact, and stiffness impact. This measure yields a standardized T-score for each domain, with a mean of 50 and a standard deviation of 10. Higher scores indicate better

health. T-scores more than one standard deviation below the mean indicated clinically significant impairment in that domain. Internal consistency for the five domains was high for each subscale in a national sample of adults with SCD (emotional impact ( $\alpha = 0.90$ ), pain impact ( $\alpha = 0.94$ ), sleep impact ( $\alpha = 0.93$ ), social functioning impact ( $\alpha = 0.92$ ), and stiffness impact ( $\alpha = 0.92$ )). In this study, Cronbach's alpha coefficients for all ASCQ-Me domains were adequate, with from  $\alpha = 0.73$  for emotional impact,  $\alpha = 0.79$  for sleep impact,  $\alpha = 0.89$  for social functioning impact and stiffness impact, and  $\alpha = 0.93$  for pain impact.

**The Sickle Cell Self-Efficacy Scale (SCSES).** The SCSES (Edwards et al., 2000) includes 9 items related to patients' perceptions of their ability to function on a day-to-day basis and to manage their SCD (e.g., *As compared to other people with SCD, how sure are you that you can manage your life from day-to-day?*). Response choices ranged from *not at all sure* to *very sure*. Total scores are obtained by summing responses, with high scores indicating higher self-efficacy. In a previous study of 113 AYA with SCD, the SCSES demonstrated high internal consistency ( $\alpha = 0.89$ ). In this study, the SCSES demonstrated acceptable internal consistency ( $\alpha = 0.75$ ).

**The Newest Vital Sign.** The Newest Vital (Caldwell et al., 2018) sign evaluates both literacy and numeracy as well as the ability to locate and apply information. It is a 6-item measure based on the ability to read and apply information from a nutrition label. Scores are calculated by receiving one point for each correct answer with the total score used for correlational analysis. Scores are also categorized into three levels, including: high likelihood of limited literacy (score = 0–1), possibility of limited literacy (score = 2–3), and adequate literacy (score = 4–6). Internal consistency for this measure has ranged from  $\alpha = 0.63$  to  $\alpha = 0.76$  (Caldwell et al., 2018).

**Morisky Medication Adherence Scale (MMAS-8).** The MMAS-8 (Lam & Fresco, 2015; Tan, 2014) includes 8 yes/no questions about adherence, such as forgetting, carelessness, reasons

for stopping or starting, and situations related to adherence. A total sum score of all items is computed and can range from 0 to 8. MMAS scores are categorized into three levels of adherence: high adherence (score = 8), medium adherence (score = 6 to <8), and low adherence (score < 6). This measure has a reported association with biomarkers to adherence and has demonstrated a high internal consistency of  $\alpha = 0.83$ . In this study, the MMAS-8 demonstrated acceptable internal consistency ( $\alpha = 0.72$ ).

**Transition Knowledge Questionnaire.** Transition knowledge was assessed using 24 items from prior research (Newland et al., 2008). The items assess knowledge of SCD in seven areas: (1) pathophysiology, (2) genetics, (3) physical manifestations, (4) treatment, (5) self-care, (6) psychosocial and developmental issues, and (7) healthcare delivery system. A total score is calculated as the sum of the number of correct answers, ranging from 0 to 24. In previous research (Newland, 2008) this measure demonstrated acceptable internal consistency ( $\alpha = 0.71$ – $0.79$ ) In this study, the Transition Knowledge Questionnaire demonstrated high internal consistency ( $\alpha = 0.81$ ).

**Attitudes Towards Chronic Illness.** This 21-item measure (Arenson et al., 2008; Veloski et al., 2011) assessed student's perceptions towards control managing chronic illness (e.g., *Think of yourself as a physician caring for a patient, how comfortable or uncomfortable do you think you feel with dealing with inability to cure patients?*), student's perception of patient factors (e.g., *Please indicate the degree to which you agree or disagree with the following statements: it's important for patients to understand the specific mechanisms of their illness*), and personal interest in patients (e.g., *How comfortable or uncomfortable do you think you feel with long-term professional relationships with patients?*). Items were all reviewed individually for change.

**Satisfaction Survey.** Satisfaction surveys were adapted from Ritterband et al. (2008), to determine the utility (usefulness and enjoyment), impact (perceived effectiveness in improving targeted skills) and adherence (engagement) to the intervention. Satisfaction was assessed using 14-items using a scale of 1 (*not at all*) to 5 (*very much*), and participants responded to open-ended items about their favorite part of the program, how they felt they changed as a result of the program, how they felt about having a medical student as a mentor (mentees), and what they would change about the program. Surveys were adapted for both mentors and mentees. These items were meant to be evaluated separately, so no internal consistency was reported.

**Working Alliance Inventory- Short Form Revised (WAI-SR).** The mentor-mentee relationship was evaluated by a modified version of the Working Alliance Inventory- Short Form Revised (WAI-SR; Hatcher & Gillaspy, 2005), which is a validated measure of the quality and strength of a therapeutic relationship. The inventory is comprised of ten items in three domains: agreement about tasks (3 items, e.g., *We agree about the steps to be taken to improve his/her transition*), agreement about goals (3 items, e.g., *We are working towards mutually agreed upon goals*), and development of a bond (4 items, e.g., *I appreciate my mentee as a person*). Question responses follow a five-point Likert scale from *always* to *seldom*. In this patient sample, the task and bond subscales demonstrated acceptable internal consistency (task,  $\alpha = 0.71$ ; bond,  $\alpha = 0.81$ ), while the goal subscale demonstrated only moderate internal consistency ( $\alpha = 0.40$ ). In this medical student sample, all subscales demonstrated high internal consistency (goal,  $\alpha = 0.83$ ; task,  $\alpha = 0.90$ ; and bond,  $\alpha = 0.90$ ).

**Table 1***Measures Used*

Measure	Completed By	Timepoint Completed	
		Baseline	Post-Intervention
Sickle Cell Transition Intervention Program-Readiness for Transition (TIP-RFT) (Treadwell et al., 2015)	Mentee	x	x
Adult Sickle Cell Quality of Life Measurement System (ASCQ-Me) Short Form (Keller et al., 2014)	Mentee	x	x
The Sickle Cell Self-Efficacy Scale (Edwards, et al., 2000)	Mentee	x	x
The Newest Vital Sign (Caldwell et al., 2018)	Mentee	x	x
Morisky Medication Adherence Scale (MMAS-8) (Lam & Fresco, 2015; Tan, 2014)	Mentee	x	x
Transition Knowledge Questionnaire (Newland, 2008)	Mentee	x	x*
	Mentor		
Mentee Satisfaction Survey (Ritterband et al., 2008; Thorndike et al., 2008)	Mentee		x
Attitudes Towards Chronic Illness Survey (Arenson et al., 2008; Veloski, 2011)	Mentor	x	x
Mentor Satisfaction Survey (Ritterband et al., 2008; Thorndike et al., 2008)	Mentor		x
Working Alliance Inventory-Short Form (Hatcher & Gillaspy, 2005)	Mentee		x
	Mentor		

\*Mentors repeated the Transition Knowledge Questionnaire following the mentor training rather than post-intervention.

***Mentor Program***

The mentor program consisted of *monthly* medical student mentor video calls using Doxy.me (Doxy LLC, 2017), an encrypted HIPAA-compliant video conference system, supplemented by *weekly* text messages (using WhatsApp, an encrypted text messaging service). Each month, the mentors addressed specific content related to transition, based on the SMART

constructs and the results of the qualitative study. Table 2 shows the content for the monthly mentor calls.

Each patient participant was matched with a medical student mentor. The medical student mentor made initial contact by sending a secure text message to their mentee to set up a time to video chat. The objective of the first video call was to establish rapport and to talk about what the mentee feels are his or her biggest challenges with regards to transition. The mentor and the mentee then established a day and time for the next call. Each month the mentor and mentee discussed one of the planned content topics (Table 2). For the tour of the hospital and meeting staff, the mentor and mentee arranged a mutually convenient time (usually before or after the mentee's routine clinic visit). In addition to the monthly video calls, mentors sent text messages to their mentee at least once a week to check in with the mentee and to offer brief encouragement, support, or to answer any questions. This dose was selected based on feedback from medical students and patients, as well as prior peer mentoring interventions (Ahola Kohut et al., 2016; Stinson et al., 2016).

**Table 2***Content for the Monthly Mentor/Mentee Phone Calls*

	<u>Content and activities</u>	<u>Patient need addressed</u>
Monthly call 1	Introductions: identify and discuss patient concerns about transition; assess disease knowledge (SCD background, genetics of SCD, how/why crises occur, disease complications, treatment options)	SCD knowledge, emotions about transition
Monthly call 2	Goal setting for transition: self-management goals (hydration, medication adherence, increasing responsibility for medical care)	Goal setting and motivation, self-management knowledge
Monthly call 3	Health-related quality of life: information on substance use effects (alcohol, tobacco, illicit drugs); sexual health and pregnancy; medical marijuana; diet and nutrition; exercise	Healthy behaviors
Monthly call 4	Pain and health management: pain management includes strategies for preventing crises, the importance of medication adherence and strategies for improving adherence, and managing stress. Health management includes knowing how to fill a prescription, knowing how to make doctor's appointments, understanding bloodwork/labs, knowing required specialist care and time intervals to receive care.	Pain management, healthcare navigation self-efficacy, and skills
Monthly call 5	Patient self-advocacy: strategies for communication in the emergency room; knowing what information patients should be able to provide in the ER (fluid requirements, pain medication/ dosages, personal 'normal' blood values)	Navigating provider relationships and communication, managing expectations for the emergency room, self-advocacy
Monthly call 6	Tour the hospital with the mentee (emergency department, transfusion center, adult hematology clinic); introductions with relevant hospital staff; identify the main differences between pediatric and adult care.	Managing expectations for adult care

***Mentor Recruitment, Training, and Supervision***

**Recruitment.** Medical student recruitment took place at the medical school. An email was sent to the entire student body (using the medical student Listserv) describing the program and the



application process. The mentor program was offered as a non-credit elective. Rutgers Robert Wood Johnson Medical School defines non-credit electives as specific training in a topic spanning one to two years of participation. Successful completion of non-credit electives are included on students' transcripts.

Following guidelines from the National Mentoring Research Center (Garringer, Kupersmidt, Rhodes, Stelter, & Tai, 2015) potential mentors completed an application including two letters of recommendation. The candidates were interviewed to evaluate their interpersonal skills, level of commitment to the program, and counseling or related experience. To be eligible to participate as a mentor, candidates needed to be a current medical student in good standing and be between the ages of 21 and 29 years old. Recruitment occurred from November 2018 through May 2019 to meet the needs of mentee recruitment. After completing informed consent (Appendix I), mentors completed a baseline survey (including basic demographic questions, measuring attitudes towards chronic illness, and assessing expectations for the experience, see Appendix J).

**Mentor Training.** Mentors attended a four-hour training workshop, which included education on the content for the monthly telephone calls, expectations for the program, ethics, and a role-playing session to practice communicating with patients. Each mentor received a handbook, which was adapted from Dr. Devine's established Peer Mentor Training Handbook and the Big Brothers Big Sisters Volunteer Training Guide (Big Brothers Big Sisters, 2018). Clinical providers (pediatric hematologist, pediatric nurse practitioner, and adult hematologist) provided clinical instruction and answered questions. Mentor training achieved all of the essential benchmarks described by the Elements of Effective Practice for Mentoring (Garringer et al., 2015). An initial training was held with the first group of mentors, and additional training sessions took place as needed to match recruitment.

The content for the mentor training was informed by the SMART theoretical framework (Schwartz et al., 2011) and the formative qualitative interviews. The clinical team educated the medical students about SCD, common barriers to transition, treatment for SCD, and guidelines for specialist care in SCD. Second, students were taught appropriate benchmarks for a successful transition. Third, the mentors were taught about pain management strategies for SCD including hydroxyurea treatment, blood transfusions, iron chelation therapy, and infection prophylaxis. Strategies for encouraging medication adherence were also be provided. Fourth, medical students learned about the relevant social issues for adolescents and young adults with SCD (e.g., the impact of disease on vocations, fertility, and family planning). Fifth, mentors were educated about obtaining health insurance (including healthcare.gov and Medicaid). Finally, medical students received a tour of the hospital and were introduced to the relevant medical staff.

Ethical issues, including confidentiality and setting appropriate boundaries with mentees, were discussed. Mentors were told that they were not allowed to provide medical advice to their mentees and that they should not set up in-person meetings with their mentees outside of the clinical setting. A series of role-playing exercises were used to reinforce the training material and to serve as practice for their first patient interaction.

**Supervision.** Mentors attended a monthly group supervision meeting, which has been identified as an evidence-based dose for mentor support (Olshan, 2018). The meetings allowed mentors to discuss with one another and the clinical experts any challenges that arose related to their role as a mentor. Mentors were required to report to the study team the number of times and the method of communication they used with their mentee over the previous month using a google spreadsheet. If a mentor was unable to attend the group session, then an individual supervision was

scheduled. Additionally, all mentors were encouraged to contact the research staff and clinical team throughout the month with specific questions or concerns.

**Treatment Integrity.** Mentors were required to audio record their video calls with their mentees (with patient consent) for use for fidelity checks, supervision, and content analysis. Each monthly education session had a corresponding checklist of items enumerating topics that should have been covered during the course of the call as well as non-specific items (e.g., empathy; see Appendix K). For the first mentee-pairing for each mentor, the first of the six education calls was reviewed, as well as 20% of the remaining calls for the pairing (~1 additional call). Mentor feedback was provided on (at least) a monthly basis.

