

2022

Readiness of Adolescent and Young Sickle Cell Patients to Transition from Pediatric to Adult Care

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Walden University

College of Health Professions

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Tanisha D. Belton

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Walden University
2022

Abstract

Readiness of Adolescent and Young Sickle Cell Patients to Transition from Pediatric to

Adult Care

by

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MPH, Walden University, 2011

BS, West Chester University, 2008

Doctoral Study Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Public Health

Walden University

November 2022

Abstract

Patients with sickle cell disease (SCD) face many challenges as they enter adulthood; therefore, preparing for the transition to adult care is crucial. Assessing the knowledge and skills adolescents and young adults (AYAs) possess before transitioning to adult care can aid in the success of their transition. However, a gap exists regarding factors attributed to guiding patients' sense of readiness. The purpose of this quantitative study, driven by the theory of self-care management of SCD, was to examine the self-perceived readiness of SCD patients as they prepare to transition to adult care. Cross-sectional survey data were collected from 68 sickle cell patients from a center in the northeastern U.S. Data analysis was conducted to examine the differences in readiness among AYAs based on several experiences and self-management skills. Data were analyzed using descriptive statistics, composite scores, Cronbach's alpha test, and linear regression techniques. Meeting with an adult care provider was shown to have a positive impact on young adults' self-perceived readiness ($F(4,51) = 9.975, p < .001$). Results also indicate a significant association between self-perceived readiness and one's perceptions of adult-oriented care ($F(4,51) = 12.092, p < .001$). The social change implications of these findings include guiding the development of transition programs that are more targeted at meeting the transition needs of young adults with SCD.

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Dedication

This doctoral study is dedicated to my two amazing children, Kennadi, and Caleb, who were the reason I started this journey. Mommy loves you both so very much!

Acknowledgements

This journey has been one I could not have completed without the support from those around me. To my family and friends, your support has meant more to me than you will ever know. The constant encouragement and motivation pushed me in so many ways. To my coworkers, thank you for always checking in on me to make sure I stayed on track. To Dr. Sharma, Dr. Tawfik, and Dr. Kyulo, thank you for your guidance and direction throughout this process. Finally, thank you to Dr. Angela Ellison for allowing me access to her research data.

Table of Contents

List of Tables	iv
List of Figures	v
Section 1: Foundation of the Study and Literature Review	1
Introduction.....	1
Background of the Problem	2
Problem Statement	3
Purpose of the Study	4
Research Questions and Hypotheses	5
Theoretical Foundation for the Study	6
Nature of the Study	7
Definitions of Terms	8
Assumptions.....	9
Scope and Delimitations	10
Limitations	10
Literature Review.....	10
Search Strategy	12
Transition Readiness	12
Challenges Faced by SCD patients	14
Youth Transition Programs.....	16
SCD Transition Programs	21
The Transition Readiness Assessment Questionnaire	24

Summary	27
Section 2: Research Design and Data Collection	28
Research Design and Rationale	28
Methodology	30
Population	30
Sample Size.....	30
Data Collection	31
Instrumentation	32
Operationalization.....	33
Data Analysis Plan	35
Threats to Validity	38
Ethical Procedures	39
Summary	40
Section 3: Presentation of the Results and Findings Section	41
Introduction.....	41
Data Collection Methods	41
Descriptive Statistics.....	41
Testing Assumptions.....	44
Results.....	44
Research Question 1	44
Research Question 2	45
Summary	46

Section 4: Application to Professional Practice and Implications for Social

Change	47
Interpretation of the Findings.....	47
Limitations and Recommendations for Future Research.....	50
Implications for Practice and Social Change	51
Conclusions.....	52
References.....	53

List of Tables

Table 1. Operationalization of Variables	33
Table 2. Descriptive Statistics for the Sample	43
Table 3. Parameter Estimates Predicting TRAQ for Research Question 1	45
Table 4. Parameter Estimates Predicting TRAQ for Research Question 2.....	46

List of Figures

Figure 1. Theory of Self Care Management for Sickle Cell Disease..... 7

Figure 2. Power Analysis for Hierarchical Linear Regression 31

Section 1: Foundation of the Study and Literature Review

Introduction

Sickle cell disease (SCD) is an inherited blood disorder estimated to affect a total of 100,000 persons within the United States and is associated with considerable morbidity and early mortality (Centers for Disease Control and Prevention [CDC], 2020). Over the past 40 years, life expectancy for patients with SCD has improved significantly in high-income countries, with an average survival of more than 60 years (Piel et al., 2017). The importance of transitioning from pediatric to adult care providers has been documented, and barriers to effective transition have been identified. However, factors attributed to guiding patients' sense of readiness, such as knowledge and self-management skills in preparation for transition, have not been established (Bemrich-Stolz et al., 2015). Barriers to successful transition include lack of knowledge of the SCD adult health care system, limited decision-making experience, and loss of health insurance coverage (Bemrich-Stolz et al., 2015).

Transition refers to the transfer of medical care between pediatric and adult providers. Ideally, this process incorporates a broader understanding of the patient's concurrent developmental tasks, such as establishing independence in relationships and self-care management (Tuchman et al., 2010). For patients with SCD, transitioning from pediatric to adult providers marks a vulnerable period. It has been noted that youth with SCD have elevated rates of acute health care utilization and hospitalization during the transition, which is indicated by a higher number of total hospital days, increased

emergency department and urgent care visits leading to disproportionate care delivery in the acute setting (Blinder et al., 2015).

Background of the Problem

Sickle cell anemia is a public health concern that is linked to higher levels of health care utilization. As youth enter adulthood, the risks associated with the disease continue to grow. Informing providers and health care professionals of youths' self-perceived readiness to transition can aid in the development of more detailed and patient-oriented transition programs. Literature has pointed out curricula such as the Sickle Cell Disease Age Based-Curriculum (SCD-ABC) Transition program as an effective tool for improving knowledge (Griffin et al., 2013). The SCD-ABC transition program includes an SCD community needs assessment, an annual patient and family education day, an SCD teen clinic, and a transition day event. This program's success depends on engagement from various stakeholders, which may not be applicable or accessible on a national level due to limited support from community stakeholders and providers to implement the program's components (Griffin et al., 2013). Acknowledging and assessing their readiness can help to increase their knowledge before transitioning, making for a more successful transition. Understanding areas in which youth lack knowledge, such as medication adherence, appointment keeping, and other self-advocacy skills, can support families and social workers, health insurance companies, and other stakeholders involved in transitioning to adult care, contributing to social change.

Reviews of health care utilization showed that young adults with sickle cell anemia ages 18–30 show a high need for hospital-based care and utilize the emergency

room twice as much as patients aged 10–17 years due to the challenges encountered during the transition period (Lebensburger et al., 2012). Adults living with SCD face increased morbidities, including multiorgan failure, chronic pain, and neurocognitive deficits. This growing demand for healthcare has revealed the limited number of providers patients have access to, therefore potentially contributing to the utilization of emergency rooms and urgent care facilities (Evensen et al., 2016). Procuring a successful transition from pediatric to adult care is necessary for disease management and maintaining access to health care services (Porter et al., 2014).

Researchers have stressed the barriers and issues around successful transition. But few have explored the factors that guide patients' sense of readiness, such as knowledge and self-management skills necessary for preparation for transition. This study can help to strengthen existing transition programs and assist in the development of new transition programs. Implications for positive social change from this study include gaining a better understanding of the needs of patients preparing for transition. Ensuring that adolescents successfully transition will help in the reduction of health care utilization costs and potentially reduce the morbidity and mortality associated with SCD. This study will also support the need for transition to be a fluid, ongoing process with patients, families, and healthcare providers (Porter et al., 2014).

Problem Statement

The many advances in treatment for those living with SCD have increased the life expectancy among this population. Nevertheless, during the age of transition from pediatric to adult care, AYAs are faced with significant challenges. Among SCD patients

18 years and older, there has been an increasing number of acute care encounters, rehospitalizations, and deaths that have been reported shortly after transfer to adult care (Brousseau et al., 2010; Johnson et al., 2020). It is noted that \$25 to \$45 billion health care dollars have been lost due to inept transitional care methods, including unnecessary health complications, frequent emergency department visits, and hospital admissions (Brousseau et al., 2010; Johnson et al., 2020). Difficulty in coordinating care during the transition process is a contributing factor to the overwhelming increase in mortality and acute care utilization (DeBaun & Telfair, 2012). The literature stresses the need to develop and expand the components of transition programs to reduce the mortality increases among this population. By further understanding the gaps in self-management skills at a young age for SCD patients, transition programs can tailor to meet the needs of youth before the transition period.

Purpose of the Study

The purpose of this quantitative study was to determine the impact of meeting with an adult provider and perceptions of adult-oriented care (PAOC) on youth (ages 15–21) self-perceived readiness to transition to adult care assessed through skills of self-advocacy and self-management. The study was conducted to assess self-perceived readiness by exploring skills necessary for young adults to transition to adult care successfully. In this study, I examined youth ages 15–21 self-perceived readiness to transition from the pediatric to the adult care setting in Philadelphia, Pennsylvania. The survey data collected from a sickle cell center in Philadelphia used for this study include survey questions assessing whether the young adult has met with an adult provider during

the transition process and self-management and self-advocacy skills. This study provides insights regarding the transition process and contribute to developing effective transition programs to improve outcomes among this population.

Research Questions and Hypotheses

Research Question 1 (RQ1): Is there an association between meeting with an adult care provider and self-perceived readiness to adult care transition among youth aged 15–21 years old diagnosed with SCD in Philadelphia, PA, while controlling for gender, ethnicity, and education?

H₀1: There is not an association between meeting with an adult care provider and self-perceived readiness to adult care transition among youth aged 15–21 years old diagnosed with SCD in Philadelphia, PA, while controlling for gender, ethnicity, and education.

H_a1: There is an association between meeting with an adult care provider and self-perceived readiness to adult care transition among youth aged 15–21 years old diagnosed with SCD in Philadelphia, PA, while controlling for gender, ethnicity, and education.

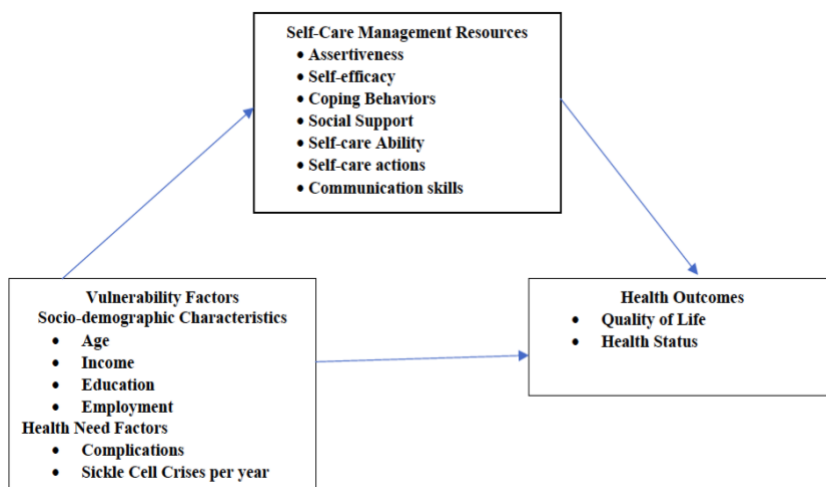
Research Question 2 (RQ2): Is there an association between PAOC and self-perceived readiness to adult care transition among youth aged 15–21 years old diagnosed with SCD in Philadelphia, PA, while controlling for gender, ethnicity, and education?

H₀2: There is not an association between PAOC and self-perceived readiness to adult care transition among youth aged 15–21 years old diagnosed with SCD in Philadelphia, PA, while controlling for gender, ethnicity, and education.

H_{a2}: There is an association between PAOC and self-perceived readiness to adult care transition among youth aged 15–21 years old diagnosed with SCD in Philadelphia, PA, while controlling for gender, ethnicity, and education.

Theoretical Foundation for the Study

The theory of self-care management for sickle cell disease provides the framework for this study. The theory of self-care management for sickle cell disease is based on the theory of self-care management for vulnerable populations, which was created to “describe variables that influence self-care management, health status, and quality of life among people who experience or are at risk for health disparities” (Jenerette & Murdaugh, 2008, p.357). According to the theory of self-care management for sickle cell disease, vulnerability and health care factors can negatively affect self-care management resources. However, self-care management of SCD positively mediates the association between health outcomes and vulnerability factors (Jenerette & Murdaugh, 2008). See Figure 1 for an illustration of the applicability of the theory to this study.

Figure 1*Theory of Self Care Management for Sickle Cell Disease***Nature of the Study**

The nature of this study is quantitative research with a cross-sectional observational design. Observational studies are used to evaluate the distribution of characteristics or events, looking for possible associations between specific traits and health outcomes (Gallin & Ognibene, 2012). Collected data for this study was from young adults with SCD who receive care from The Comprehensive Sickle Cell Center at The Children's Hospital of Philadelphia.

This study assessed youth's self-perceived readiness to transition to adult care by examining their self-management skills and PAOC through the Transition Readiness Assessment Questionnaire (TRAQ) and a modified version of the patient assessment of health care survey. The survey contained questions around demographics, managing medications, appointment keeping, tracking health issues, talking with providers,

managing daily activities, and perceptions of healthcare. The TRAQ is divided into four subscales, and they are scored by taking the average score from the responses which are scored one to five, with one being assigned to “No, I do not know how” and five being assigned to “Yes, I always do this when I need to.” The modified version of the patient assessment of health care survey is scored by taking an average score from the responses, which are scored one to five, with one being assigned to “strongly disagree” and five being assigned to “strongly agree.” All patients aged 15–21 years old with SCD seen in the clinic during the study recruitment phase were eligible for survey completion. The only exclusion criterion was the history of a stroke.

Definitions of Terms

Adolescents and Young Adults (AYAs): This refers to the population of this study that includes individuals between the ages of 15 and 21.

Appointment keeping: This refers to skills associated with scheduling, attending, and managing doctor’s appointments.

Health care transition: This refers to moving from pediatric to adult-oriented medicine (Reiss et al., 2005).

Managing daily activities: This refers to skills associated with the management of household responsibilities.

Managing medications: This refers to skills associated with taking prescribed medications.

Self-efficacy: This refers to the belief in one’s ability to initiate health behavior change, complete health-related tasks, and reach health goals (Treadwell et al., 2016).

Self-management skills: This refers to taking responsibility for one's behavior and well-being.

Sickle cell disease (SCD): This refers to a genetically inherited disorder of the hemoglobin that can lead to serious health complications, including infection, stroke, and acute and chronic pain (Bulgin et al., 2018).

Talking with providers: This refers to skills associated with communication with providers.

Tracking health issues: This refers to skills associated with tracking one's medical history and keeping track of scheduled or upcoming medical appointments.

Transition readiness: This refers to indicators that patients and those in their support system can begin, continue, and finish the transition process from child-centered to adult-oriented healthcare through the event of transfer (Schwartz et al., 2013).

Assumptions

A few assumptions should be considered in this study. First, I assumed the participants responded honestly to the survey questions and that it is also believed that the characteristics measured in this survey relate to one's perceived readiness to transition to adult care. It is essential to mention the assumption that the study's findings will be generalizable to the field of SCD and young adults ages fifteen to twenty-one preparing for transition.

Further, I believed that self-perceived readiness contributes to a successful transition to adult care among young adults with chronic diseases, specifically SCD. Therefore, self-efficacy and knowledge were assumed to be associated with better

preparation for the transition of care. This assumption is critical to the meaningfulness of the study as it will assist in showing the importance of skill-building and self-efficacy of young adults before to the transition of care. It is essential to assume that increasing skills related to disease management helps in the transition process. If it were felt that such skills had no positive effect on youths' self-perceived readiness, there would be no indications to study.

Scope and Delimitations

The scope of this study includes patients with SCD who are at an age to begin the discussion to prepare for transition to an adult provider, 15 to 21 years old. The population identified in this study are male and female AYAs adults living in the northeastern United States with SCD. Statements made about the results of this study will be generalizable to young adults with SCD living in the United States.

Limitations

The results of this study will be limited to the relationship and correlation of the independent variables (meeting with an adult provider, and PAOC) and the dependent variable (self-perceived readiness). Covariates for external validity (gender, ethnicity, and education) for self-perceived readiness were used to describe the population. Internal validity for accuracy of the information on self-advocacy and self-management skills could affect the results of this study.

Literature Review

SCD is the most common genetic blood disorder in the United States, affecting about 100,000 Americans, and it occurs in one out of every 365 Black or African

American births (Matthie et al., 2016; CDC, 2020). The disease is associated with “abnormal hemoglobin and sickle-shaped red blood cells that result in vaso-occlusion, ischemia, tissue damage, progressive organ damage, and early death” (Matthie et al., 2016, p.1442). The number of patients with SCD continues to increase due to the gains in life expectancy among those affected due to newborn screening, primary stroke prevention, and hydroxyurea treatment (Piel et al., 2017). Life expectancy has improved over the past 40 years, with life expectancy being close to that in the general population, 60 years.

SCD is nationally and internationally associated with pain, high health care costs, and impaired quality of life. SCD is characterized by chronic pain with acute, severe pain, known as a pain crisis, that occurs throughout life and are often unpredictable. Disease management primarily occurs at home, focusing on pain management, hydration, and preventing complications that result in a pain crisis (Matthie et al., 2016).

Young adults with SCD are faced with health-related challenges while navigating an unfamiliar adult health system. Research has shown that approximately 1.8 years after young adults’ transition from pediatric to adult care, there is a high risk of early death. Young adults have limited knowledge of the adult SCD care system and limited decision-making experience, which poses challenges when faced with the phase of transition (Matthie et al., 2016).

To support youth in the transition process, it is necessary to understand the skills related to self-management and readiness to transition. This study addressed the self-perceived readiness of youth 15 to 21 years old living with SCD in Philadelphia,

Pennsylvania to transition from pediatric to adult care. The purpose of this chapter is to discuss existing research related to SCD, the transition to adult care, and the experiences of young adults with SCD.