Eleven patients who completed at least one call agreed to have their video-chats audio-recorded (one patient who completed follow-up did not complete any calls, four participants declined being recorded). From these, the first call for every participant was assessed for fidelity. In addition, one other call from each participant was chosen at random to be assessed. Twenty-two audio-recordings were reviewed in all. On average, sessions achieved a score of 9.4 out of 10, with 100% achieving above 8 out of 10 points of treatment integrity.

### **Advisory Board**

We sought to include an advisory board of young adult participants who had already transitioned to review content and support the medical students. The advisory board attended the first monthly mentor meeting and participated in a panel discussion. The mentors had the opportunity to ask questions about living with SCD, transition, and issues that the advisory board anticipated might come up with their mentees. The advisory board members were encouraged to offer feedback and support to the mentors as needed throughout the intervention.

The advisory board was recruited based on physician recommendations. Advisory board members had to have already transitioned to an adult hematologist and have physician recommendation that these patients were managing their care successfully.

### **Statistical Analysis Overview**

Quantitative data analysis consisted of descriptive and inferential statistical analyses using SPSS version 26. The descriptive statistical analyses summarize the characteristics of the study sample. Descriptive statistical analysis of the medical student sample included age, sex, current year in school, race/ethnicity, and expected medical specialty. Descriptive statistical analysis of the patient sample included age, hemoglobinopathy status, sex, race/ethnicity, highest level of education completed, and health insurance status. Continuous variables (age) were examined for mean, median, standard deviation, and range. Categorical variables (sex, year in medical school, race/ethnicity, medical specialty, hemoglobinopathy status, their highest level of education completed, and health insurance status) were examined for frequency and percent. To compare the differences between the study and non-study participants, an independent sample *t*-test was conducted for age. Chi-square analysis was used to compare the sex, racial background, and hemoglobinopathy status of participants to non-participants.

Inferential statistics were used to describe the relationships, trends, and patterns between study variables to draw conclusions and make inferences (Pallant, 2013; Urdan, 2010). Continuous variables (TIP-RFT transition readiness scale and total scores, ASCQ-Me Scale scores, healthcare knowledge, Newest Vital Sign health literacy scores, MMAS-8 medication adherence scores) were examined for the mean, median, standard deviation, range of scores, skewness, and kurtosis to describe the data and evaluate the assumptions of parametric tests, including normality. The values for skewness and kurtosis between -2 and +2 were considered acceptable to prove normal

univariate distribution. Dependent t-tests were used to assess the changes in outcomes between the two time points. Because of the small sample size in this study and the lack of power to adequately detect statistical significance, Cohen's d measure of effect size was used to describe the magnitude of the differences in the means between the two time points. An effect size of 0.2 was considered small, 0.5 was considered medium, and 0.8 was considered large (Cohen, 1998). We chose to focus on effect size rather than statistical significance to better assess the impact of the intervention on our exploratory outcomes. Relationships between demographic factors, intervention completion, and changes in psychosocial outcomes were evaluated using Pearson bivariate correlation coefficients, Chi-square tests for independence, or independent t-tests.

***Specific Aim 2A, RQ1***

The number of students who applied for the program, who were interviewed, and who were ultimately selected, was described.

***Specific Aim 2A, RQ2***

Program completion was calculated as a percentage of medical students who initiated the program (completed the baseline survey), who ultimately completed all of the program components (training, video-chat sessions with a mentee, attended group supervisions, follow-up survey, and exit interview).

***Specific Aim 2A, RQ3***

Mentor satisfaction was assessed using descriptive statistics (mean ratings, frequencies) of overall satisfaction with the program, satisfaction with the mentor training content and materials, and satisfaction with the program duration and format. Descriptive statistics were also used to describe the extent mentors felt participation affected their clinical skills, communication skills, transition knowledge, and knowledge about managing chronic illness.

Satisfaction was also assessed through exit interviews with each mentor (interview guide included in Appendix L). Thematic analysis of the qualitative data was conducted to analyze themes in the data to describe if mentors' expectations were met, how they felt being a mentor program impacted them, how well prepared they felt to act as a mentor, and their feedback on the program content and format.

***Specific Aim 2A, RQ4***

The mean and standard deviation for each subscale of working alliance (goal, task, and bond) was calculated for the mentor sample.

***Specific Aim 2B, RQ1***

Study enrollment rates were calculated as a percentage of enrolled patients of total eligible patients. Feasibility was assessed as recruiting >50% of eligible individuals. Benchmarks for feasibility were established based on prior feasibility studies in this population (Crosby et al., 2017; Green et al., 2017).

***Specific Aim 2B, RQ2***

Study completion includes both retention and adherence to the intervention. Retention was defined as completing both the baseline and follow-up surveys. Adherence was defined as completing monthly calls. Benchmarks for feasibility were established based on prior feasibility studies in this population (Crosby et al., 2017; Green et al., 2017), and were set at a retention rate of >80% (complete all surveys), and adherence rate of >60%. Reasons for study dropouts were recorded if possible.

***Specific Aim 2B, RQ3***

Mentee satisfaction was assessed using descriptive statistics (mean ratings, frequencies) of overall satisfaction with the program, satisfaction with each of the monthly video call topics, and

satisfaction with the program duration and format.

Every patient who completed the intervention also completed an exit interview (exit interview guide included in Appendix M) to assess patient satisfaction with the program and to provide feedback on the program content, barriers to participation, and recommendations to improve the program. Thematic analysis of the qualitative data was conducted to analyze themes in the data to describe if mentees' expectations were met, how they felt being in the program impacted them, and their feedback on the program content and format.

#### ***Specific Aim 2B, RQ4***

The mean and standard deviation for each subscale of working alliance (goal, task, and bond) was calculated for the mentee sample. The relationship between mentee and mentor scores was assessed using Pearson's bivariate correlation.

#### ***Specific Aim 3A, RQ1 and RQ2***

Changes in knowledge and attitudes towards chronic illness were assessed using dependent t-tests.

#### ***Specific Aim 3B, RQ1-6***

Changes in continuous variables (transition readiness overall score and subscales, SCD health-related quality of life subscales, medication adherence, SCD self-efficacy, SCD knowledge, and health literacy) were assessed using dependent t-tests.

#### ***Specific Aim 3B, RQ7***

Pearson correlations were used to examine the relationships, both strength and direction, of age on the continuous variable psychosocial outcomes (transition readiness, HRQOL subscales, medication adherence, self-efficacy, disease knowledge, and health literacy).

#### ***Specific Aim 3B, RQ8***

Independent t-tests were used to examine the relationships between sex and each of the psychosocial outcomes (transition readiness and subscales, health-related quality of life (HRQOL) subscales, medication adherence, self-efficacy, disease knowledge, and health literacy).

***Specific Aim 3B, RQ9***

Pearson correlations were used to examine the relationships, both strength and direction, of the three subscales of working alliance (goals, task, and bond) with the psychosocial outcomes (transition readiness, HRQOL subscales, medication adherence, self-efficacy, disease knowledge, and health literacy).

***Specific Aim 3B, RQ10***

The number of sessions completed was dichotomized as completed all sessions versus did not complete all sessions. Independent t-tests were used to examine the differences in changes in the psychosocial outcomes (transition readiness subscales, HRQOL subscales, medication adherence, self-efficacy, and disease knowledge, health literacy) by whether participants completed all sessions or not.

**Chapter Summary**

In summary, this chapter presented the methodologies employed in the formative qualitative phase and feasibility and acceptability study of this dissertation. This included the rationale for and description of the study designs, samples, settings, measures, and methods of data collection. It also provided details of the intervention development and implementation. Finally, the rationale and methods used for data management and analysis are presented for each aim and research question.



## **CHAPTER FOUR RESULTS**

### **Overview of the Chapter**

Patients with SCD require lifelong comprehensive care, necessitating patient compliance with primary care appointments, specialist appointments, medications, transfusions, and regular health maintenance. As patients transition from pediatric care to adult care, they are at risk for lapses in care that can result in serious complications, making the period of transition a medically vulnerable time. It is critical that young adults with SCD continue to get regular care during this transition period. However, there are many barriers to a successful transition from pediatric to adult care and a lack of standardized evidence-based programs for transition care for young adults with SCD. As of this writing, no published research has examined the impact of a social support or mentor intervention for young adults with SCD.

This dissertation aims to fill the gap in the SCD transition literature by understanding the perspectives of young adults with SCD on transition, identify intervention targets, and then develop and assess the feasibility, acceptability, and explore the preliminary efficacy of a mentoring intervention for young adults with SCD. This chapter presents the results of both the formative qualitative study of young adult barriers to transition (Phase 1, Specific Aim 1) as well as the evaluation of the feasibility, acceptability, and preliminary efficacy of the developed mentor intervention (Phase 2, Specific Aim 2 and 3). For Phase 1, the chapter presents study recruitment and enrollment, study sample characteristics, qualitative analysis of the formative interviews, and how these results informed the development of the intervention. For Phase 2, the results are presented according to each research question, including recruitment, enrollment, retention, and satisfaction of intervention participants, comparison between participants and non-participants, study sample characteristics, changes in outcomes for medical student mentors, and changes in psychosocial outcomes for patient participants.

## **Phase 1, Aim 1: Barriers to Transition**

### ***Recruitment and Enrollment***

The perspectives of both young adults preparing to transition from the pediatric clinic and young adults who recently transitioned to the adult clinic were essential for understanding the transition experience to inform the development of a medical student mentoring intervention. Therefore, a purposeful sample of participants (Wu et al., 2016) was recruited from two outpatient hematology clinics (one pediatric, The Comprehensive Sickle Cell Center at the Rutgers Cancer Institute of New Jersey, and one adult, the outpatient hematology clinic at Robert Wood Johnson University Hospital). Recruitment took place between October 2017 and November 2018. All participants who were approached agreed to participate in the study. All participants who completed the informed consent process also completed the study.

### ***Sample Demographic Characteristics***

The sample consisted of 20 young adults, 10 who had not yet transitioned ( $M age = 21.40$  years,  $SD = 1.71$ ; 80% female) and 10 who had completed the transition process ( $M age = 23.90$  years,  $SD = 3.31$ ; 60% female). All but one patient self-reported as Black/African American and no participants self-reported as being Hispanic/Latino.

**Table 3***Sample Sociodemographic Characteristics as N (%) and M (SD)*

Characteristic		Pre-transition (N = 10) N (%)	Post-transition (N = 10) N (%)	Full sample (N = 20) N (%)
Sex				
	Female	8 (80.0)	6 (60.0)	14 (70.0)
	Male	2 (20.0)	4 (40.0)	6 (30.0)
Age (years)		21.4 (1.6)	23.9 (3.1)	
Racial background				
	Black or African American	10 (100.0)	9 (90.0)	19 (95.0)
	Other	----	1 (10.0)	1 (5.0)

**Research Question 1**

What are the barriers, challenges, and deficits in transition readiness associated with the transition to adult care from the perspective of young adults with SCD?

***Barriers and Challenges to Transition***

The perspectives on the barriers, challenges, and transition needs of participants were organized using the SMART framework. These fell into two categories: preexisting objective factors and modifiable factors. Under preexisting objective factors, three subthemes were identified: sociodemographics and culture, stigma and lack of awareness, and medical status/risk. Under modifiable factors, six subthemes were identified: knowledge, beliefs/expectations, skills and self-efficacy, goals and motivation, relationships/communication, and psychosocial factors.

***Preexisting Objective Factors***

**Sociodemographics/Culture.** Participants reported that developmental milestones, including education (college and graduate school) and employment, interfered with the transition process. One pre-transition patient mentioned the difficulty of balancing college with the medical

transition, suggesting that the healthcare team delayed transition to mitigate the impact. “I think they try to keep you here during college because that is the last thing you need to deal with. But, I think the switch would be around the time after I graduate, so they kind of do it like that on purpose” (19-year-old female). Three young adults also discussed the complexity of obtaining and keeping a job while simultaneously undergoing the transition process. They emphasized the difficulty of juxtaposing new life responsibilities with their new care coordination and self-management responsibilities.

**Stigma and Lack of Awareness.** Both pre- and post-transition participants experienced stigma and lack of awareness of SCD in the medical setting. Young adults expressed discrepancies in different healthcare providers’ knowledge and awareness about proper treatment for SCD. Young adults reported feeling fearful about selecting a new physician, wanting someone who “needs to know my condition.” Another common theme was reporting incorrect treatment (e.g., fluids, pain medications or dosing), most often within the adult emergency room setting ( $n = 7$ ). One patient expressed hesitancy going to the emergency room for treatment due to perceived stigma, stating “Sicklers [people with sickle cell disease] don’t go to the emergency room, [or they] wait until the last minute until they feel like they are going to die because of the mistreatment they have experienced. They don’t want people to think ‘oh he is just looking for drugs; he looks like he just wants drugs’” (30-year-old male, post-transition).

Young adults also reported a lack of awareness about SCD within the community at large. This created difficulties as young adults had a hard time explaining their illness to roommates, friends, or potential employers. One pre-transition patient and three post-transition patients mentioned the impact of SCD on their ability to get and maintain a job. For example, a 22-year-old pre-transition female said, “I think they don’t understand, they don’t understand that you can’t

control it and they don't understand how severe it is. They say if you don't feel well you can still come to work but if you are in pain and in bed you can't come to work." Another 26-year-old post-transition female patient said, "So you have to get a job where you explain things to your boss and they can be patient with you."