Search Strategy

For this analysis, I accessed several online databases through Walden University's online library, including Academic Search Complete, ProQuest, Embase, PubMed, and Science Direct. Search terms included *sickle cell disease, children and sickle cell disease, transition, young adults and healthcare transition, sickle cell transition, transition readiness assessments, transition programs, transition readiness, and bio-social ecological model.*

Transition Readiness

Due to the increase in the life expectancy of AYAs with chronic diseases in the past 50 years, now more than 90% of them will survive into adulthood (Feinstein et al., 2017). This increase supports the need for focusing on transitioning from the pediatric health care system to adult care. To date, for AYAs with SCD, transition recommendations have been solely based on expert opinions or single-center non-randomized trials. There remains a need to establish consensus metrics for the transition of SCD patients from pediatric to adult healthcare (Feinstein et al., 2017).

Transition is defined as adolescents moving from child-centered to adult-centered health care (Speller-Brown et al., 2015). Transition readiness is the decisions and actions taken to build the ability of the AYAs, parents, and providers to prepare for transition and see it through to finish the transition process (Speller-Brown et al., 2015). It is

recommended for patients with special health care needs that the transition process should begin early in adolescence, between ages 12–14 years. To begin, in the clinical practice, a discussion regarding the transition policy should take place with both youth and parents, with the process continuing over time to ensure readiness and planning for adult-centered care at age 18 and for transfer to an adult provider before the age of 22 (McManus et al., 2015).

In AYA's with SCD, poor transition has been associated with a lack of continuity of care, disengagement from services, and increased morbidity and mortality. Poor transition does not only affect young adults, but it also has an impact on the health care system (Speller-Brown et al., 2015). The impacts of poor transition on the health care system and the AYA's living with SCD points to the importance of a successful transition (Speller-Brown et al., 2015).

When planning for transition, improving self-care management is necessary to prepare youth for the adult care system (Treadwell et al., 2016). Theories of self-care management suggest that in SCD, health outcomes associated with the transition of care can be improved, focusing on enhancing self-care management. Self-efficacy, a core construct of self-management, is the belief in one's ability to initiate health behavior change and reach health goals (Treadwell et al., 2016). Assessment of AYAs self-efficacy related to managing their SCD is essential to a successful transition from pediatric to adult care. Researchers conducted a study to identify behaviors AYAs feel are most associated with their perceived overall readiness to take responsibility for their healthcare. Results have shown that explaining their medical condition to others,

knowing details about insurance coverage, attending medical appointments, and communicating with staff over the phone were the behaviors associated with their overall perceived readiness for transition (Speller-Brown et al., 2015).

Problem-solving skills is also a vital part of self-management, specifically among this population who need these skills to manage their disease and health care. Interventions focusing on improving problem-solving skills through education have been shown to improve outcomes in a variety of chronic conditions, mainly in adults (Melita et al., 2019). Problem-solving education teaches problem-solving skills to cope with life stressors and consists of a series of sessions in which participants establish goals, identify solutions, implement, and evaluate the outcomes. Researchers have conducted focus groups to identify facilitators and barriers to self-management, with participants describing SCD management as daily self-management tasks, managing acute pain, daily reminders, SCD knowledge, and motivation for self-management (Melita et al., 2019). When discussing the transfer of responsibility from caregivers to adolescents, participants discussed ways to help encourage independence in adolescents and the emotional impact on caregivers of allowing them to have more autonomy (Melita et al., 2019).

Challenges Faced by SCD patients

Researchers have conducted research to describe perceptions of young adults with SCD related to their disease experience. Matthie et al. (2016) found that young adults have challenges related to maintaining or achieving a good quality of life or life satisfaction, strategies to maintain self-care, interruptions to family, work, social roles, and difficulties accessing needed health care. As young adults transition from the

nurturing, family-oriented pediatric environment, they need to learn how to balance self-care and navigate the health care system to manage their health (Matthie et al., 2016). Young adults have described the uncertainty of SCD as a significant challenge. Young adults have reported uncertainty associated with any pain, potentially leading to a pain crisis, and how it would impact school or other activities they enjoy (Kulandaivelu et al., 2018). Young adults discuss that they feel they have a lack of control over their lives. As young adults with sickle cell age, they are faced with stigma, cultural and racial, specifically when dealing with peers and utilizing emergency departments (Kulandaivelu et al., 2018). Individuals living with SCD face vaso-occlusive crises (VOC) and pain which are the main symptoms in SCD, and first show themselves around 5 months. Painful episodes can occur without warning and are described as sharp, intense stabbing, or throbbing. These pain episodes lead to the frequent emergency department and hospital visits (Sarri et al., 2018). There is currently no pharmacotherapeutic cure for SCD. In most cases, management of the disease is palliative, and a key therapeutic goal is to reduce pain crises (Sarri et al., 2018).

Young adults living with SCD have been dependent on others throughout their childhood, including their pediatric providers. When entering adolescence, young adults face the potential loss of health insurance, primary healthcare, and access to ambulatory care (Molter & Abramson, 2015). During the transition period, deficits in preparation, planning, care coordination, and available skilled adult providers lead to low engagement rates in adult care and disruption in care continuity (Hankins et al., 2018).

Evidence shows that AYAs ages 18 to 30 years with SCD are a vulnerable group, experiencing the highest mortality rates, emergency room visits, and hospitalizations than other age groups. Rates of depression in children and adolescents with SCD are as high as 46%. There are also reports of low motivation levels to engage in self-management behaviors due to lack of confidence and anxiety about how their condition may impact their ability to achieve future goals and milestones. Poor self-management also includes low self-efficacy and cognitive deficits resulting from stroke or silent cerebral infarct (Allemang et al., 2019). Another factor in the development of transition programs is the consideration of location. Young adults living in rural areas face an additional barrier when preparing for transition due to the limited resources (Mennito et al., 2014). These, among other factors, speak to the complexities of this transitional period and the importance of designing interventions to address these barriers.

Youth Transition Programs

Healthcare for youth with chronic illnesses has been the focus of attention, with several reports highlighting the need for improvement to their needs better (Aldiss et al., 2015). The role of the young person, and their parents or caregivers, will evolve with the young adult wanting and being expected to exercise greater independence in the management of their condition. The transfer of adolescents from child to adult services is a crucial time in the health of young people who may potentially fall into a poorly managed 'care gap.' Although there is a clear definition of transition, young adults tend to have varying experiences of transition, which may not meet the goals of the definition (Aldiss et al., 2015).

Gaining an understanding of the roles of families and the community is vital to the success of the transition of young adults and the development of transition programs. Research has not examined how the integration of community and healthcare resources affects youth in their chronic illness management. Researchers conducted a study to understand how family, healthcare providers, and community supports can assist young adults with special healthcare needs during the transition period (Okumura et al., 2015). Results showed a common theme of families fighting to gain access to the healthcare that patients need, highlighting the need for parents to advocate on the patients' behalf to ensure access. Additionally, the findings suggest that transition research should focus on youth working towards autonomy and involve other stakeholders for those who cannot reach such autonomy, including parents, providers, or community agencies (Okumura et al., 2015).

The American Academy of Pediatrics has established guidelines for clinicians to begin the transition as early as age 12 to allow for the acquisition of skills necessary for children's independence when they become adults. Researchers posit it is best to begin the conversations and education early so that the transfer of care is a natural expectation (Bashore & Bender, 2016). Nearly 750,000 adolescents and emerging adults with special healthcare needs reach the developmental stage of adulthood every year and enter an adult healthcare system that lacks the service capacity and expertise to care for them. Health centers have begun making efforts to develop, implement, and test models that meet the needs of these AYAs to facilitate their successful transfer to adult care and transition to adulthood (Betz et al., 2016). Transition programs have been implemented to

improve the quality of care for AYAs with chronic health conditions. Varying definitions of successful transition exists, including attendance at the first adult appointment or retention in adult services for one-year post-transfer (Allemang et al., 2019). Barriers to successful transition include the lack of specialized providers, insurance or coverage, fear of leaving familiar pediatric clinics, and inadequate preparation for adult care (Allemang et al., 2019).

A review was conducted by Feinstein and colleagues (2017) to examine the literature related to the transition of patients with specific illnesses, including cystic fibrosis, SCD, and childhood cancer. Authors suggested making the transition to adult care a gradual process, remembering that parents are going through a transition as well, and collaboration with a focus on improving transition, and the creation of a transition program that begins early in adolescence, along with the ability for youth to meet with adult providers before transition (Feinstein et al., 2017).

Systematic reviews have shown interventions aimed to facilitate the successful transition and transfer among youth with chronic diseases, have not adequately met the needs of youth, with an estimate of 60% not receiving necessary services to transfer successfully (Weissberg-Benchell & Shapiro, 2017). Interventions that involve a transition coordinator have been successfully assisted in the transition process and facilitated conversations between youth and adult care providers. The authors also assessed the effectiveness of implementing transition programs which involve the opportunity for youth to meet with both the pediatric and adult providers in a clinic setting, a tour of the adult program, and assisting in scheduling the first appointment with

the adult provider (Weissberg-Benchell & Shapiro, 2017). Results showed an increase in attendance at adult provider appointments and improvement in overall health outcomes. The researchers suggest that enhancing pediatric programs will help to improve health outcomes and improve youth's preparation for a successful transition.

Young adults with medical conditions may face many challenges, yet a study by Eaton et al. (2017) compared this group to healthy peers to assess transition readiness and general self-efficacy. Results showed that AYAs with medical conditions have significantly higher transition readiness than their healthy peers. In addition, with a decrease in parental involvement in completing a medical task, and an increase in AYAs self-involvement, transition readiness is enhanced (Eaton et al., 2017).