Commonly, when patients reported experiencing stigma it was followed by a statement of sadness or frustration. For example, a pre-transition patient said, "I just don't tell certain people because I feel like they don't understand. Other people don't even think I am sick because I don't *look* like I have a disease" (20-year-old female). Another pre-transition patient explained that lack of awareness can occur within their own family, stating, "I don't really have much support, my siblings don't get it, they don't have sickle cell" (23-year-old female).

**Medical Status/Risk.** Several participants ( $n = 10$ ; 4 pre-transition, 6 post-transition) discussed challenges related to the severity of their disease, including frequent admissions ( $n = 2$ ) and the unpredictable course of SCD ( $n = 4$ ). Several patients also reflected on their mortality, viewing it as a potential complication of poor medical treatment ( $n = 3$ ) or inadequate self-management ( $n = 1$ ). There was frustration evident among patients who expressed a perceived lack of control over their medical status with one participant stating, "the thing with this illness is you can get sick anywhere and you can't control when it happens. Even when you do everything right and by the book, pain can still happen" (26-year-old female, post-transition).

### ***Modifiable Factors***

**Knowledge.** Many participants voiced that they wanted more knowledge about SCD and about the transition process. Three participants preparing for transition indicated that they felt like the knowledge they had was inadequate for them to transition successfully. Three patients who had already transitioned echoed this concern stating, "I still feel like I am going into this blindly,"

(21-year-old male) and “I wasn’t prepared... I thought I was going to have [the pediatric providers] there longer” (19-year-old female).

Two types of knowledge, SCD knowledge and knowledge about self-management and required care, emerged as important for a successful transition. Half of the post-transition patients and two pre-transition patients mentioned the importance of SCD-specific health knowledge (i.e., medications, fluids, disease variant, medical history) for advocating for oneself in the emergency room and with new providers. Knowledge about self-management (specialist care, when and what medication to take, how to manage pain at home) was also mentioned as important. One post-transition patient stated, “One thing you need to know when coming from pediatrics is what medicine you take, what works for you. That way when you go to the adult world and they don’t listen to you, you can tell them what you want” (26-year-old female).

**Skills/Self-efficacy.** When talking about skills necessary for transition and patients’ perceptions of their self-efficacy, three themes emerged: skills related to self-management (e.g., remembering to take medications, hydration), skills related to healthcare navigation (e.g., making doctor’s appointments, filling prescriptions, insurance), and skills related to pain management. Among the patients preparing to transition, only three indicated that they were already entirely responsible for managing their own care and navigating the healthcare system. The remaining participants reported that their parents were still responsible for several tasks, including reminding to take medication ( $n = 4$ ), making appointments ( $n = 3$ ), filling prescriptions ( $n = 3$ ), and attending appointment ( $n = 2$ ). When asked if they thought about when they might need to become fully responsible for their care, two participants indicated that they had not thought about that at all, one stating, “I don’t want to cross that bridge yet” (20-year-old female).

Post-transition patients indicated that becoming fully responsible for their own self-

management was a process. One participant who recently transitioned stated, “I am responsible, but I will admit I just fully became responsible. I was really bad at remembering what I needed to take and at what time, but now I have created a schedule and I am in charge of it” (23-year-old female). Another recently transitioned participant indicated that learning skills for how to manage her own care without relying on her mom “was like a transition by itself” (23-year-old female). Young adults reported learning transition skills by observing their parents, asking providers, or talking to other young adults through chatrooms and online forums. The post-transition patients indicated that some of the most important skills were strategies for tracking health information (e.g., keeping a SCD notebook), adhering to treatment (including keeping appointments), and effectively communicating with providers, particularly while in pain. “Once I learned how to drive I learned how to go [to appointments] alone and I needed to learn how to communicate I have sickle cell by myself. Like how to talk to my doctor and how to talk to other people, but do it myself. My mom used to talk for me” (23-year-old male post-transition).

Patients also expressed that successful self-management extended past their medical demands. Six young adults mentioned difficulty with general “life-management” such as paying bills, applying for jobs, and getting disability.

**Beliefs/Expectations.** Among the young adults who had not yet transitioned, four reported that they felt their new provider would “not care as much.” Five participants expected that their new provider would not know as much about SCD or how to treat them appropriately. Some young adults expected that their new provider would communicate with their pediatric provider before they transitioned ( $n = 2$ ). Of the young adults who already transitioned, several expressed that the transition was not as simple as they had expected it to be. One said, “whatever expectation you have in the pediatric, throw it out the window” (26-year-old female). Overall the young adults did

not feel that the quality of care was different in the adult setting, but rather that the “bonuses” of the pediatric setting, such as the hands-on coordination and “hand-holding” through healthcare navigation, was lost once in the adult world. Overall, young adults recommended that patients preparing to transition needed to manage their expectations before transitioning so that they would not expect to be “treated with kid gloves” (22-year-old female post-transition).

Young adults also expressed distinct beliefs about the adult emergency room and expected vast differences in treatment from their prior experiences in the pediatric emergency room. Some of these expectations stemmed from personal experience, while some patients based their expectations on anecdotes from friends and family or from chatrooms of other young adults with SCD. Some of the young adults expressed concern that emergency room doctors would classify them as drug-seeking when they were in pain ( $n = 3$ ). Others expressed concerns about wait times being longer or about not being listened to by the staff regarding appropriate medications or fluids. One participant said, “That is probably the one thing about the transition I really don’t like. The adult ER [emergency room] is hectic. If you are in a crisis it is awful ...they want you to be really patient and it is hard to be patient when you are in that much pain. It is hard to wait” (26-year-old male, post-transition).

**Goals/Motivation.** Motivation for autonomy in self-management was most frequently tied to life events such as attending college or moving away from home. Young adults expressed not wanting to be “limited” because of their disease. Some specifically cited career goals as a reason to become independent, while others noted that they felt like it was time to make health a priority (now that they were living on their own).

**Relationships/Communication.** Participants described how relationships with family, friends, and providers significantly impacted their transition. Many young adults reported that their



parents provided support and encouragement to take over their healthcare management. Family support included helping with healthcare logistics (scheduling appointments, transportation, reminders or “check-ins”) as well as providing an example for self-advocacy and how to communicate with providers. Participants voiced varying levels of autonomy, as many were already living on their own or at college.

In terms of relationships with providers, several themes emerged. The first was a strong attachment to the pediatric team and hesitancy to find a new provider. Six of the ten young adults who had not yet transitioned voiced strong feelings of attachment, making statements such as “When I come here I know I am safe and I trust what they do because I have been around them so long” (19-year-old female) and “Whenever they kick me out is the soonest I will transfer. I don’t plan on leaving until I have to” (20-year-old female).

Young adults described apprehension and challenges in relationships with their adult providers. Apprehension was more often related to feeling like the adult provider was not going to “understand them” versus an insecurity about the lack of medical knowledge that the adult provider would have. Young adults preparing to transition also expressed that they had received significant support from pediatric providers, including coordinating specialist referrals, providing nutrition and hydration counseling, and assisting with school-related activities such as applying for tuition assistance, obtaining individualized education plans, and acquiring specialized housing in college. They felt that this type of support would not be reciprocated by their new adult providers. Young adults who had already transitioned confirmed that care coordination ( $n = 4$ ) and identifying support resources ( $n = 2$ ) were more difficult after the transition.

With regard to communication, eight of the post-transition young adults specifically mentioned difficulty in the emergency room. Statements such as, “the ER [emergency room]

providers don't really care" (30-year-old male, post-transition) and "You can say as much as you want to say but they don't take you serious" (23-year-old female, pre-transition), indicate that these young adults do not feel as if they are being heard by providers in the ER. Specifically, patients reported difficulty expressing that they were receiving incorrect fluids or medications. Several of the young adults relayed their strategies for better communication while in pain, including keeping a journal or notebook with all relevant health information. In terms of transition preparation, eight of the young adults emphasized how important it was to learn how to effectively self-advocate before transitioning to adult care and the adult ER.

Three post-transition patients also mentioned difficulty regarding effectively communicating with their physician about pain management. These participants expressed a concern that some young adults may be buying opioid medications on the streets due to feeling uncomfortable talking to their physician about their pain, lack of access, or difficulty getting prescriptions filled. These young adults felt that part of transition preparation should include strategies for communicating with their physician about ineffective pain management, as well as information about how to access pain medication including alternative modalities such as medical marijuana (or marijuana use for pain management in general).

**Psychosocial/Emotions.** When asked about their feelings about transition, the majority of young adults ( $n = 17$ ) expressed negative emotions such as feeling "scared," "depressed," and "uncertain." Many young adults who had already transitioned described the situation as "hard." One participant said, "It was really hard. You are used to your whole life being treated one way and you get used to it. So being an adult where you have to change all of what you are used to, it is like living a different life" (26-year-old female). Two young adults preparing to transition felt more optimistic, describing the transition as "bittersweet." They both indicated feeling sad because

they had known their physician and nurses since they were young but overall felt optimistic about moving on and getting to know new people.

## **Research Question 2**

What modifiable transition care needs can be targeted by an intervention?

### ***Intervention Targets***

Relevant topics and patient priorities elicited from the patient interviews guided the selection of educational modules for monthly video-chat calls between the mentee and mentor. The following ten needs were selected as priorities to be incorporated into the educational calls: SCD knowledge, self-management knowledge and skills, healthcare navigation skills, pain management, healthy behaviors, managing expectations for the emergency room, navigating patient-provider relationships, self-advocacy, managing expectations for adult care, and support resources.

### ***Program Development, Feedback, and Refinement***

**Development of Program Content.** A multi-component medical student mentor intervention was developed to address the needs of patients preparing to transition from pediatric to adult care. Components include a half-day mentor training with both clinical and research staff, six education-based videoconference calls, a mentor and a mentee manual with resources relevant to each of the six monthly calls, and weekly text-messages for general social support. Relevant topics and patient priorities elicited from the patient interviews guided the selection of educational modules for monthly video-chat calls between the mentee and mentor.

**Feedback and Refinement.** The topic areas were iteratively reviewed and refined by our team of SCD experts, including two adult hematologists, one pediatric hematologist, one pediatric nurse practitioner, and one pediatric patient navigator. We then created mentor and mentee

handbooks that contained the final content for the monthly education calls and clinical information on SCD (Appendix E and Appendix F). Both manuals were reviewed by the team of SCD experts as well as a patient advisory board. The patient advisory board was composed of four patients designated by the SCD experts as young adults who had a successful transition and who were currently managing their care well. Several iterations of the manual were generated before both the patient advisory board and the SCD experts agreed that the materials met patient and mentor needs. Table 4 describes the program components.

**Table 4***Components of the Medical Student Mentor Program*

Patient Need	Content To Be Addressed	Mentor Program Component
Disease knowledge	<ul style="list-style-type: none"> <li>• SCD background, genetics of SCD, how/why crises occur, disease complications, treatment options</li> </ul>	<ul style="list-style-type: none"> <li>• Patient manual provides basic information about SCD genetics, treatment options and a visual description of why crises occur</li> <li>• Monthly call 1 includes a discussion with the mentee to assess knowledge and/or deficits</li> </ul>
Self-management knowledge and skills	<ul style="list-style-type: none"> <li>• Annual recommended specialist care</li> <li>• Hydration, importance of medication adherence</li> <li>• Goal setting</li> </ul>	<ul style="list-style-type: none"> <li>• Patient manual includes table of recommended specialist care with time intervals</li> <li>• Monthly call 2 includes goal-setting session with mentee.</li> </ul>
Healthcare navigation skills	<ul style="list-style-type: none"> <li>• Types of insurance, how to obtain</li> <li>• Transportation assistance</li> <li>• How to make an appointment</li> <li>• How to fill a prescription</li> <li>• Basics of understanding bloodwork/labs</li> </ul>	<ul style="list-style-type: none"> <li>• Patient manual includes sample insurance card with explanation of components, description of types of insurance, sample script for making a doctor's appointment, schematic of how to fill a prescription, sample blood work with a description of the components</li> <li>• Monthly call 2 includes a review of all materials. Specific questions are also addressed.</li> </ul>
Pain management	<ul style="list-style-type: none"> <li>• Importance of medication adherence</li> <li>• Strategies for preventing crises</li> <li>• How to manage stress</li> </ul>	<ul style="list-style-type: none"> <li>• Patient manual includes tips for pain crisis prevention and medication adherence</li> <li>• Monthly call 4 includes a discussion about the mentee's current pain management and how effective it has been. This call may also include goal setting for medication adherence.</li> </ul>
Healthy behaviors	<ul style="list-style-type: none"> <li>• Information on substance use (drugs, alcohol, tobacco)</li> <li>• Medical marijuana</li> <li>• Sexual health</li> <li>• General lifestyle (diet and exercise)</li> </ul>	<ul style="list-style-type: none"> <li>• Patient manual includes infographics about the impact of alcohol, tobacco and illicit drugs on someone who has SCD.</li> <li>• Monthly call 3 includes a discussion about the impact of substances, and the importance maintaining a healthy lifestyle. This call can include goal setting (e.g., diet, exercise)</li> </ul>
Managing expectations for the emergency room	<ul style="list-style-type: none"> <li>• Information you should be able to provide in the emergency room (fluids, pain medication, dosages)</li> <li>• Strategies for effective ER communication</li> </ul>	<ul style="list-style-type: none"> <li>• Patient manual includes a list of information that one should be able to provide in the emergency room as well as tips for effective communication</li> <li>• Monthly call 5 includes a discussion about past ER experiences and strategies for the future.</li> </ul>
Navigating patient provider relationships	<ul style="list-style-type: none"> <li>• Suggested strategies for successful doctor's appointments and communication</li> </ul>	<ul style="list-style-type: none"> <li>• Patient manual includes tips for communicating with your doctor.</li> <li>• Monthly call 5 includes a role-play activity for navigating difficult provider conversations.</li> </ul>
Self-advocacy	<ul style="list-style-type: none"> <li>• Suggested strategies for self-advocacy</li> </ul>	<ul style="list-style-type: none"> <li>• Patient manual includes tips for self-advocacy.</li> <li>• Monthly call 5 includes a role-play activity.</li> </ul>
Managing expectations for adult care	<ul style="list-style-type: none"> <li>• Resources available through adult provider</li> <li>• Differences between adult and pediatric providers</li> <li>• Tour of hospital and meet adult providers</li> </ul>	<ul style="list-style-type: none"> <li>• Patient manual includes a table that directly compares pediatric to adult care (e.g., obtaining medication, scheduling, and support resources available).</li> <li>• Month 6 includes a tour of the adult facilities at our institution.</li> </ul>
Resources	<ul style="list-style-type: none"> <li>• College scholarships</li> <li>• SCD organizations</li> <li>• Financial support</li> </ul>	<ul style="list-style-type: none"> <li>• Patient manual includes a list of resources and corresponding points of contact for organizations.</li> </ul>

**Program Format Preferences.** During the qualitative interviews, participants were presented with the idea of a medical student mentoring program to help with the transition process. Young adults were asked about the acceptability of using a medical student as a mentor, their preferred mode of communication, their desired frequency of communication, and any particular characteristics they consider important when matching with a mentor. Receptivity to working with a medical student as a mentor was positive ( $n = 17$ ), with only three participants stating that they might prefer a peer who also had SCD. Among those who felt positively, five people explicitly mentioned that they felt that it would not only give them the opportunity to learn, but also the opportunity to teach. “I think it is a great idea actually. Because we have to take it on, we can tell you first-hand how it feels, what you have to do, how you might feel, what you should be prepared for” (19-year-old female, pre-transition participant). Another post-transition patient echoed this sentiment saying, “They are both learning, they can somewhat teach each other stuff” (19-year-old female). Other participants felt that having a mentor would be a good source of social support saying, “yeah, it would be another person you could talk to about how you feel besides like your mom or doctor that could comfort you” (19-year-old female, pre-transition). Some participants felt that a medical student’s connection to the healthcare system could be useful. “The good thing is that they know some medical information so they can help explain things to me in different terms” (19-year-old female, pre-transition). Overwhelmingly, text messaging was mentioned as a preferred method of communication (80%), and more than half of the participants preferred to communicate at least once per week. Only five participants (4 female, 1 male) said they would prefer to be matched by sex, citing reasons such as not wanting to talk to a male about going to the gynecologist (a female), or that a male mentor (from a male participant) might have similar interests “like sports and stuff.”

**Phase 2, Aim 2: Program Feasibility*****Aim 2A: Program Feasibility among Medical Students***

**Research Question 1.** Will medical students enroll and participate as mentors for AYAs transitioning from pediatric to adult care?

In January 2019, 7 medical students completed an application including required letters of recommendation, were interviewed, and were accepted into the program. The first mentor training took place at the end of January 2019. As patient recruitment increased, there was a need to add additional mentors to the program to meet the demand. In May 2019, two additional medical students were recruited and completed the mentor training.

The sociodemographic characteristics of the medical student mentors are shown in Table 5. All of the mentors were in the first year of medical school at the time of recruitment. The mentors were predominantly female ( $n = 7$ , 77.8%) and were a mean age of 23.8 years ( $SD = 2.0$ ). The sample was majority Black/African American ( $n = 5$ , 55.6%). When asked about plans for future medical specialty, there was a range of responses, including general pediatrics, pediatric specialty, obstetrics/gynecology, surgical specialty, and emergency medicine.

**Table 5***Sociodemographic Characteristics of the Medical Student Mentors as N (%) and M (SD)*

Demographic	N (%) or M (SD)
<b>Sex</b>	
Female	7 (77.8)
Male	2 (22.2)
<b>Age</b>	23.8 (2.0)
<b>Racial background</b>	
Black or African American	5 (55.6)
White	2 (22.2)
Asian	1 (11.1)
More than one race	1 (11.1)
<b>Hispanic or Latino</b>	0 (0.0)
<b>School/ employment status</b>	
Pediatrics	1 (11.1)
Pediatric specialty	3 (33.3)
Obstetrics/ gynecology	2 (22.2)
Surgical specialty	2 (22.2)
Emergency medicine	1 (11.1)
<b>Graduating class of medical school</b>	
Class of 2022	9 (100.0)

**Research Question 2.** Will medical students **complete** all program requirements?

To receive non-credit elective credit, medical students were required to complete all program components including attending the mentor training, completing the baseline and follow-up survey, completing video calls and weekly text messages with at least one mentee, and attend all monthly check-in meetings. All nine of the medical students who started the mentor program completed these requirements. Mentors had between one and three mentees over the duration of the study, with the majority having two mentee relationships. The mentors were required to complete the follow-up survey once (upon completing their last mentoring relationship) but completed a working alliance inventory for each relationship.

**Research Question 3.** How do medical student mentor participants rate their satisfaction with the program?



Mentor satisfaction is presented in Table 6. Medical students reported greatest satisfaction with the content of the mentor manual ( $M = 4.50$ ,  $SD = 0.76$ ), the content of the mentor training ( $M = 4.38$ ,  $SD = 0.74$ ), and the program overall ( $M = 4.38$ ,  $SD = 0.52$ ). When asked to what extent they felt their participation in the program affected them, the two highest reported areas were knowledge of transition ( $M = 4.50$ ,  $SD = 0.76$ ), and knowledge about managing a chronic illness ( $M = 4.25$ ,  $SD = 0.71$ ).

When asked about their favorite part of the intervention, two-thirds of the mentors commented on the relationship they developed with their mentees. One mentor reported, “I thought my relationship with [name] was incredible. I felt as though we were friends and was touched by her sharing very personal aspects of her life with me.” Many mentors ( $n = 4$ ) also reported that their favorite part was learning from their patients and getting a patient’s perspective of what it was like to live with SCD.

When asked in what ways they felt they changed by participating as a mentor, nearly every response emphasized gaining a new understanding of the impact of living with a chronic illness such as SCD. One mentor reported, “I became aware of the experiences of individuals with sickle cell face and how easy it is for people in the transition period to fall through the cracks. While I was already sensitive to the experiences people face when they don’t have insurance or see a physician regularly, I am even more aware of how someone could end up in that situation.” Another mentor shared, “I learned a lot about the transition itself, but I think hearing from these patients has made me more aware of certain stereotypes that may exist within the field. I think this awareness will hopefully help make me a more understanding and competent physician.”

Suggested improvements for the program included increasing the frequency of the interactions (video-chat), having the option for phone calls versus video calls, and meeting the mentees in person prior to beginning their virtual relationship.

**Table 6***Medical Student Mentor Satisfaction*

How satisfied were you with the...	Not at all %	Slightly %	Somewhat %	Quite a bit %	Very %	<i>M (SD)</i>
Program overall	0	0	0	33.3	66.6	4.38 (0.52)
Content of mentor training	0	0	11.1	33.3	55.6	4.38 (0.74)
Content of mentor manual	0	0	11.1	22.2	66.6	4.50 (0.76)
Frequency of text messages	0	0	33.3	33.3	33.3	4.00 (0.93)
Frequency of video chat calls	0	11.1	11.1	33.3	44.4	4.13 (1.13)
Contact with your mentee	0	0	33.3	22.2	44.4	4.00 (0.93)
Monthly check-in meetings	0	0	33.3	33.3	33.3	4.00 (0.93)
How much do you feel like your participation as a mentor improved your...	Not at all %	Very Little %	Some %	Quite a bit %	Very Much %	<i>M (SD)</i>
Clinical skills	0	11.1	44.4	44.4	0	3.38 (0.74)
Patient communication	0	11.1	22.2	33.3	33.3	3.88 (1.13)
Knowledge of transition	0	0	11.1	22.2	66.6	4.50 (0.76)
Knowledge about managing chronic illness	0	0	11.1	44.4	44.4	4.25 (0.71)

**Research Question 4.** How do medical student mentor participants rate their relationship quality with their mentees?

Medical student mentors had high ratings for the bond domain of working alliance ( $M = 19.63$ ,  $SD = 0.62$ ). Response distributions for this scale tended to be skewed toward better bonds (score of 20) and could be representative of a ceiling effect. Lower scores were reported for the “goals” and “task” domains (Table 7).

**Table 7**

*Medical Student Ratings of Working Alliance*

Working Alliance Subscale	$M$ ( $SD$ )	Range
Goal	11.71 (3.12)	3–15
Task	11.88 (3.26)	4–15
Bond	19.63 (0.62)	18–20

***Aim 2B: Program Feasibility among Patient Participants***

**Research Question 1.** Will adolescents with SCD **enroll** in a transition program utilizing medical student mentors?

All patients within our eligibility age range who were current pediatric patients, or within one year of their transition to an adult hematologist, were identified from the medical record in January 2019. New patients who were in our eligibility age range were identified through August 2019. This yielded a total patient population of 41. Of the potential study participants, 3 were excluded from the study because they did not meet the inclusion criteria due to cognitive impairment ( $n = 3$ ). Three patients were excluded because they transferred to a hospital system outside of Robert Wood Johnson University Hospital. Of the remaining eligible patients ( $n = 36$ ), seven (19.4%) declined to participate and seven (19.4%) did not respond to recruitment efforts. Twenty-one (58.3%) consented to participate in the study. Within this sample, 18 participants were

current pediatric patients and three had transferred to the adult clinic within the past year. The results from the screening, enrollment, and accrual of the study sample are presented in Figure 2.

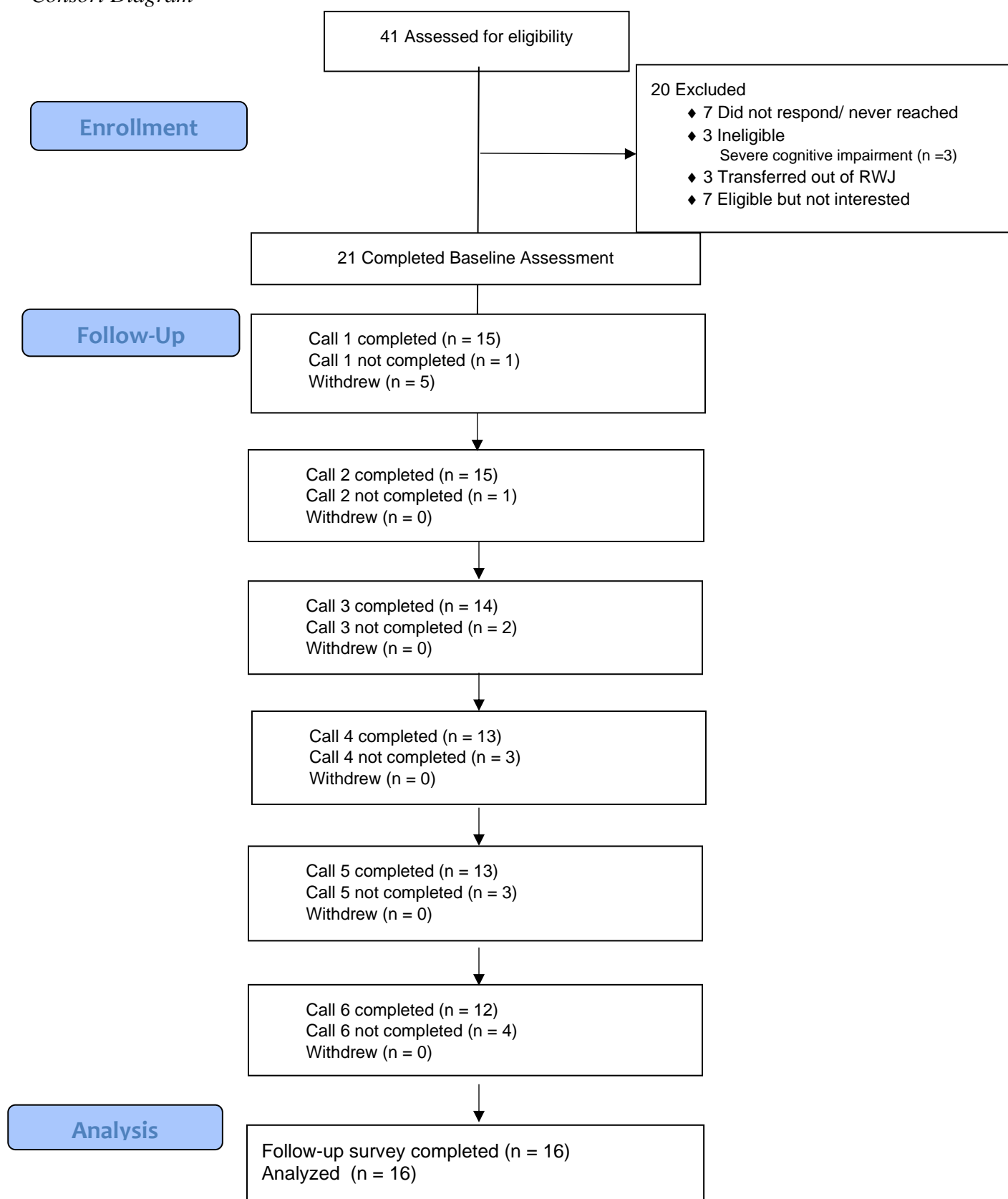
**Study Sample.** The sample was comprised of predominantly African American/Black AYAs ( $n = 19$ , 90.5%). There were slightly more male ( $n = 12$ , 57.1%) participants than female participants ( $n = 9$ , 42.9%). As expected, the hemoglobinopathy status was distributed across three major genotypes: HbSS, HbSC, and HbS $\beta^+$  Thalassemia, with 76.2% of patients having a HbSS genotype, 14.3% of patients having a HbSC genotype, and 9.5% of patients with a HbS $\beta^+$  Thalassemia. At the time of enrollment, the mean age of participants was 20.2 years ( $SD = 2.3$ ). The level of education extended from 11<sup>th</sup> grade to graduate school. Only one participant was not currently living at home with parents or siblings. Lastly, patients reported having health insurance through their parents ( $n = 9$ , 42.9%), through an employer or school ( $n = 2$ , 9.5%), through Medicaid or another public assistance program ( $n = 3$ , 14.3%), or through another state assistance program ( $n = 9$ , 42.9%). The sample sociodemographic characteristics are presented in Table 8.