Researchers evaluated the contributions of factors associated with transition readiness, such as adolescent healthcare responsibility barriers to medication adherence and satisfaction with care and gender and age. Findings from a national survey report that only 17% of youth with special healthcare needs receive transition planning, compared to 14% of youth without special healthcare needs (Lebrun-Harris et al., 2018). Participants ages 14 to 21 completed self-report measures, assessing adolescent healthcare responsibility, barriers to medication adherence, and patient satisfaction (Haarbauer-Krupa et al., 2019). The population included 33% with a diagnosis of cystic fibrosis, 29% were diagnosed with SCD, and 38% were transplant recipients. Study findings indicated that patients perceive themselves as more ready to transition to adult care when they perceive greater responsibility for their health self-management and fewer barriers to medication adherence. This study emphasizes the importance of understanding the

individual's perceptions and needs of AYAs during the transition to adult care (Haarbauer-Krupa et al., 2019).

Chu and colleagues (2015) aimed to identify the effects of transition interventions on care transitions for individuals with chronic illness. A total of 6167 articles were reviewed, with only five articles meeting inclusion criteria. The inclusion criteria specified that the intervention must include a "comparison group and measure transfer as a discreet outcome (Chu et al., 2015, p.22). Patients in the studies included AYAs between 14 and 25-year-olds from five different countries. The review described four interventions that included patients with Type-1 diabetes and one intervention with SCD. Three of the interventions added pediatric nurse case managers, health system navigators, or transition coordinators. They were responsible for contacting patients about the transition process, setting up patients' appointments at the adult clinics, and making phone calls to check in on patients once they have transitioned to adult care (Chu et al., 2015). Others included physicians leading the transition intervention during clinic appointments or offering a Saturday morning clinic that was explicitly intended for adolescents. Three of the five studies showed that patients in the transition programs have higher rates of successful transition and higher attendance rates in adult clinics than patients who did not participate in the programs. The remaining two studies found no statistically significant differences in transfer rates between transition and control groups. This systematic review highlights that the very definition of successful transition varies. Some studies focus on attendance at an initial adult-center appointment, others on the time gap between adult and pediatric visits.

In contrast, others base success on initiation and continuation of adult care (Chu et al., 2015). The challenge exists that not all aspects are consistently assessed or reported, yet all are crucial aspects of the transfer. The development of a more precise definition of the transfer process is needed to determine which measures of transfer are most associated with clinical outcomes. A more clearly defined process will help improve the designs of future studies and guide quality improvement initiatives for transitioning AYAs with chronic illness (Chu et al., 2015).

SCD Transition Programs

Researchers have tested the effectiveness of transition programs with different components. Due to the limited number of local providers with expertise in sickle cell anemia, many patients are transferred to a general internist for their adult care (Bryant et al., 2015). Therefore, the Center for Health Care Transition Improvement proposes using six core elements of transition as a framework to guide best practices. These include developing a health care transition policy, identifying transitioning youth in a transition registry, and assessing and tracking transition readiness. While also addressing healthcare transition needs with the youth and family, direct communication between pediatric and adult health care providers during the transfer of care and contacting the youth three months after transfer to ensure successful completion (Bryant et al., 2015). Utilization of a transition readiness assessment by pediatric programs can aid in determining the best time for transition and assist in preparing youth. Also, patients should have periodic neuropsychological evaluations to identify deficits that may impact their disease management skills and academic and transition planning (Bryant et al., 2015).

Researchers have explored the success of various transition programs for this population to improve the transition process for AYAs with SCD.

Transition surveys were administered as a part of a descriptive study that examined age specific SCD knowledge, self-management skills, and educational goals of patients and parents. Surveys were distributed during scheduled clinic visits. Results showed that parents and patients had a basic knowledge of SCD. However, AYAs lack the disease knowledge necessary to become independent and thrive in managing their disease and care into adulthood (Speller-Brown et al., 2019).

Furthermore, Porter et al. (2017) explored the use of transition materials and identified the unmet needs of adolescents with SCD and their caregivers. Focus groups were conducted with 14 adolescents and 20 caregivers. A total of four themes emerged, including transition skills and knowledge needs, healthcare responsibility, adult SCD concern, and transition strategies and resources. Consistent with previous SCD research, results showed concerns from AYAs and caregivers regarding deficiencies in transition programming and readiness. These results support the need to conduct periodic assessments in preparation for transitioning, providing learning based on readiness level, and the importance of building support networks to encourage improved skills (Porter et al., 2017).

Researchers conducted a single-center study to assess the feasibility and effectiveness of skill-based educational handouts on improving self-management and transition readiness in adolescents with SCD. Using items from the Adolescent Autonomy Checklist, which assesses the skill level of adolescents in completing activities

necessary for self-care and independent living, respondents were asked to mark responses ranging from “can do already”, “needs practice”, “plan to start” or “accomplished” for each item. Based on the responses, one-page educational fact sheets were provided to the youth around skills needed (Calhoun et al., 2019). Participants ages 13–21 completed the survey at baseline in a subsequent clinic visit; a total of 61 baselines and follow-up surveys were completed. Results showed no differences based upon gender, insurance type, history of stroke, or presence of formal educational support. At baseline, patients reported needing the most help with skills and money management, living arrangements, vocational skills, emergency management, and healthcare skills. Results from this study suggest that a clinic-based educational intervention is an easily implementable tool to improve transition skills and AYAs with SCD (Calhoun et al., 2019). The younger patients were more likely to complete the follow-up assessments, suggesting that providing skills-based education at an early age will provide more opportunity for prospective data collection and reinforcement of knowledge. The intervention resulted in improved skills in tasks needed to transition to adult care, most notably related to health care skills. Strengthening health knowledge and self-management is crucial to improve patient outcomes during the high-risk period of transition to adult care (Calhoun et al., 2019). Outcomes of older versus younger sickle cell adults was investigated to help provide insight into the issues older adults with SCD face after the transition. Results showed fewer emergency visits and better quality of life among the transition group, whereas the older group faced more challenges (McClish et al., 2017).

An essential component of transition programs is to include perspectives of AYAs with SCD. A study was conducted with SCD patients who had transitioned into adult care to examine perspectives of transition and readiness (Porter et al., 2017). When describing the critical components of a transition program, AYAs identified choosing an adult provider, emergency care, understanding medications and adherence, SCD complications, and being aware of the impact of health behaviors (Porter et al., 2017). These components should be explored when developing transition programs for AYAs with SCD.

Transition navigators have been used to improve transition readiness for youth with SCD. Patient navigators have been found to be effective in assisting those with complex health conditions and healthcare needs. Utilizing components from GOT TRANSITION, an intervention was conducted to improve patient knowledge and skills for disease self-management and prepare for transition (Manwani et al., 2020). GOT TRANSITION is a federally funded national resource center on healthcare transition. GOT TRANSITION aims to improve transition from pediatric to adults' care using evidence-driven strategies. The intervention included an individualized transition plan, a portable medical summary, education about SCD and the skills needed for disease self-management, education of family members about their role in transition, and facilitating transfer to an adult provider (Manwani et al., 2020).

The Transition Readiness Assessment Questionnaire

The TRAW is a 29-item patient-report instrument that assesses AYAs self-management and healthcare utilization during healthcare transition, which was used in

this study (Wood et al., 2014). After assessing validity and reliability, the TRAQ now contains 20 questions that measure transition readiness in five domains: managing medication, appointment keeping, tracking health issues, talking with providers, and managing daily activities. Questions are answered on a 5-point scale based on the theoretical model from “No, I do not know how to do this” to “Yes, I always do this when I need to.” The Stages of Change model were adapted as a framework for responses on the TRAQ; therefore, developers feel the instrument can identify the developmental stage of readiness to transition (Sawicki et al., 2011). The TRAQ was studied in a cohort of patients with various pediatric onset chronic conditions, including SCD, spina bifida, cerebral palsy, and diabetes mellitus (Jensen et al., 2017). Validated measures of transition-related skills can assist the provider, patient, and family in evaluating these skills, setting goals, and guiding interventions to prepare adolescents for transitioning. TRAQ self-management and self-advocacy scores were positively associated with age in the initial study, and the TRAQ self-advocacy score was higher in females. The TRAQ is one of the few available validated, patient-reported, disease non-specific transition readiness tools (Jensen et al., 2017).

Research by Johnson et al. (2020) utilized the TRAQ to evaluate improved readiness to transition using a preintervention -postintervention design. The study included ten young adults 18 years or older; they were provided an intervention that comprised two components and addressed readiness assessment and other self-management skills using an educational video and question-and-answer session. The TRAQ was used to measure transition readiness, and results found that mean TRAQ

scores differed for females and males. Higher mean scores for females indicated more significant improvement in transitional readiness. Females showed improvement in transitional readiness for managing medications, tracking health issues, talking with providers, and managing daily activities (Johnson et al., 2020). Authors suggest that utilizing advanced practice nurses who are competent in transitioning adolescents into adult services may help to decrease healthcare costs and adverse patient outcomes.