Participants and non-participants were compared to determine if there were any differences in age, race, sex, and hemoglobinopathy status between those who participated and those who did not. The results indicated that there was not a significant difference observed for any of these variables (age,  $t(33) = -1.31$ ,  $p = 0.32$ ; race,  $X^2(2) = 0.27$ ,  $p = 0.61$ ; sex,  $X^2(1) = 0.99$ ,  $p = 0.32$ ; hemoglobinopathy status,  $X^2(2) = 1.74$ ,  $p = 0.41$ ).

**Table 8***Patient Demographics as N (%) and M (SD)*

Demographic	N (%) or M (SD)
Sex	
Female	9 (42.9)
Male	12 (57.1)
Age	20.2 (2.3)
Hemoglobinopathy status	
HbSS	16 (76.2)
HbSC	3 (14.3)
HbSβ <sup>+</sup>	2 (9.5)
Racial background	
Black or African American	19 (90.5)
White	1 (4.8)
More than one race	1 (4.8)
Hispanic or Latino	2 (9.5)
School/ employment status	
Part-time student	2 (9.5)
Full-time student	13 (61.9)
Working part-time	2 (9.5)
Working full-time	2 (9.5)
Unemployed	1 (4.8)
Other	1 (4.8)
Highest grade completed	
10 <sup>th</sup> to 11 <sup>th</sup> grade	3 (19.1)
High school graduate	13 (61.9)
2 year college	3 (14.3)
4 year college	1 (4.8)
Graduate degree	1 (4.8)
Marital status	
Single/never married	21 (100.0)
Current living situation	
At home with parents (and siblings)	20 (95.2)
On own, with roommate(s) or partner	1 (4.8)
Health insurance status <sup>a</sup>	
Yes, through employer/school	2 (9.5)
Yes, through parents	9 (42.9)
Yes, covered through Medicaid or public assistance program	3 (14.3)
Yes, covered through another state program	2 (9.5)
Other	3 (14.3)

<sup>a</sup>Two participants did not respond to this question

**Figure 2***Consort Diagram*

**Research Question 2.** To what extent will young adults with SCD complete a transition program utilizing medical student mentors?

Of the 21 participants who completed the baseline assessment, 16 completed the final assessment (76.2%), while the remaining five were lost to follow-up. Participants completed an average of 5.1 ( $SD = 1.2$ , range = 0 to 6) video chat calls. Of the sixteen, 15 completed at least two calls (93.8%), 14 completed at least three calls (87.5%), 13 completed at least five calls (81.2%), and 12 (75.0%) completed all six of the scheduled video calls (see Figure 2). One participant did not complete any of the video chat calls but communicated via text-message communication with his/her mentor for over six months.

Five participants in total were lost to follow-up. One withdrew after severe medical complications and an extended hospital stay. Another participant was displaced from their home and no longer felt like they could be involved. The other three remaining participants stopped responding to repeated contact from their mentors and the research team. Those who did not complete the study were younger ( $M = 18.2$ ;  $SD = 0.5$ ) than those who completed the study ( $M = 20.8$ ;  $SD = 2.4$ ;  $t(19) = -4.17$ ,  $p = 0.001$ ), but did not differ on other demographic variables. Those who did not complete the study demonstrated lower baseline health literacy ( $M = 1.2$ ;  $SD = 1.1$ ) than those who completed the study ( $M = 3.0$ ;  $SD = 2.4$ ;  $p = 0.03$ ), but did not differ on any other outcome measure at baseline.

**Research Question 3.** How will patient-participants rate their satisfaction with the program?

Participants reported greatest satisfaction with the quality of the video chat calls with their mentor ( $M = 4.53$ ,  $SD = 1.06$ ), the frequency of the video chat calls with their mentor ( $M = 4.33$ ,  $SD = 1.11$ ), the content of the text messages with their mentor ( $M = 4.31$ ,  $SD = 0.95$ ), and the



program overall ( $M = 4.25$ ,  $SD = 0.86$ ). When asked about topics that they found particularly helpful, differences between pediatric and adult care ( $M = 4.73$ ,  $SD = 0.80$ ), healthy lifestyle ( $M = 4.67$ ,  $SD = 0.90$ ), and self-advocacy ( $M = 4.40$ ,  $SD = 1.24$ ) emerged as the three highest-rated topics. Over 87% of patients reported that they would be *quite a bit* or *very* likely to recommend this program to other young adults who are preparing to transition.

When asked about their favorite part of the intervention, two clear themes of participants' responses emerged: education and social support. Twelve participants (75%) reported that they valued the relationship they developed with their mentor (see Table 9). When asked in what ways participation in the program made them change, three themes emerged: self-management skills, self-confidence, and self-advocacy (see Table 10 for demonstrative quotes).

Suggested improvements for the program included increasing the frequency of the interactions (video-chat), adding a group component where the mentees could interact with other young adults with sickle cell, and having the mentor sessions occur in person during the mentee's clinic visit. One participant, in particular, had extreme difficulty scheduling calls due to complex work and school schedules, and reported that their only "free time" to have completed the educational sessions was during his/her scheduled clinic visits.

When asked what they thought about working with a medical student as the mentor, the responses indicated that the mentee participants found that being similar in age made the mentor relatable, that it was a great opportunity to learn from each other, and that the mentors were knowledgeable and provided helpful insights. There were no negative responses to working with medical students.

**Table 9***Mentee Satisfaction*

How satisfied were you with the...	Not at all %	Slightly %	Somewhat %	Quite a bit %	Very %	<i>M (SD)</i>
Program overall	0	6.3	6.3	43.8	43.8	4.25 (0.86)
Content of mentee manual	0	6.3	18.8	25.0	50.0	4.19 (0.98)
Content of text messages	0	6.3	12.5	25.0	56.3	4.31 (0.95)
Frequency of text messages	0	12.5	18.8	18.8	50.0	
Quality of video chat calls with your mentor	6.3 <sup>a</sup>	0	0	18.8	68.8	4.53 (1.06)
Frequency of video chat calls	6.3 <sup>a</sup>	6.3	0	25.0	56.3	4.33 (1.11)
Length of the program	12.5	12.5	0	25.0	43.8	3.93 (1.39)
Which topics did you find particularly helpful?	Not at all %	Slightly %	Somewhat %	Quite a bit %	Very %	<i>M (SD)</i>
Goal setting for transition	0	18.8	6.3	18.8	50.0	4.19 (1.28)
Healthy lifestyle	0	6.3	0	18.8	62.5	4.67 (0.90)
Pain management	0	12.5	12.5	12.5	43.8	4.33 (1.29)
Medication adherence strategies	0	12.5	18.8	18.8	31.3	4.13 (1.30)
Information about SCD	0	6.3	18.8	25.0	37.5	4.20 (1.08)
Physician communication	0	6.3	12.5	25.0	46.7	4.33 (1.05)

Self-advocacy	0	6.3	25.0	0	50.0	4.40 (1.24)
Differences between pediatric and adult care	0	0	12.5	6.3	68.8	4.73 (0.80)
	Not at all %	Slightly %	Somewhat %	Quite a bit %	Very %	<i>M (SD)</i>
How likely are you to recommend this program for other young adults who are preparing to transition?	0	0	12.5	25.0	62.5	4.50 (0.73)
How much did the program help you improve your own management of your healthcare?	0	12.5	18.8	50.0	18.8	3.75 (0.93)
How much did the program improve your confidence for transition to healthcare?	0	6.3	12.5	43.8	37.5	4.06 (1.06)

<sup>a</sup>One participant did not complete any of the six calls

**Table 10***Themes of Mentee Responses to Open-Ended Questions*

Favorite part of the program	Example quotes
Education	<p>“Being informed on things I did not know about sickle cell”</p> <p>“I learned how to speak up and advocate in a respectful way.”</p> <p>“I got to ask a lot of questions especially about insurance and now know how to write a check and about co-pays.”</p>
Social Support	<p>“I was able to talk to him like I knew him for years. I treated him like a brother, and he did the same to me.”</p> <p>“Getting to talk to someone who won’t judge me and learn things that I did not know before.”</p> <p>“Talking about my concerns and venting about them”</p> <p>“My mentor was around my age. It always felt like a comfortable conversation and not like she was teaching/talking at me.”</p>
<b>Ways Mentees Changed</b>	
Self-management skills	<p>“Helped me grow up a little bit. I started taking better care of myself and staying on my meds.”</p> <p>“I became more responsible for my own care, and I adapted to taking my medicine at different times.”</p>
Self-confidence	<p>“Stayed on top of my prescriptions a little more.”</p> <p>“I feel more confident about my transition.”</p> <p>“I am not as nervous to transition to adult care.”</p> <p>“I was more confident in coming to my appointments.”</p>
Self-advocacy	<p>“I learned how to advocate for myself when I am sick in a respectful way.”</p> <p>“I learned how to speak up for myself.”</p>
<b>Suggestions/ Improvements</b>	
More frequent communication	<p>“I think the phone calls should be every other week.”</p> <p>“Call should be more like two times per month.”</p> <p>“Didn’t talk too much during text, would rather hear her voice. More frequent calls would help.”</p>
Meet others with SCD	<p>“If people feel comfortable, maybe meeting others around the same age in this program so that we can support each other in the transition.”</p>

**Research Question 4.** How do patient (mentee) participants rate their relationship quality with their mentor?

Overall patients had high ratings for each of the three domains of working alliance. The lowest scores were reported in the “goals” domain (Table 11).

**Table 11**

*Mentee Rating of Working Alliance*

Working Alliance Subscale	<i>M (SD)</i>	Range
Goal	17.87 (2.07)	13–20
Task	18.27 (1.87)	15–20
Bond	18.73 (1.71)	16–20

When asked about the relationship with their mentor, mentee participants reported that they “enjoyed it” ( $n = 5$ ), found their mentor easy to talk to and relatable ( $n = 6$ ), and felt that their mentors were helpful ( $n = 5$ ). Two participants also mentioned that being the same age as their mentor was particularly beneficial.

***Aim 3A: Impact of Mentor Program on Medical Student Outcomes***

**Research Question 1.** Among medical student mentors, are there improvements in SCD knowledge?

At baseline, medical students answered an average of 19 out of 22 items correctly. At follow-up, the mean score was 21.6 (0.7) indicating that the medical students got nearly every item correct (Table 12). The increase in knowledge from baseline to post training was 2.5 points which was a statistically significant increase,  $t(7) = 3.13$ ,  $p = 0.014$ .

**Table 12***Change in Medical Student Mentor Knowledge*

	Baseline <i>M (SD)</i>	Follow-up <i>M (SD)</i>	Mean Difference (95% CI)	<i>p</i>	<i>d</i>
Knowledge score	19.1 (2.2)	21.6 (0.7)	2.5 (0.61, 4.05)	0.014	1.04

**Research Question 2.** Among medical student mentors, are there improvements in attitudes towards chronic illness?

Medical students were asked to think of themselves as a physician caring for a patient and to answer questions about their comfort level dealing with patients in different situations (Table 13). Interestingly, there was a decrease in comfort for all situations with the exception of an increase in comfort in dealing with a patient who does not follow advice, though none of these changes were statistically significant. Effect sizes were small to moderate for each of the items, with the greatest effect seen in comfort level dealing with severe pain and suffering ( $d = -0.65$ ).

**Table 13***Change in Comfort Level Dealing with Medical Situations from Baseline to Follow-up*

	Baseline <i>M (SD)</i>	Follow-up <i>M (SD)</i>	Mean Difference (95% CI)	<i>p</i>	<i>d</i>
Patients as equal decision makers	4.63 (0.52)	4.25 (1.39)	-0.38 (-1.71, 0.96)	0.53	-0.23
Patients with different views or values	4.38 (0.52)	3.88 (1.25)	-0.50 (-1.76, 0.76)	0.38	-0.33
Uncertainty of diagnosis or treatment	3.25 (0.89)	2.87 (1.36)	-0.38 (-1.14, 0.39)	0.29	-0.41
Not being in control	2.75 (0.71)	2.50 (1.07)	-0.25 (-1.32, 0.82)	0.60	-0.20
Handling stressful situations	4.13 (0.64)	3.88 (1.36)	-.025 (-1.14, 0.91)	0.63	-0.18
Dealing with inability to cure patients	3.00 (1.07)	2.75 (1.39)	-.025 (-1.14, 0.91)	0.63	-0.18
Long-term professional relationships with patients	4.63 (0.74)	4.00 (1.20)	-0.63 (-1.51, 0.26)	0.14	-0.41
Dealing with severe pain or suffering	3.50 (0.76)	2.63 (1.30)	-0.88 (-2.01, 0.26)	0.11	-0.65
Working with a patient who does not follow advice	2.63 (0.74)	2.88 (0.64)	0.25 (-0.14, 0.64)	0.17	0.54
Including family members in patient care	4.75 (0.46)	4.25 (1.39)	-0.50 (-1.84, 0.84)	0.41	-0.31
Working with a patient with multiple problems	4.13 (0.64)	3.75 (1.17)	-0.38 (-1.55, 0.80)	0.48	-0.27

Medical students reported to what extent they agreed or disagreed with statements about patients who have chronic illnesses (Table 14). There were no statistically significant differences on any of the items from baseline to follow-up. Effect sizes for all items were small to moderate, with the greatest effect (indicating less agreeance from baseline to follow-up,  $d = -0.41$  for all) for items including, “I feel frustrated when patients don’t take their medication, don’t follow diets or ignore other professional advice;” “Some patients I’ve encountered with chronic illness are their own worst enemies;” and “I really can't understand why patients with lung diseases don't stop smoking.”



**Table 14***Changes in Agreement from Baseline to Follow-up*

	Baseline <i>M (SD)</i>	Follow-up <i>M (SD)</i>	Mean Difference (95% CI)	<i>p</i>	<i>d</i>
I feel frustrated when patients don't take their medication, don't follow diets or ignore other professional advice.	4.13 (0.35)	3.75 (0.89)	-0.38 (-1.14, 0.39)	0.29	-0.41
Some patients I've encountered with chronic illness are their own worst enemies.	2.50 (1.07)	2.13 (1.13)	-0.38 (-1.14, 0.39)	0.29	-0.41
Patients with chronic illness often lack family support at home.	2.13 (0.64)	2.38 (0.92)	0.25 (-0.72, 1.22)	0.56	0.21
I really can't understand why patients with lung diseases don't stop smoking.	2.75 (0.89)	2.25 (0.89)	-0.50 (-1.50, 0.50)	0.28	-0.41
I could never work with dying patients in hospice.	2.63 (0.74)	2.38 (1.19)	-0.25 (-1.32, 0.82)	0.60	-0.20
It's important for patients to understand the specific mechanisms of their illnesses.	4.63 (0.52)	4.50 (0.76)	-0.13 (-0.82, 0.57)	0.69	-0.15
Teaching patients about chronic illness is best done by nurses or health educators.	2.88 (0.83)	2.75 (1.04)	-0.13 (-1.34, 1.09)	0.82	-0.09
I feel excited about the challenge of helping patients manage multiple comorbidities.	4.13 (0.64)	4.00 (1.20)	-0.13 (-0.95, 0.70)	0.73	-0.13
It's futile to try to manage some chronic illnesses aggressively when it's virtually certain the patients will die anyway.	1.13 (0.42)	1.25 (0.46)	0.13 (-0.17, 0.42)	0.35	0.35
Electronic medical records compromise patients' personal privacy.	1.88 (1.36)	1.75 (1.04)	-0.13 (-1.26, 1.01)	0.80	-0.09

**Aim 3B: Impact of Mentor Program on Patient Outcomes**

**Research Question 1.** Among patients, are there improvements in transition readiness from baseline to intervention completion?

Table 15 shows a comparison of transition readiness scores at baseline and at follow-up. Statistically significant changes in overall transition readiness ( $t(15) = 5.41$ ,  $p < 0.001$ ), healthcare knowledge and skills ( $t(15) = 3.76$ ,  $p = 0.002$ ), and independent living skills ( $t(15) = 2.93$ ,  $p = 0.01$ ) were identified. These results indicate a large effect in improving overall transition readiness ( $d = 1.35$ ) and healthcare knowledge and skills ( $d = 1.35$ ), and a moderate effect on improving independent living skills ( $d = 0.73$ ). No significant changes were seen in the education and vocation planning skills nor the social support skills subscales.

**Table 15**

*Change in Transition Readiness Scores at Baseline and Follow-up*

	Baseline <i>M (SD)</i>	Follow-up <i>M (SD)</i>	Mean Difference (95% CI)	<i>p</i>	<i>d</i>
Overall transition readiness	98.25 (5.29)	105.06 (4.12)	6.81 (4.13, 9.50)	<0.001	1.35
Healthcare knowledge and skills	25.94 (3.43)	29.11 (1.2)	3.13 (1.35, 4.90)	0.002	0.94
Education and vocation planning	18.13 (1.75)	18.81 (1.17)	0.69 (-0.24, 1.61)	0.14	0.40
Social support skills	16.69 (2.80)	17.75 (2.62)	1.06 (-0.53, 2.66)	0.18	0.35
Independent living skills	37.50 (3.01)	39.44 (0.73)	1.94 (0.53, 3.35)	0.01	0.73

**Research Question 2.** Among patients, are there improvements in health-related quality of life from baseline to intervention completion?

Table 16 shows a comparison of HRQOL subscale scores at baseline and at follow-up. Overall, the mean scores for the sample were within the normal range at both time points. There were only a handful of patients who reported clinically impaired HRQOL ( $T < 40$ ) in the domains of pain impact ( $n = 2$ ), social functioning impact ( $n = 1$ ), and stiffness impact ( $n = 1$ ) at baseline. No patients reported clinically impaired HRQOL at follow-up. There were no statistically significant changes in any of the five HRQOL subscales.

**Table 16**

*Change in Health Related Quality of Life Scores at Baseline and Follow-up*

HRQOL dimension	Baseline <i>M (SD)</i>	Follow-up <i>M (SD)</i>	Mean Difference (95% CI)	<i>p</i>	<i>d</i>
Emotional impact	54.66 (5.25)	56.90 (6.03)	2.24 (-1.6, 6.1)	0.23	0.31
Pain impact	54.25 (10.23)	54.43 (8.00)	0.18 (-5.50, 5.86)	0.95	0.02
Sleep impact	52.08 (6.19)	55.03 (7.08)	2.95 (-1.16, 7.05)	0.15	0.38
Social function impact	54.19 (7.53)	58.13 (9.24)	3.93 (-0.30, 8.16)	0.07	0.50
Stiffness impact	53.01 (9.51)	55.19 (7.42)	2.18 (-4.11, 8.45)	0.47	0.19

**Research Question 3.** Among patients, are there improvements in medication adherence from baseline to intervention completion?

At baseline, the mean medication adherence score was 3.71 ( $SD = 1.82$ ). In our sample, there were no patients who reported high levels of adherence at baseline. Only three out of the 19 patients who are prescribed medication/vitamins to take daily reported moderate adherence, with the remaining 16 participants falling into the low adherence category.

At follow-up, the mean medication adherence score was significantly improved to 4.34 ( $SD = 1.43$ ;  $p = 0.02$ ; Table 17). This indicated a moderate improvement ( $d = 0.68$ ) in medication adherence. However, there was little change in the distribution of medication adherence levels, with the majority of participants still categorized as low adherence.

**Table 17**

*Changes in Medication Adherence Scores from Baseline to Follow-up*

	Baseline <i>M (SD)</i>	Follow-up <i>M (SD)</i>	Mean Difference (95% CI)	<i>p</i>	<i>d</i>
Medication adherence score	3.11 (1.61)	4.11 (1.25)	1.00 (-0.21, 1.79)	0.02	0.68

**Research Question 4.** Among patients, are there improvements in self-efficacy from baseline to intervention completion?

Table 18 shows the changes in self-efficacy scores from baseline to follow-up. There was a statistically significant increase in SCD self-efficacy from baseline to follow-up,  $t(15) = 4.38$ ,  $p = 0.001$ . This indicates a large effect ( $d = 1.09$ ) on SCD self-efficacy.

**Table 18**

*Changes in SCD Self-Efficacy Scores from Baseline to Follow-up*

	Baseline Mean (SD)	Follow-up Mean (SD)	Mean Difference (95% CI)	<i>p</i>	<i>d</i>
SCD self- efficacy score	32.63 (4.53)	36.69 (7.09)	4.06 (2.08, 6.04)	0.001	1.09

**Research Question 5.** Among patients, are there improvements in SCD knowledge from baseline to intervention completion?

Preliminary analyses demonstrated that the SCD knowledge scores at Time 2 had skewness (-2.05) and kurtosis (5.83) values outside of the acceptable range. Graphing the distribution revealed one outlier contributing to the skewness and kurtosis. The outlier does not appear to be valid based on the response ratings for each item (all 24 items had the same answer choice selected). Therefore, analyses were run excluding the outlier, and are presented in Table 19. At baseline, participants answered an average of 19 out of 24 items correctly. Participants demonstrated a 0.87-point increase in knowledge from baseline to follow-up (result not significant).

**Table 19**

*Changes in SCD Knowledge Scores from Baseline to Follow-up*

	Baseline <i>M (SD)</i>	Follow-up <i>M (SD)</i>	Mean Difference (95% CI)	<i>p</i>	<i>d</i>
Knowledge score (outlier excluded, <i>n</i> = 15)	19.27 (1.91)	20.13 (2.03)	0.87 (-0.18, 1.91)	0.10	0.50

**Research Question 6.** Among patients, are there improvements in health literacy from baseline to intervention completion?

Tables 20 and 21 show the changes in health literacy from baseline to follow-up. At baseline participants had a mean health literacy score of 2.57 (*SD* = 2.32), with nearly half the sample (*n* = 10) demonstrating a high likelihood of limited literacy, three (14.3%) participants demonstrating the possibility of limited literacy, and eight (38.1%) participants demonstrating adequate literacy. At follow-up, participants had a mean score of 3.94 (*SD* = 2.31), with a greater proportion demonstrating adequate literacy (*n* = 12). The

improvement in raw score approached statistical significance ( $p = 0.06$ ) and represented a moderate effect size ( $d = 0.51$ ).

**Table 20**

*Changes in Health Literacy Scores from Baseline to Follow-up*

	Baseline <i>M (SD)</i>	Follow-up <i>M (SD)</i>	Mean Difference (95% CI)	<i>p</i>	<i>d</i>
Health literacy score	3.00 (2.39)	3.94 (2.21)	0.94 (-0.45, 1.92)	0.06	0.51

**Table 21**

*Distribution of Health Literacy Scores at Baseline and Follow-up*

	High likelihood of limited literacy <i>N (%)</i>	Possibility of limited literacy <i>N (%)</i>	Adequate literacy <i>N (%)</i>
Number of participants at baseline <sup>a</sup>	6 (37.5)	2 (12.5)	8 (50.0)
Number of participants at follow-up	3 (18.8)	1 (6.3)	12 (75.0)

<sup>a</sup>Only includes the 16 participants who also completed the follow-up measure

**Research Question 7.** Is age associated with change in any of the psychosocial outcomes (transition readiness, health-related quality of life, medication adherence, self-efficacy, SCD knowledge, health literacy)?

There were no statistically significant relationships found between age of the participant and any of the psychosocial variables (Table 22).

**Table 22***Relationship of age to the psychosocial variables as  $r$  ( $p$ )*

Psychosocial variable	$r$	$p$
Transition readiness (overall)	-0.13	0.64
Healthcare Knowledge Skills	0.13	0.63
Education/Vocation Skills	0.15	0.60
Social Support Skills	-0.11	0.68
Independent Living Skills	-0.37	0.15
Emotional Impact	0.08	0.77
Pain Impact	-0.32	0.23
Sleep Impact	-0.05	0.85
Social Functioning Impact	0.10	0.71
Stiffness Impact	-0.08	0.76
Sickle Cell Self-Efficacy	0.02	0.95
Health Literacy	-0.02	0.95
SCD Knowledge <sup>a</sup>	-0.15	0.60
Medication Adherence	0.30	0.31

<sup>a</sup>Excluding outlier (n =15)

**Research Question 8.** Is participant sex associated with change in any of the psychosocial outcomes (transition readiness, health-related quality of life, medication adherence, self-efficacy, SCD knowledge, health literacy)?

There were no statistically significant differences in the change in any of the psychosocial outcomes by sex of the participant (Table 23).

**Table 23***Relationship of sex to dependent psychosocial variables*

	Mean Difference (male - female)	(95% Confidence Interval)	<i>p</i>
Transition readiness (overall)	-0.38	(-5.96, 5.21)	0.88
Healthcare Knowledge Skills	1.00	(-2.64, 4.64)	0.57
Education/Vocation Skills	0.63	(-1.27, 2.52)	0.49
Social Support Skills	-2.13	(-5.22, 0.97)	0.16
Independent Living Skills	0.13	(-2.81, 3.06)	0.93
Emotional Impact	-2.80	(-10.59, 4.99)	0.45
Pain Impact	-0.14	(-11.97, 11.70)	0.98
Sleep Impact	0.45	(-8.09, 8.99)	0.91
Social Functioning Impact	0.11	(-8.70, 8.92)	0.98
Stiffness Impact	2.03	(-11.00, 15.08)	0.74
Sickle Cell Self-Efficacy	2.38	(-1.51, 6.27)	0.21
Health Literacy	-0.88	(-2.85, 1.11)	0.36
SCD Knowledge <sup>a</sup>	0.52	(-1.85, 2.89)	0.63
Medication Adherence	0.57	(-1.04, 2.19)	0.46

<sup>a</sup>Excluding outlier (n =15)

**Research Question 9.** Is mentee report of working alliance between the mentor and mentee associated with change in any of the psychosocial outcomes (transition readiness, health-related quality of life, medication adherence, self-efficacy, SCD knowledge, health literacy)?

Report of higher “goal” alliance was found to be associated with a reduction in sleep impact ( $r = -0.53, p = 0.05$ ) as well as a reduction in stiffness impact ( $r = -0.60, p = 0.02$ ; Table 24). Higher ratings of “bond” alliance was found to be negatively correlated with stiffness impact ( $r = -0.64, p = 0.01$ ). We cautiously interpret these results due to the exploratory nature of this analysis, and because we did not adjust for multiple comparisons.