Transition readiness scores among patients with SCD were analyzed as part of an ongoing quality improvement initiative within a clinic and compared their scores with other populations of youth with special healthcare needs (Brown & Sobota, 2016). Fifty patients completed the survey, which was a representation of 58% of patients in this practice. Patients reported high readiness in areas of medication management, with 69% stating they always take medications correctly. Comparatively, only 22% of respondents reported always filling prescriptions, and 27% reordering medications when they run out (Brown & Sobota, 2016). Low scores were reported concerning insurance coverage, understanding how to apply for insurance and knowing what insurance covers. When comparing these results to reported TRAQ scores among other chronic illnesses, SCD patients had lower scores managing medications, appointment keeping, and tracking health issues (Brown & Sobota, 2016). Results from this study show room for improvement among this population, suggesting the need to improve self-management and self-advocacy skills among patients with SCD.

Summary

Children living with chronic illnesses such as SCD have now lived longer lives due to medical advancements and continued research. Due to this, the development of transition programs, and an assessment of transition readiness is essential to a healthy life for these AYAs. The research has shown the growing literature that supports the value of understanding the needs of AYAs and assessing their skills related to transition readiness and self-management of their chronic disease. However, there is a need to explore the self-management skills young adults with SCD possess to help better prepare them for transitioning to adult care. Exploring these factors will fill the literature gap to help create transition programs to improve the knowledge and self-management skills needed to successfully transition to adult care.

Section 2: Research Design and Data Collection

In this quantitative study, I examined the impact knowledge and skills (independent variables) have on AYAs with SCD self-perceived readiness (dependent variable) to transition to adult care in the city of Philadelphia, Pennsylvania. I evaluated the relationship between self-perceived readiness by evaluating factors such as gender, ethnicity, and education. Results from this study can be utilized to educate SCD providers and stakeholders around the need for increased preparation and the development of more targeted transition programs to support AYAs living with SCD.

In Section 2, I will explain the study's research design and rationale. This will include the RQs, variables, purpose of the study, methodology, population, and data collection. I will also discuss instrument reliability, validity, and measurement of variables. Data analysis including software, data cleaning, hypotheses testing, threats to validity, ethical procedures, and a summary will also be provided.

Research Design and Rationale

I examined the relationship between the independent variables, meeting with an adult provider and PAOC, and the dependent variable self-perceived readiness. Covariates assessed include gender, ethnicity, education. Association was examined through the following RQS developed along with their hypotheses:

- RQ1: Is there an association between meeting with an adult care provider and self-perceived readiness to adult care transition among youth aged 15–21 years old diagnosed with SCD in Philadelphia, PA, while controlling for gender, ethnicity, and education?

- H_{01} : There is not an association between meeting with an adult care provider and self-perceived readiness to adult care transition among youth aged 15–21 years old diagnosed with SCD in Philadelphia, PA, while controlling for gender, ethnicity, and education.
- H_{a1} : There is an association between meeting with an adult care provider and self-perceived readiness to adult care transition among youth aged 15–21 years old diagnosed with SCD in Philadelphia, PA, while controlling for gender, ethnicity, and education.
- RQ2: Is there an association between PAOC and self-perceived readiness to adult care transition among youth aged 15–21 years old diagnosed with SCD in Philadelphia, PA, while controlling for gender, ethnicity, and education?
- H_{02} : There is not an association between PAOC and self-perceived readiness to adult care transition among youth aged 15–21 years old diagnosed with SCD in Philadelphia, PA, while controlling for gender, ethnicity, and education.
- H_{a2} : There is an association between PAOC and self-perceived readiness to adult care transition among youth aged 15–21 years old diagnosed with SCD in Philadelphia, PA, while controlling for gender, ethnicity, and education.

This study utilized a cross-sectional design. A cross-sectional research design is used for population-based surveys and measures the outcome and the exposures in study participants simultaneously (Setia, 2016). This type of design provided information about

the prevalence of outcomes. It also provides the ability to estimate the odds ratios to study the association between exposure and the outcomes (Setia, 2016).

Methodology

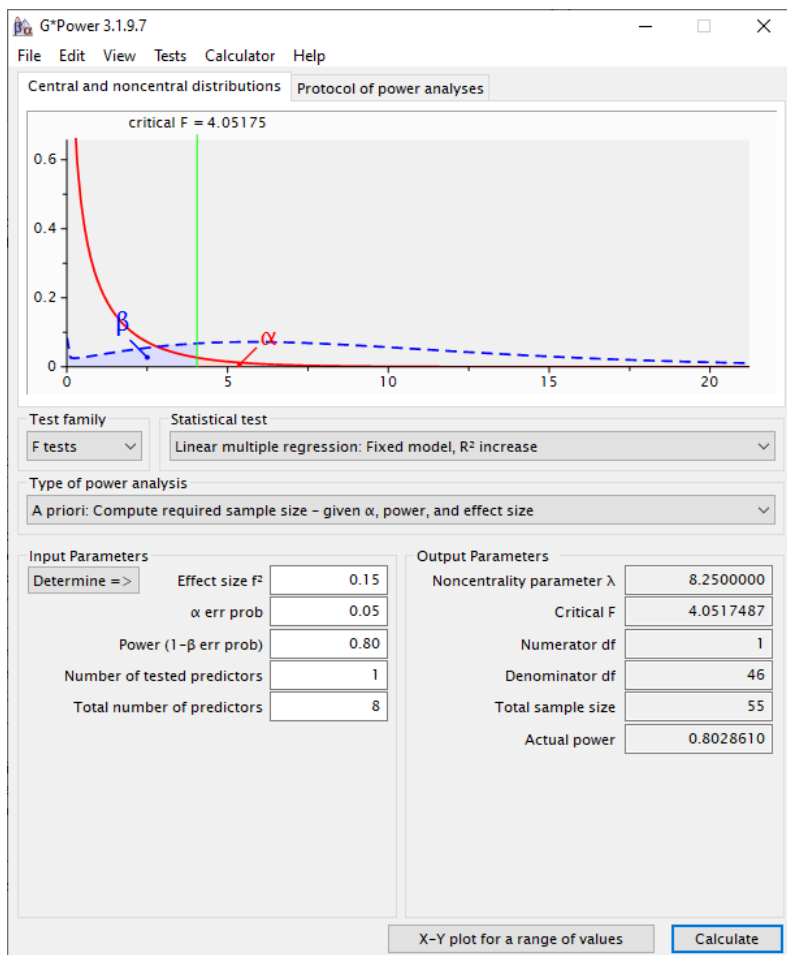
In this section, I will describe the sample population, data collection, instrumentation, operationalization, and data analysis plan.

Population

The target population for this study are AYAs ages 15 to 21 years old, diagnosed with SCD, and receiving care at a sickle cell center in Philadelphia, Pa. A total of 68 AYAs were recruited for participation in this study.

Sample Size

For RQs 1 and 2, a power analysis was conducted using G*Power 3.1.7 (Faul et al., 2014). Since the power analysis varies based on the research question, the research question with the most predictor variables were used, which in this case is RQ2 with eight predictors. Applying a medium effect size ($f^2 = .15$), a conventional alpha of .05, a power of .80, one tested predictor and eight total predictors, it was determined that a minimum of 55 participants would be sufficient for the hierarchical linear regression. See Figure 2 for the power analysis conducted for hierarchical linear regression.

Figure 2*Power Analysis for Hierarchical Linear Regression***Data Collection**

Patients were screened for eligibility by a trained research assistant or the lead study investigator. Inclusion criteria include male and females ages 15–21 with any genotype of SCD. Patients were required to be developmentally able to complete the questionnaire, parental/guardian permission was provided for those under 18, and appropriate child assent was completed. Exclusion criteria included previous participation in the study, non-English speaking patients, non-verbal patients, and patients with prior

documented stroke. Eligible patients were approached by research staff during a scheduled clinical appointment to assess interest in the study. Patients were asked to complete the questionnaire during their clinical visit. Once completed, data were entered into a secure data collection database, REDCap.

Instrumentation

Survey questions included a combination of standardized instruments and stand-alone questions. The TRAQ is a validated tool that addresses domains of self-advocacy and self-management. The TRAQ has been widely used to assess transition readiness across various chronic conditions, including SCD. The TRAQ is a 20-item tool that assesses readiness for transition across subscales related to medication, appointments, tracking health information, talking with providers, and daily living. Responses use stages of change model, ranging from “I do not need to do this” to “I always do this when I need to.” The TRAQ is a disease-neutral tool that provides the opportunity for applicability beyond SCD alone. While SCD-specific tools have been developed, the TRAQ has been well validated across numerous studies while also evaluating many of the same domain (Sawicki et al., 2011; Treadwell et al., 2011; Wood et al., 2014). Transition preparation was assessed by a stand-alone question asking whether the patient has met with an adult provide as part of their preparation.

A modified patient assessment of health care survey was utilized to assess patient perception of adult-oriented health care. The questionnaire covers five domains of care: nurse communication, doctor communication, physical environment, pain management, and medication and symptom communication. For this study, the survey was shortened to

assess three out of five domains: doctor communication, pain management, and medication and symptom communication. The domains were assessed to provide an overall score. Demographic questions included age, transportation, education, zip code, insurance, income, and race/ethnicity.