**Table 24***Relationship of working alliance to dependent psychosocial variables as  $r(p)$* 

	Goal $r(p)$	Task $r(p)$	Bond $r(p)$
Transition readiness (overall)	0.26 (0.58)	0.05 (0.86)	0.47 (0.09)
Healthcare Knowledge Skills	0.16 (0.58)	-0.05 (0.86)	0.25 (0.38)
Education/Vocation Skills	0.04 (0.90)	0.01 (0.98)	0.30 (0.30)
Social Support Skills	0.02 (0.95)	-0.05 (0.88)	0.32 (0.27)
Independent Living Skills	0.41 (0.15)	0.38 (0.18)	-0.03 (0.93)
Emotional Impact	-0.45 (0.11)	-0.06 (0.84)	-0.13 (0.67)
Pain Impact	-0.20 (0.48)	0.03 (0.93)	-0.42 (0.14)
Sleep Impact	-0.53 (0.05)	-0.31 (0.28)	-0.35 (0.22)
Social Functioning Impact	-0.39 (0.17)	0.11 (0.72)	-0.23 (0.43)
Stiffness Impact	-0.60 (0.02)	-0.19 (0.52)	-0.64 (0.01)
Sickle Cell Self-Efficacy	-0.23 (0.44)	0.32 (0.27)	-0.15 (0.60)
Health Literacy	0.07 (0.81)	0.18 (0.54)	-0.02 (0.95)
SCD Knowledge <sup>a</sup>	-0.29 (0.31)	0.11 (0.71)	-0.44 (0.12)
Medication Adherence	0.38 (0.23)	0.41 (0.19)	0.16 (0.62)

<sup>a</sup> Excluding outlier (n =15)

**Research Question 10.** Was completion of sessions associated with changes in any of the psychosocial outcomes (transition readiness, health-related quality of life, medication adherence, self-efficacy, SCD knowledge, health literacy)?

Participants who completed all sessions scored 6.25 points higher on the transition readiness assessment compared to those who did not complete all sessions,  $t(14) = 2.50$ ,  $p = 0.03$ . Similarly, those who completed all sessions scored 2.41 points higher on the educational/vocational subscale than those who did not complete all sessions,  $t(14) = 2.96$ ,  $p = 0.01$ . Finally, those who completed all sessions demonstrated a 1.5 point greater increase in knowledge as compared to those who did not complete all sessions,  $t(13) = -2.26$ ,  $p = 0.04$ . No other statistically significant changes were found.

**Table 25***Relationship of Completion of Sessions to Dependent Psychosocial Variables*

	Mean Difference	(95% Confidence Interval)	<i>p</i>
Transition readiness (overall)	6.25	(0.88, 11.60)	0.03
Healthcare Knowledge Skills	-0.17	(-4.43, 4.09)	0.93
Education/Vocation Skills	2.41	(0.67, 4.16)	0.01
Social Support Skills	2.58	(-0.96, 6.13)	0.14
Independent Living Skills	1.42	(-5.86, 8.70)	0.59
Emotional Impact	0.42	(-8.76, 9.59)	0.92
Pain Impact	-9.71	(-22.19, 2.77)	0.12
Sleep Impact	2.80	(-6.94, 12.54)	0.55
Social Functioning Impact	-3.07	(-13.10, 6.94)	0.52
Stiffness Impact	-7.21	(-21.76, 7.34)	0.31
Sickle Cell Self-Efficacy	1.91	(-2.72, 6.54)	0.39
Health Literacy	-1.59	(-3.76, 0.59)	0.14
SCD Knowledge	1.5 <sup>a</sup>	(0.05, 2.95)	0.04
Medication Adherence	-0.18	(-2.01, 1.66)	0.84

<sup>a</sup>excluding outlier (n =15)**Chapter Summary**

In summary, this chapter presented the results of the qualitative formative study (phase 1, aim 1) and the results of the feasibility and acceptability study (phase 2, aims 2 and 3). The results included an overview of the recruitment, enrollment and sample characteristics for each phase. The findings from the qualitative phase of the research were organized by themes corresponding to SMART model components. Additionally, the translation of the findings from the interviews into the intervention development was described. The feasibility of the intervention was presented for both the patient participants as well as the medical student mentors. Finally, the results of the exploratory analyses examining preliminary efficacy on outcomes for both patient participants and medical student mentors were presented.

## **CHAPTER 5 DISCUSSION**

### **Overview of Research**

For young adult patients with SCD, the transition period from pediatric to adult care is a time of increased morbidity and high rates of mortality (Brousseau et al., 2010; Blinder et al., 2013). The absence of well-defined programs for the transition from pediatric to adult care results in young adult patients being generally unprepared for the transition to the adult healthcare system and leads to reduced utilization of necessary preventive treatment and health maintenance (Bemrich-Stolz et al., 2015). There are few published reports of effective transition programs, with a noticeable gap in using peer or mentor support to improve transition outcomes. At the time of this writing, this dissertation is the first effort to assess the feasibility, acceptability, and preliminary efficacy of a medical student mentor program for transition from pediatric to adult care for young adults with SCD.

Intervention development followed a formative phase, which included a theory-driven qualitative review of patient-reported barriers to transition, transition priorities, and preferences for a transition mentor program. The feasibility and acceptability study was then implemented, and feasibility was assessed through enrollment rates, reasons for refusal, retention rates, engagement with the intervention, satisfaction, and reasons for dropout. Patient psychosocial outcomes (i.e., transition readiness, sickle cell specific health-related quality of life, self-efficacy, medication adherence, SCD knowledge, and health literacy) were examined for changes between baseline and the conclusion of the intervention. Medical student mentor outcomes including SCD knowledge and attitudes towards chronic illness were also evaluated for change.

The findings of this dissertation have implications for the SCD transition literature as well as the medical student education literature. The interpretation of the findings within the context of

the published literature is presented for each aim. The implications of the findings from this research as well as the strengths and limitations of the dissertation are discussed. Finally, clinical implications and directions for future research are addressed.

### **Phase 1, Aim 1: Barriers to Transition and Intervention Targets**

Young adults in our study reported barriers to transition and unmet needs that aligned with the SMART framework, including lack of disease knowledge, self-management skills, and healthcare navigation skills. These results are consistent with prior research, who reported similar barriers to transition for AYAs preparing to transition to adult care (Mulchan et al., 2016; Porter et al., 2017). Despite the older age of our pre-transition population compared to other studies examining barriers to transition care and self-management (Porter et al., 2017), our participants highlighted that unmet knowledge and support needs persisted even into young adulthood. The young adults post-transition reported that they needed a new skill set to help them manage their care and overall health as they moved into the adult healthcare setting and through other life transitions (e.g., college, moving away from home). Participants reported a loss of care coordination and healthcare navigation provided by the pediatric team. A novel finding in our sample was that participants articulated a loss of other support resources, such as educational and vocational support services, during the transition. Thus, in addition to targeting healthcare navigation skills as part of our transition intervention, an emphasis on independent living skills as well as connecting patients to relevant community resources was needed. These results informed the content of our transition intervention, which included SCD education, self-management skills, healthcare navigation skills, pain management, healthy lifestyle behaviors, appropriate expectations for the emergency room, patient-provider communication, self-advocacy, expectations for adult care, and community support resources.

Consistent with a prior survey of young adults with SCD, the majority of participants expressed communication preferences for intervention delivery using technologically-based methods that could be accessed at home such as text messaging, phone calls, or video chats (Williams et al., 2015), with fewer participants being interested in an in-person intervention. At least half of the participants were willing to communicate at least once per week with the mentor, consistent with the recommended dosing for mentor relationships (Ahola Kohut et al., 2016; Olshan, 2018; Stinson et al., 2016).

Among participants in the current study, there was high receptivity to the idea of having a medical student serving as a mentor to assist with the transition. Participants expressed interest for different reasons, including the direct benefit of being in close contact with someone connected to the medical system, having a new source of social support, and wanting to educate the next generation of doctors about SCD to promote awareness about the disease. Mentoring has been found to be an acceptable method of intervention among other adolescents and young adults with chronic illnesses such as irritable bowel disease, juvenile arthritis, chronic pain, and juvenile diabetes (Ahola Kohut et al., 2016; Mackner et al., 2014); however, these studies utilized patient peers as mentors rather than medical students.

### **Phase 2, Aim 2: Program Feasibility**

Feasibility among medical students was assessed through recruitment, adherence, completion, and satisfaction with the program. Nine medical students enrolled in the study and completed all requirements of the program. Medical students were able to devote an average of one hour per week to their mentee, consistent with prior research demonstrating that medical students actively participate in extra-curricular activities (Cirone & Saks, 2015; Viola et al., 2019). Of note, the medical students who participated in this program were not demographically

representative of the make-up of the medical school. For example, more females than males participated, whereas the class is nearly evenly split between males and females. Additionally, there were five (out of nine) Black/African American mentors, whereas the medical student population is only about 8% Black/African American. Minority students may have been more interested than their peers in working with a predominantly minority patient population.

Medical students reported high satisfaction with the program, including the mentor training, program materials, and relationship with their mentees. Consistent with prior research that utilized medical student mentors (George et al., 2015; Vijn et al., 2017), medical students felt that this experience deepened their understanding of barriers to health and enhanced their didactic medical education about topics like managing a chronic illness and transitions of care. Therefore, a mentor intervention like ours is one strategy to address gaps in training regarding the management of chronic illness and the transition from pediatric to adult care reported by physicians (Darer et al., 2004; Montenegro et al., 2014) and pediatric and internal medicine residents (Patel & O'Hare, 2010).

Mentors found the length and content of the mentor training adequate in preparing them for their mentor relationship and the educational calls. In other studies of peer mentoring, length of training has varied from thirty minutes to twenty hours of face-to-face training (Ahola Kohut et al., 2017; Douglas et al., 2018; Westerlung et al., 2006). Like our program, two other programs (Ahola Kohut et al., 2017; Jerson et al., 2013) also provided training manuals. Our mentors reported referring to their manuals for almost every video call, and this resource is something that would be updated continually for future iterations of the program. Thus, we concluded that this program was feasible and acceptable to medical student mentors.

Feasibility was assessed among patient participants through benchmarks of study enrollment rate (>50% of eligible individuals), retention rate (>80% complete all surveys), and adherence to the intervention (percentage of monthly calls completed, >60%). We were able to reach 28 out of the 36 eligible participants (80.6%), with 21 out of those 28 consenting to participate in the intervention (75%). Out of the 21 participants who completed the baseline measurements, 16 completed the intervention for a retention rate of 76.2%, just short of our 80% benchmark. Other studies of transition interventions for young adults with SCD have shown similar or worse rates of retention. Interventions delivered in conjunction with clinic appointments generally had higher rates (range: 50%–100%; Allemang et al., Crosby et al., 2017; Calhoun et al., 2019; Smith et al., 2011 ), whereas interventions that required participant involvement outside of dedicated clinic time had lower rates (40%–45.8%; Hankins et al., 2012; Rodger-Melnick et al., 2017). Our rate of nearly 80% surpassed any of the current published studies of interventions delivered outside of the clinic setting and was in line with interventions delivered in conjunction with clinic appointments. Despite our intervention taking place outside of clinic time, the use of digital methods (text messaging and video calls) allowed participants to fit the intervention into their schedule. Virtual meetings with their mentors also removed geographic and transportation barriers that often limit patient participation to interventions. AYAs are digital natives and high utilizers of technology. It may be important for researchers to consider using digital modalities into transition interventions to improve retention and adherence.

Adherence to the intervention was high (on average, 5.1 out of 6 calls or 85.0%). Most participants who completed one call went on to complete all six calls. The most common time of dropout was between completing baseline and the first phone call. Mentors were required to send a text message to their mentees on the day of mentee recruitment, but there was no deadline for

scheduling or completing the first call. The consistent drop out at this time point may suggest that a text message contact is not enough to sufficiently engage the mentee or initiate the relationship. Future iterations of this intervention could potentially benefit from an in-person meeting of the mentee and mentor at baseline, or by requiring the first phone call to occur within one week of completing the baseline measures. Some of the reasons for dropout were unavoidable (severe illness, becoming homeless) and speak to the complexity of the disease and the issues faced by young adults during this developmental period of transition. It is also of note that participants who did not complete any calls (loss to follow-up following baseline assessment) were younger on average than those who completed the program. The youngest participants recruited in our study were 18 years old, and current recommendations for transition planning suggest beginning preparations as early as 12 years old (American Academy of Pediatrics, 2002). However, younger patients, particularly at our institution where the age of transition is typically 23-years-old, may not feel a sense of urgency about transition preparations, thus limiting their engagement with the program.

Satisfaction with the intervention was very high, including the content and frequency of the text messages and the content of the video chat calls. Although participants were largely satisfied with the content of the monthly calls, they suggested adding more information about health insurance. This is consistent with patient reports of changing or losing insurance during the time of transition, creating additional obstacles in the transition process (Bemrich-Stolz et al., 2015). The most common critique of the program was that the video chat calls should have been more frequent (e.g., two times per month versus one time per month), which is an important consideration for refining the intervention.



Patients also reported high satisfaction with their mentor relationships, demonstrated by high scores on the working alliance scales and qualitative remarks during exit interviews. Social support meets an important developmental need of AYAs (Bell et al., 2008; Domhardt et al., 2015), and the interpersonal support offered by a one-on-one relationship with a mentor may offer psychosocial benefits above and beyond the educational component of the intervention. Medical students were chosen as mentors because they uniquely have specialized knowledge of the healthcare system and serve as a similar-aged “peer” who can offer developmentally appropriate support to the patient. Patients reported that the medical students were relatable and that being similarly aged made them easy to talk to. The patients also appreciated the medical students’ perspective and knowledge about the healthcare system.