Operationalization

The variables include meeting with an adult care provider (yes/no), age (15–21 years old), gender (male/female), education (eighth grade–some college), and ethnicity (Hispanic/Non-Hispanic). The correlation between skill development and self-perceived readiness is assessed by the TRAQ, which is measured by taking the average score across items. Each item is scored 1–5, with one being assigned for responses of “No, I do not know how” and five assigned for responses of “Yes, I always do this when I need to.” Race and gender are identified as covariates. For the RQs, gender was operationalized as male or female. For this survey, race and ethnicity were broken down into Black/African American, White, or Caucasian, Asian, Native Hawaiian or American Indian, or Other; and ethnicity described as Hispanic, Non-Hispanic, and Other. The highest level of education was broken down into eighth grade, ninth grade, 10th grade, 11th grade, graduated high school, and some college. See Table 1 for an operationalization of variables.

Table 1

Operationalization of Variables

Variable	Categories	Variable Type	Level of Measurement
Gender	Male or Female	Covariate	Dichotomous

Education	8 th -12 th grade, Graduated High School, Some college	Covariate	Categorical
Age	15 years-21 years	Covariate	Continuous
Ethnicity	Non-Hispanic, Hispanic, or Other	Covariate	Categorical
Meeting with adult provider	Yes or No	Independent Variable	Dichotomous
Perceptions of adult- oriented care	Strongly Disagree, Disagree, Agree Strongly Agree	Independent variable	Continuous independent variables developed through a mean score 10 items
Self-perceived readiness	No, I do not know No, but I want to know No, but I am learning to do this Yes, I have started doing this Yes, I always do this when I need to	Dependent variable	Continuous dependent variables developed through a mean score 20 items

Data Analysis Plan

The raw survey data were transferred into SPSS version 27.0. Respondents who did not answer most of the survey questions were removed from further analysis. A running record was provided to identify how many participants are being removed due to missing responses. Descriptive statistics were conducted to examine trends in the sample demographics and the research variables used in the analysis. Frequency and percentages were calculated for the nominal and ordinal level variables. Means and standard deviations were used to describe continuous level data.

Composite scores were developed for PAOC and self-perceived readiness through an average of the respective items comprising the scales. Potential outliers were identified through use of standardized values, or z scores. Tabachnick and Fidell (2019) recommend removing z scores that exceed 3.29 standard deviations from the mean. Additionally, Cronbach's alpha test of internal consistency and reliability was examined for the subscales. The strength of the alpha values was interpreted through use of the guidelines suggested by George and Mallery (2020), in which $\alpha \geq .9$ Excellent, $\alpha \geq .8$ Good, $\alpha \geq .7$ Acceptable, $\alpha \geq .6$ Questionable, $\alpha \geq .5$ Poor, and $\alpha < .5$ Unacceptable.

Data analysis answered the following RQs:

- RQ1: Is there an association between meeting with an adult care provider and self-perceived readiness to adult care transition among youth aged 15–21 years old diagnosed with SCD in Philadelphia, PA, while controlling for gender, ethnicity, and education?

- H_{01} : There is not an association between meeting with an adult care provider and self-perceived readiness to adult care transition among youth aged 15–21 years old diagnosed with SCD in Philadelphia, PA, while controlling for gender, ethnicity, and education.
- H_{a1} : There is an association between meeting with an adult care provider and self-perceived readiness to adult care transition among youth aged 15–21 years old diagnosed with SCD in Philadelphia, PA, while controlling for gender, ethnicity, and education.
- RQ2: Is there an association between PAOC and self-perceived readiness to adult care transition among youth aged 15–21 years old diagnosed with SCD in Philadelphia, PA, while controlling for gender, ethnicity, and education?
- H_{02} : There is not an association between PAOC and self-perceived readiness to adult care transition among youth aged 15–21 years old diagnosed with SCD in Philadelphia, PA, while controlling for gender, ethnicity, and education.
- H_{a2} : There is an association between PAOC and self-perceived readiness to adult care transition among youth aged 15–21 years old diagnosed with SCD in Philadelphia, PA, while controlling for gender, ethnicity, and education.

To address RQ1, an individual hierarchical linear regression was conducted to assess if there is an association between meeting with an adult care provider and self-perceived readiness to adult care transition among youth aged 15–21 years old diagnosed with SCD in Philadelphia, PA, while controlling for gender, ethnicity, and education. To

address RQ2, an individual hierarchical linear regression was conducted to assess if there is an association between self-perceived readiness and PAOC among youth aged 15–21 years old diagnosed with SCD in Philadelphia, PA, while controlling for gender, ethnicity, and education. A hierarchical linear regression is the appropriate form of analysis to assesses the relationship between nominal, ordinal, or continuous predictor variables on a continuous criterion variable, while controlling for additional factors (Tabachnick & Fidell, 2019). The dependent variable for the regression models corresponds to self-perceived readiness, which was treated a continuous variable in the models.

Linear regression is conducted by entering each block of independent variables one step at a time. In this case, for each linear regression, the demographic variables were entered as the first block of the model. Gender was a dichotomous variable with two possibilities, male and female. Ethnicity consisted of three possibilities: Hispanic/Latino, Non-Hispanic/Latino, and Other. The ethnicity variable was dummy coded into two variables prior to entry into the regression model. Education will be a nominal variable with three possibilities: eighth-11th grade, graduated high school, and some college. Education was dummy coded into two variables prior to entry into the regression model.

In the second block of the model for RQ1, meeting with an adult care provider was added to the model. Meeting with an adult care provider is a dichotomous variable that was coded: 1 = *yes* and 0 = *no*. In the second block of the model for RQ2, PAOC were added to the model. Each of these subscales are continuous measurements.

Prior to analysis in the regression, the assumptions of normality of residuals, homoscedasticity of residuals, and absence of multicollinearity were tested. Normality was assessed with a normal P-P scatterplot. If the data closely followed the diagonal trend line in the scatterplot, the assumption of normality was supported (Howell, 2013). Homoscedasticity was tested through visual examination of a residual's scatterplot. If there was not a recurring pattern in the scatterplot, then the assumption for homoscedasticity was supported (Field, 2013). Absence of multicollinearity was tested with examination of variance inflation factors (VIFs). Stevens (2009) indicates that VIFs lower than 10 indicate a low correlation among the predictors and the assumption will be met.

An F test was used in each block of the model to assess whether the set of independent variables collectively predict self-perceived readiness to adult care transition. The change in R -squared was reported between each block to explain how much additional variance the key predictors contribute to the model, beyond what the control variables alone explain. Individual t tests were used to determine the significance of each predictor, and beta coefficients identified the magnitude and directionality of prediction for each independent variable.

Threats to Validity

Internal validity refers to the extent to which observed results represent the truth in the population we are studying and are not due to methodological data (Patino & Ferreira, 2018). External validity implies that the results of a study are generalizable to patients in the sample population that the study is thought to represent. Internal validity

can be influenced by those selected to participate in the study due to those who tend to miss scheduled clinical appointments. The Children's Hospital of Philadelphia represents a population-based sample of patients with SCD as it is one of only two regional referral centers in Philadelphia licensed by the Pennsylvania Department of Health to treat newborns diagnosed with hemoglobinopathies. This enables the study to provide a representation to the general SCD population.

Ethical Procedures

IRB approval was obtained to use survey data from data collection site, which requires its own IRB review and approval. The study data has been kept confidential as required by law. Upon enrollment, subjects were assigned a unique study number. To assure anonymity and encourage, consent was documented as completion of the first question of the survey. This was to assure that there is no written connection between the patient and their responses. A master list of subjects who participate and refuse was kept for study duration to assess response rate and so that the same potential participants were not approached more than once. Names were not attached to actual study participants or surveys. When not in use, the master list was kept in a locked file cabinet and purged upon completion of the study. IRB approval was obtained from Walden University per guidelines set by the university (approval no. 05-06-22-0155082).

x

Summary

This study addressed the impact of knowledge and self-efficacy skills on self-perceived readiness to transition to adult care while examining factors such as meeting

with an adult provider, gender, and ethnicity's impact on self-perceived readiness. The instruments used were the TRAQ and an adapted version of the patient assessment of healthcare survey, along with demographic questions. Logistic regression was utilized to examine self-perceived readiness as the dependent variable and gender, ethnicity, and education used as covariate.

Section 3: Presentation of the Results and Findings Section

Introduction

The purpose of the present study was to examine self-perceived readiness of SCD patients as they prepare to transition to adult care. Specifically, I examined the impact of meeting with an adult provider and their perception of adult-oriented care on their self-perceived readiness to transition. To answer these RQs, I employed a quantitative research design. I utilized logistic regression and Cronbach's Alpha to test the impact of the independent variables on the dependent variable. In this chapter I will review the descriptive statistics along with an examination of the data and test of assumptions for all variables. I will also present results from the individual logistic regression. I will conclude this chapter with a summary of the results.

Data Collection Methods

The data were collected by a sickle cell center in Philadelphia, Pa. The target population was youth between ages 15 years old and 21 years old. Data were collected from 68 youth served by the sickle cell center. This met criteria for the minimum sample requirements to detect an effect.

Descriptive Statistics

Of the 68 participants, ages were distributed evenly across all years. With 51.5% being females, and 44.1% being male, with three participants missing gender. Education was reported as 10th grade or higher for 85% of the sample. In addition, 62% of the participants reported an ethnicity of non-Hispanic, 22.1% reported other, and ethnicity was missing for 16% of the sample. In addition, 21% of the sample has met with an adult

provider, while 76% has not met with an adult provider prior to completing this survey, responses were missing for two participants. See Table 2 for descriptive statistics for the sample.