An important piece of feedback from mentee participants was the request to add a peer group component to the intervention. Suggestions for the group component were varied with some suggesting an in-person meeting and others preferring the use of digital groups (text messaging or through social media). Consistent with prior research (de Montalembert & Guitton, 2013), many of the patients with SCD reported that they did not know anyone else with the disease or only knew one or two people. Future iterations of the program should consider adding a group component, either in-person group meetings of mentees or virtual meetings utilizing social media (e.g., Facebook group, WhatsApp text messaging group) so that AYAs could talk with one another in addition to talking to their mentor. There is a clear demonstrated need for social support in this patient population that could be targeted through multiple avenues.

### **Aim 3: Preliminary Efficacy (Exploratory Aim)**

The goal of this intervention was to determine feasibility, so the analyses of change in psychosocial outcomes were exploratory, and only had statistical power to detect large effects. Thus, these findings are interpreted with caution.

Medical students demonstrated a significant increase in SCD knowledge following a four-hour training. This indicates that the students were able to absorb and apply the new information learned within a short time frame. In the future, it might be important to assess medical student knowledge over time to see if this increase in knowledge is maintained for the duration of the program.

Medical student mentors demonstrated non-significant changes in attitudes towards chronic illness. At baseline, medical students reported high comfort levels with dealing with patients with chronic illness. The slight reduction in comfort may have been a result of learning more about the complexity of coordinating and managing the care of a chronically ill patient. As our medical student mentors were all in their first year of medical school, most had limited experience with patient management. Realizing how many factors contribute to patient care, and learning about barriers to care may have made the medical students realize how much more they needed to learn.

Although physician attitudes and predispositions towards patients can be difficult to change (Haywood et al., 2010), a prior intervention exposing physicians to listen to patient stories about the challenges they face led to improved attitudes. Specifically, physicians were randomized to watch an 8-minute video of three adult SCD patients discussing the barriers they faced when seeking treatment for pain. Physicians in the intervention group showed a significant reduction in negative attitudes towards patients SCD and decreased the extent to which they perceived certain behaviors as concern raising (Haywood et al., 2010). The authors concluded that exposure to

patients outside of a traditional clinical setting and a typical patient-provider dynamic could reduce negative attitudes towards patients (Haywood et al., 2010). Our lack of significant findings in changing attitudes towards chronic illness in this sample may be due to lack of prior experience with real patients or may be a result of the measure used to capture attitudes towards chronic illness. However, it stands to reason that exposing rising physicians to patients with SCD may reduce negative attitudes towards these patients moving forward.

Our qualitative results suggested that mentors experienced benefits from participating that were not captured in our quantitative data, such as increased knowledge about managing a chronic illness, increased knowledge about transition, enhanced empathy for patients navigating the complex healthcare system, improved skills in patient communication, and greater understanding barriers to healthcare. This is similar to prior work that found being a peer mentor enhanced leadership skills, increased confidence, and improved problem-solving and interpersonal skills (Douglas et al., 2018). These outcomes may be prudent to explore in the future as other potential benefits of participation in the program. It would also be valuable to follow these students over the course of their medical education and assess how this experience affected their medical education. Comparing students who participated in the program to students who did not over time would help determine if participants experienced lasting changes in attitudes towards chronic illness or compassion.

Patient participants demonstrated promising improvements in transition readiness, self-efficacy, and medication adherence, but non-significant improvements in knowledge, possibly due to high levels of knowledge demonstrated at baseline (19 out of 24 items correct) on this measure.

The significant increase in transition readiness was largely driven by improvements in healthcare knowledge/skills and independent living skills. This is one of the first studies of youth

with SCD to demonstrate improved transition readiness after a program. Another intervention, which used a patient navigator to help young adults get appointments in the adult clinic, also found improved transition readiness among participants (Manwani et al., 2017). Assessing transition readiness has been a barrier in delivering high-quality transition care with few programs assessing transition readiness at multiple time-points or at all (Sobota et al., 2014). However, there has been a call for evidence-based assessment of transition readiness for AYAs with SCD and other chronic illnesses (Schwartz et al., 2018). This study was a first step in establishing benchmark values for transition readiness, and capturing changes associated with a transition readiness intervention. Repeated use of transition readiness tools, tracked with patient clinical outcomes could be used to establish a critical threshold that indicates when a patient is developmentally ready to transition to adult care. There is still debate about how to best measure transition readiness, and the TIP-RFT is just one of two disease-specific tools. More studies should be conducted using this and other SCD specific transition readiness tools to confirm which tool has the most utility in a clinical setting.

We also found significant improvements in self-efficacy, consistent with previous studies (Crosby et al., 2017). This is important as self-efficacy has been associated with reduced healthcare use and improved health outcomes including HRQOL (Goldstein-Leever et al., 2018). Among AYA with SCD, disease self-efficacy has also been associated with increased readiness to transition (Treadwell et al., 2016; Molter & Abrahamson, 2015). Self-efficacy is an important underlying mechanism for achieving better self-management (Jenerette & Phillips, 2006). Edwards and colleagues (2001) demonstrated that adolescents with SCD who display higher self-efficacy also engaged in more self-care behaviors such as drinking enough fluids and taking

prescribed medication. Interventions that increase self-efficacy may, in turn, adjust and increase participant's self-management behaviors and contribute to better health outcomes.

Similar to previous studies demonstrating an increase in medication adherence after working with a patient navigator (Allemang et al., 2018), AYA in our study demonstrated significant improvement in medication adherence after working with a medical student mentor. Like Allemang and colleagues' patient navigator intervention, our medical student mentor intervention also focused on providing social support for patients. Social support interventions have been shown to be associated with higher levels of medication adherence across multiple disease populations (Boardman, McCann, & Kerr, 2014; Mondesir et al., 2018), and the impact of the support, as well as adherence strategies provided by the mentor, could have contributed to our findings of increased adherence. Future studies might more closely examine the role of social support in promoting adherence, or capture patient's perceptions of their support around adherence pre- and post-intervention to determine if social support contributed to the increased positive behavior. Despite improvements in medication adherents, participants reported categorically low levels of medication adherence at both time points. Poor adherence is common among AYA with SCD (Badawy et al., 2017). Despite improvements, the low levels suggest additional intervention may be needed to improve adherence even more.

Age, sex, and working alliance were not significantly associated with changes in any of the psychosocial outcomes; however, there was some indication that completing all sessions (versus not completing all sessions) was associated with a greater increase in transition readiness and SCD knowledge. A larger sample size would have allowed us to explore a dose-response relationship between intervention sessions and patient outcomes more directly, but these initial findings indicate that six sessions was adequate to see improvement in some outcomes. Patient participants

reported satisfaction with the dose of the intervention overall, but a few participants reported that they would have preferred more video call sessions. Future research investigating the impact of varied doses of the intervention should be done to determine the number of sessions required for the greatest impact.

## **Strengths and Limitations**

### ***Formative Qualitative Study (Aim 1)***

The major strength of the formative phase of this dissertation research was the use of a theory-driven and patient-centered approach to addressing the needs and overcoming the barriers of young adults preparing to transition. Incorporating the unique needs of AYAs with SCD is important for tailoring interventions directed to improve their transition outcomes.

The formative qualitative study had some important limitations. Our focus was on young adults and did not consider the perspectives of other stakeholders such as parents and providers. Including the voices of caregivers and providers could have enhanced the findings of barriers to SCD transition. Additionally, we only interviewed a sample of young adults from one hospital system. Our patients were recruited from a comprehensive sickle cell center that provides a direct referral to an adult hematology clinic located within the same hospital system. Lack of adult providers who treat patients with SCD is an important barrier that our patients did not have to overcome (Mainous et al., 2015; Telfair et al., 2004). However, while our hospital system may represent an “ideal” system within which to transition given both pediatric and adult providers in the same system, barriers and concerns that remain for these patients even within this system represent important barriers to overcome. Our findings were also largely consistent with prior research of reported barriers to transition for AYA with SCD, giving more weight to the importance of addressing these barriers (Mulchan et al., 2016; Porter et al., 2017).

### ***Feasibility and Acceptability Study (Aim 2 and 3)***

The major strengths of this phase of the dissertation included the involvement of a multi-disciplinary team, patient-centered intervention design, and the low cost and resource requirements of the intervention that could lead to easier implementation in other settings. Both pediatric and adult hematology providers contributed to the development, refinement, and delivery of the content of the intervention and mentor training.

In addition to clinician involvement, the process for intervention development and refinement was patient-centered. User-centered approaches to intervention development incorporate the needs of the “end-user” into intervention content and delivery, allowing for the development of a tailored product. The formative phase of this dissertation identified the needs of the patients the intervention was intending to serve. The use of a patient advisory board maintained patient engagement throughout intervention development and served a role in educating and training the mentors.

Finally, the low cost and resources required for implementing the program make it easier to implement in other settings. Future iterations would only require a study coordinator to continue patient recruitment and mentor pairing. Medical students could train and recruit future “generations” of mentors to keep the program functional. In resource-poor settings, this type of intervention offers a feasible option for implementing transition programming for AYAs.

The findings of this study are limited by the use of a small sample from one clinical center, which may not be representative of all AYA with SCD. While appropriate for feasibility testing, the findings from this dissertation may not be generalizable to patients with SCD more broadly. The small sample also limited the statistical power to detect changes in the psychosocial outcomes, and as such, these findings must be interpreted cautiously. The study was not randomized and

participants in this study were self-selected, which also poses a limitation to determining the efficacy of the intervention. Selection bias, in which more motivated patients were more likely to participate in the program, could lead to better overall adherence to the program and improvements in transition readiness indicators. Participants and non-participants did not vary significantly in demographic factors, but may have differed by some unmeasured factors.

The data used to assess psychosocial outcomes are self-reported and subject to desirability bias and reporting bias. However, to minimize bias we used valid and reliable measures. Almost all of the measures demonstrated adequate internal consistency within our sample, except two subscales of the measure of transition readiness (education and vocation skill set, and social support skill set). Lack of validated transition readiness measures has been attributed to low rates of routine transition readiness assessment in clinical practice (Schwartz et al., 2018). In a review of transition readiness measures, the authors identified six generic measures of transition readiness, and seven disease-specific measures, of which two were specific to SCD (TIP-RFT and the Sickle Cell Transfer Questionnaire). Of the two SCD specific measures, both demonstrated construct validity, and the TIP-RFT also demonstrated high internal consistency except for one subscale (Treadwell et al., 2016a; Treadwell et al., 2016b). We selected the TIP-RFT due to its specificity to SCD and psychometric properties, but further research should investigate the use of other measures or utilize other quality indicators for transition (Sobota, Shah, & Mack, 2016).

Our sample excluded individuals with self-report or clinician report of cognitive delay. Patients with SCD are at increased risk for neurocognitive impairment due to complications of the disease such as stroke, silent infarct, and chronic anemia (Bryant et al., 2014). Patients with SCD who suffer from neurocognitive impairment may be at even greater risk of unsuccessful transition (Mulchan et al., 2016), and require refined and specifically tailored interventions to address their



unique needs. Future research should consider intervention modifications to meet the needs of this population.

Finally, our study was a single-arm feasibility and acceptability study. Thus, results could reflect spontaneous or natural history improvement. Future studies should include a control group and an adequate sample size to evaluate the efficacy of the intervention (Leon et al., 2011).

### **Implications for Practice and Future Directions**

In conclusion, a medical student mentor program to improve transition from pediatric to adult care for young adults with SCD is both feasible and acceptable to patients and medical students. The promising results warrant further study in an adequately powered randomized controlled trial to examine the efficacy of the intervention on psychosocial outcomes. Future research might also include other health professional students (nursing, psychology, physician assistant) as mentors in addition to medical students, as they would also be similarly aged to the AYA patients with the same experiential similarity of being integrated into the healthcare system, and could provide a larger pool of possible transition mentors.

Our study used one measure of transition readiness available for young adults with SCD in addition to other evidence-based indicators of self-management and a successful transition including self-efficacy, knowledge, medication adherence, and health literacy (Andemariam et al., 2014; Stollon et al., 2015). There has been widespread disagreement of transition quality indicators in SCD. A recent Delphi study (Sobota, Shah, & Mack, 2016) identified key transition indicators: process measures (i.e., counseling about transition, written transfer summary, direct communication between providers during transfer, interval of first appointment with adult provider), patient factors (i.e., patient keeps appointments, medication and treatment adherence, self-efficacy), and outcome measures (i.e., quality of life, trust in adult provider). The markers

identified in the Delphi survey were largely inconsistent with measures used in the published literature (ER visits, disease-specific knowledge, and re-admission rates). Our study used indicators that aligned most closely with the identified patient factors and outcomes measures, but did not consider process measures as indicators of effectiveness. Future research is warranted to identify the most important quality indicators and predictors of a successful transition to more effectively evaluate transition programs.

### **Concluding Remarks**

Young adults with SCD have significant medical, psychosocial, and educational needs that require targeted interventions to appropriately address barriers to transition. The SMART framework provided an appropriate starting point for identifying modifiable factors that could be addressed by a program to improve transition readiness among young adults with SCD. The findings in this dissertation suggest that a medical student mentor intervention is both feasible and acceptable to both patients with SCD and medical students. Furthermore, such an intervention may provide dual benefit for both patients and students. This dissertation highlights the need for further research on the efficacy of this transition program, including psychosocial and medical outcomes of care.

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