Table 2*Descriptive Statistics for the Sample*

Variable		<i>N</i>	%
Age	15	8	11.8
	16	14	20.6
	17	9	13.2
	18	11	16.2
	19	8	11.8
	20	10	14.7
	21	8	11.8
Gender	Male	30	44.1
	Female	35	51.5
Education	Grade 8	2	2.9
	Grade 9	8	11.8
	Grade 10	12	17.6
	Grade 11	12	17.6
	High School	17	25
	Some College	17	25
Ethnicity	Non-Hispanic Latino	42	61.8
	Other	15	22.1
Met with Provider	No	52	76.5
	Yes	14	20.6

Testing Assumptions

I conducted a linear regression and Cronbach's alpha for the 20 TRAQ items to address the RQs. The set of items had a Cronbach's alpha value of .846, indicating a high level of internal consistency for the items (Taber, 2018). The composite showed a mean of 3.715 for all participants (SD = .614; see Table 2). For the 10 PAOC items, the set of items had a Cronbach's alpha value of .943, indicating the highest level of internal consistency between all the items. The composite based on the average for all 10 items showed a mean of 3.634 for all participants (SD = .418). Both variables showed skewness values within the acceptable +/-2 cutoff range (see Table 2). Similarly, kurtosis values for all variables fell within the +/- 7 cutoff range (Hair, et al., 2010). This indicates that both variables were normally distributed.

Results

Research Question 1

To examine whether there is an association between meeting with an adult care provider and self-perceived readiness to adult care transition I tested assumptions and conducted a linear regression predicting TRAQ with whether participants met with a provider as the independent variable, and gender, education, and ethnicity as the covariates. The overall model was statistically significant, with the whole set of predictors accounting for 39.5% of the variance in patient readiness ($F(4, 51) = 9.975, p < .001, \text{Adj } R^2 = .395$). There was no relationship between status of meeting with a provider and patient readiness when controlling for all covariates ($B = .123, SE = .174, p$

= .482). The only covariate that was statistically related to patient readiness was education. For every additional level of education, a patient had, they reported more readiness on the TRAQ by .270 units ($B = .270$, $SE = .048$, $p < .001$). Neither gender nor ethnicity were significantly related to patient readiness. See Table 3 for parameter estimates predicting TRAQ for RQ1 1.

Table 3

Parameter Estimates Predicting TRAQ for RQ 1

Model	Unstd B	SE	t	p	Tolerance	VIF
(Constant)	2.793	0.172	16.216	< .001		
Met with provider	0.123	0.174	0.709	0.482	0.876	1.142
Gender	-0.051	0.14	-0.368	0.714	0.93	1.076
Patient Education	0.27	0.048	5.577	< .001	0.82	1.22
Ethnicity	0.248	0.158	1.572	0.122	0.952	1.05

Research Question 2

After all assumptions were tested, a linear regression was conducted predicting TRAQ, PAOC as the independent variable, and gender, education, an ethnicity as the covariates. The overall model was statistically significant, with the whole set of predictors accounting for 44.7% of the variance in patient readiness ($F(4, 51) = 12.092$, $p < .001$, $Adj R^2 = .447$). There was a statistically significant relationship between PAOC and patient readiness when controlling for all covariates, such that for every one unit increase in PAOC, there was a corresponding increase in patient readiness by .391 units ($B = .391$, $SE = .170$, $p = .025$). As before, patient education was positively, significantly related to patient readiness ($B = .273$, $SE = .044$, $p < .001$). Neither gender nor ethnicity

were significantly related to patient readiness. See Table 4 for parameter estimates predicting TRAQ for RQ 2.

Table 4

Parameter Estimates Predicting TRAQ for RQ 2

Model	Unstd <i>B</i>	<i>SE</i>	<i>t</i>	<i>p</i>	Tolerance	VIF
(Constant)	1.365	0.64	2.133	0.038		
PAOC	0.391	0.17	2.302	0.025	0.898	1.114
Gender	0.003	0.136	0.026	0.98	0.904	1.106
Patient						
Education	0.273	0.044	6.259	< .001	0.924	1.083
Ethnicity	0.162	0.156	1.042	0.302	0.892	1.121

Summary

In this chapter, the two research hypotheses designed to address the central hypothesis of this study were explored, which was that meeting with an adult care provider and PAOC would influence self-perceived readiness to transition to adult care. Findings revealed that there was a statistically significant relationship between meeting with an adult provider and self-perceived readiness. The only covariate that was statistically related to perceived readiness was education, showing more readiness for each additional year of education received.

Section 4: Application to Professional Practice and Implications for Social Change

Young adults face many challenges as they prepare for transition from pediatric to adult care. The purpose of this study was to examine the self-perceived readiness of SCD patients as they prepare to transition to adult care. Specifically, I examined the impact of meeting with an adult provider and PAOC on self-perceived readiness among youth aged 15–21 years old. The impact was examined while controlling for gender, ethnicity, and education.

Findings revealed that overall, there is an association with meeting with an adult care provider and self-perceived readiness. However, there was no relationship when controlling for all covariates. The only covariate statistically related to patient readiness was education. When examining the impact of PAOC on self-perceived readiness, findings revealed that overall, there is an association between PAOC and patient readiness when controlling for all covariates. Education was the only covariate statistically related to patient readiness.

Interpretation of the Findings

Understanding the impact of both meeting with an adult provider and PAOC on young adults with SCD self-perceived readiness was the primary focus of the present study. In this study, 21% of the participants had met with an adult provider prior to completion of this survey. Findings revealed that meeting with an adult provider has an impact on their self-perceived readiness. Prior research showed that young adults felt that one of the critical components of a successful transition process was choosing an adult provider prior to transition (Porter et al., 2017). In addition, research has stressed the

importance of the transition process being a gradual, collaborative experience. Transition programs that involve introduction of the adult provider and the facilitation of a meeting with both the pediatric and adult provider showed an increase in attendance in adult care appointments (Feinstein et al., 2017; Weissberg-Benchell & Shapiro, 2017).

Results from this study also support the points of other researchers regarding the connection and coordination of care supporting the transition period. In an examination of sickle cell transition programs, it was found that only 60% of centers had transferred care to a hematologist specializing in sickle cell anemia, stressing the challenges related to the number of available providers for this population (Bemrich-Stolz et al., 2015).

Findings revealed gender was not significantly related to patient readiness, which was not expected based on previous research. Previous research found that TRAQ scored differed between females and males. The initial TRAQ study showed a higher mean score for females specifically in readiness for managing medications, tracking health issues, talking with providers, and managing daily activities (Johnson et al., 2020). When assessing education, results showed an increase in the mean score by .270 for each year of education received.

The American Academy of Pediatrics guidelines suggest that transition conversations begin as early as age 12 to allow for development and growth of skills, yet transition should begin between ages 18 and 22 (Bashore & Bender, 2016; McManus et al., 2015). Previous research has found that there was a higher mean score among young adults compared with older and younger adolescents. Young adults have shown higher readiness in aspects of medication management but show lower scores in areas related to

insurance and coverage (Brown & Sobota, 2016). However, research has indicated that there remains room for improvement among young adults in many areas of self-efficacy. Research substantiates the findings from this study, which showed an increase in the mean score by .270 for each year of education, stressing the importance of transitioning at an appropriate age.

The second RQ assessed the association between PAOC and self-perceived readiness, and results revealed there is a significant relationship between the two. Research has stressed the fear young adults express when preparing for transition from pediatric to adult care (Allemang et al., 2019). It is imperative for adult care providers to understand the needs of young adults as they enter the new space of health care. Young adults with SCD are familiar with the family-like dynamic within the pediatric space, which typically does not exist in the adult care setting. Deficits in preparation, planning, care coordination, and available skilled adult providers lead to low engagement rates and disruption in care continuity (Hankins et al., 2018). Acknowledging and understanding young adults' goals may help improve the engagement rates and disruption in care. Findings also revealed that there was no significance when controlling for covariates of gender and ethnicity; however, education was positively associated with readiness. These findings support the American Academy of Pediatrics established guidelines focusing on transitioning young adults between ages 18 and 22.

Limitations and Recommendations for Future Research

This study had a few limitations that could be addressed in future research. First, the present study only evaluated participants at one children's hospital in the Philadelphia

area. Given the large number of sickle cell patients across the United States, this limits the generalizability of the findings to the larger sickle cell population. It may be possible that young adults receiving care at a different hospital may be prepared to transition due to the transition process at their care center.

Second, the results are based on a one time administering of the TRAQ questionnaire. This limits the understanding of the growth or changes in knowledge as young adults begin to reach the age of transition. Studies have been conducted that examine the changes over time to evaluate areas of improvement over time in skills necessary to be successful post-transition. To fully understand readiness, a follow-up study should assess transition readiness on an annual basis through transition to specifically identifies areas of weakness and provide guidance and support to strengthen those skills and feelings of readiness.

Third, secondary survey data limits the understanding of areas of improvement needed and limits the ability to get input from young adults regarding the needs in a transition program. Future research should involve a mixed methods approach to gain a deeper understanding of the needs of this population, while aiming to improve transition programs.

Several other possible limitations include the use of other covariates such as insurance and zip code. Lastly, this study did not examine all constructs within the theoretical model used. The theoretical model also examines factors such as health needs related to complications from the disease, including pain crises. These factors should also be assessed when designing transition program elements.

Implications for Practice and Social Change

The implications of this study on public health may include the enhancement of transition programs to meet the needs of young adults with SCD. Researchers have indicated that factors such as difficulty in coordination care impact the increase in mortality and acute care utilization during the transition period, therefore stressing the need for developing and expanding components of transition programs (DeBaun & Telfair, 2012). This study may also provide insight into more uses for the TRAQ to target the needs of young adults as they transition. Implementing the use of the TRAQ as a standard during the transition process annually can assist in a more targeted effort in improving readiness skills. Taking a deeper look into potential risks factors such as zip code as noted in the limitations section of this study may aid in improving outcomes related to transition.

A potential implication for social change includes use of these findings by health care providers to inform changes to improve patient transition, through program development and policy changes. As varying definitions of transition exist, the over 750,000 adolescents that reach the transition age, may receive differently structured transition programs. These findings may not only contribute to those living with SCD but for other young adults living with chronic diseases. Therefore, evaluating and increasing knowledge and skills related to transition readiness prior to transition can help improve outcomes for young adults living with SCD and other chronic diseases.

Additionally, understanding the relationship between PAOC and perceived readiness can inform sickle cell program staff on the fear's young adults experience prior

to transition. Concerns such as physician mistrust and poor understanding of the disease from non-hematologists can lead to serious health risks for patients with SCD as this may lead to discovering ways of managing complications at home (Bemrich-Stolz et al., 2015). As such, it is vital to have these conversations with young adults while preparing for transition.

Conclusions

Overall, the present study made several contributions to research focused on assessing young adults perceived readiness as they prepare to transition to adult care. Findings revealed that meeting with an adult care provider has a positive impact on young adults self-perceived readiness, and a positive relationship between PAOC and self-perceived readiness. The present finding provides important implications for future research. Specifically, when developing transition standards and programs, clinicians must consider young adults' knowledge and readiness and ensure the skills necessary for success are attained prior to transition to adult care.

References

- Aldiss, S., Ellis, J., Cass, H., Pettigrew, T., Rose, L., & Gibson, F. (2015). Transition from child to adult care— ‘It’s not a one-off event’: Development of benchmarks to improve the experience. *Journal of Pediatric Nursing, 30*(5), 638–647.
<https://doi.org/10.1016/j.pedn.2015.05.020>
- Allemang, B., Allan, K., Johnson, C., Cheong, M., Cheung, P., Odame, I., Ward, R., Williams, S., & Kuo, K. H. (2019). Impact of a transition program with navigator on loss to follow-up, medication adherence, and appointment attendance in hemoglobinopathies. *Pediatric Blood & Cancer, 66*(8).
<https://doi.org/10.1002/pbc.27781>
- Bashore, L., & Bender, J. (2016). Evaluation of the utility of a transition workbook in preparing adolescent and young adult cancer survivors for transition to adult services: a pilot study. *Journal of Pediatric Oncology Nursing, 33*(2), 111–118.
<https://doi.org/10.1177/1043454215590102>
- Bemrich-Stolz, C. J., Halanych, J. H., Howard, T. H., Hilliard, L. M., & Lebensburger, J. D. (2015). Exploring Adult Care Experiences and Barriers to Transition in Adult Patients with Sickle Cell Disease. *International Journal of Hematology & Therapy, 1*(1). <https://doi.org/10.15436/2381-1404.15.003>
- Betz, C. L., O’Kane, L. S., Nehring, W. M., & Lobo, M. L. (2016). Systematic review: health care transition practice service models. *Nursing Outlook, 64*(3), 229–243.
<https://doi.org/10.1016/j.outlook.2015.12.011>
- Blinder, M. A., Duh, M. S., Sasane, M., Trahey, A., Paley, C., & Vekeman, F. (2015).

- Age-related emergency department reliance in patients with sickle cell disease. *The Journal of Emergency Medicine*, 49(4), 513–522.
<https://doi.org/10.1016/j.jemermed.2014.12.080>
- Brousseau, D. C., Owens, P. L., Mosso, A. L., Panepinto, J. A., & Steiner, C. A. (2010). Acute care utilization and rehospitalizations for sickle cell disease. *JAMA*, 303(13), 1288. <https://doi.org/10.01/jama.2010.378>
- Brown, L., & Sobota, A. (2016). Measuring transition readiness of young adults with sickle cell disease using the transition readiness assessment questionnaire. *Blood*, 128(22), 3534–3534. <https://doi.org/10.1182/blood.V128.22.3534.3534>
- Bryant, R., Porter, J. S., & Sobota, A. (2015). APHON/ASPHO policy statement for the transition of patients with sickle cell disease from pediatric to adult health care. *Journal of Pediatric Oncology Nursing*, 32(6), 355–359.
<https://doi.org/10.1177/1043454215591954>
- Bulgin, D., Tanabe, P., & Jenerette, C. (2018). Stigma of sickle cell disease: A systematic review. *Issues in Mental Health Nursing*, 39(8), 675–686.
<https://doi.org/10.1080/01612840.2018.1443530>
- Calhoun, C. L., Abel, R. A., Pham, H. A., Thompson, S., & King, A. A. (2019). Implementation of an educational intervention to optimize self-management and transition readiness in young adults with sickle cell disease. *Pediatric Blood & Cancer*, 66(7), e27722. <https://doi.org/10.1002/pbc.27722>
- Centers for Disease Control and Prevention. (2020, December 16). *Data & statistics on sickle cell disease*. <https://www.cdc.gov/ncbddd/sicklecell/data.html>

- Chu, P. Y., Maslow, G. R., von Isenburg, M., & Chung, R. J. (2015). Systematic review of the impact of transition interventions for adolescents with chronic illness on transfer from pediatric to adult healthcare. *Journal of Pediatric Nursing, 30*(5). <https://doi.org/10.1016/j.pedn.2015.05.022>
- DeBaun, M. R., & Telfair, J. (2012). Transition and sickle cell disease. *Pediatrics, 130*(5), 926–935. <https://doi.org/10.1542/peds.2011-3049>
- Eaton, C. K., Davis, M. F., Gutierrez-Colina, A. M., LaMotte, J., Blount, R. L., & Suveg, C. (2017). Different demands, same goal: Promoting transition readiness in adolescents and young adults with and without medical conditions. *Journal of Adolescent Health, 60*(6), 727–733. <https://doi.org/10.1016/j.jadohealth.2017.01.002>
- Evensen, C. T., Treadwell, M. J., Keller, S., Levine, R., Hassell, K. L., Werner, E. M., & Smith, W. R. (2016). Quality of care in sickle cell disease: Cross-sectional study and development of a measure for adults reporting on ambulatory and emergency department care. *Medicine, 95*(35), e4528. <https://doi.org/10.1097/MD.0000000000004528>
- Faul, F., Erdfelder, E., Buchner, A., & Lang, A. G. (2014). G*Power Version 3.1.9 [computer software]. <http://www.gpower.hhu.de/en/html>
- Feinstein, R., Rabey, C., & Pilapil, M. (2017). Evidence supporting the effectiveness of transition programs for youth with special health care needs. *Current Problems in Pediatric and Adolescent Health Care, 47*(8), 208–211. <https://doi.org/10.1016/j.cppeds.2017.07.005>

- Field, A. (2013). *Discovering Statistics Using SPSS, 4th ed.* Sage Publications.
- Gallin, J. I., & Ognibene, F. P. (2012). *Principles and practices of clinical research* (3rd ed.). Academic Press.
- George, D. & Mallery, P. (2020). *IBM SPSS step by step: a simple guide a reference* (16th ed.). Boston, MA: Allyn and Bacon.
- Gray, W. N., Schaefer, M. R., Resmini-Rawlinson, A., & Wagoner, S. T. (2018). Barriers to transition from pediatric to adult care: A systematic review. *Journal of Pediatric Psychology, 43*(5), 488–502. <https://doi.org/10.1093/jpepsy/jsx142>
- Griffin, A., Gilleland, J., Johnson, A., Cummings, L., New, T., Brailey, T., Eckman, J., & Osunkwo, I. (2013). Applying a developmental–ecological framework to sickle cell disease transition. *Clinical Practice in Pediatric Psychology, 1*(3), 250–263. <https://doi.org/10.1037/cpp0000027>
- Hankins, J. S., Estepp, J. H., Hodges, J. R., Villavicencio, M. A., Robison, L. L., Weiss, M. J., Kang, G., Schreiber, J.E., Porter, J.S., Kaste, S.C., & Saving, K. L., Bryant, P. C., Deyo, J. E., Nottage, K. A., King, A. A., Brandow, A. M., Lebensburger, J. D., Adesina, O., Chou, S. T., ... Gurney, J. G. (2018). Sickle Cell Clinical Research and Intervention Program (Scrip): A lifespan cohort study for sickle cell disease progression from the pediatric stage into adulthood. *Pediatric Blood & Cancer, 65*(9), e27228. <https://doi.org/10.1002/pbc.27228>
- Haarbauer-Krupa, J., Alexander, N. M., Mee, L., Johnson, A., Wise, J., Arora Gupta, N., Schechter, M.S., Wasilewski-Masker, K., & Gilleland Marchak, J. (2019). Readiness for transition and health care satisfaction in adolescents with complex

medical conditions. *Child: Care, Health, and Development*, 45(3), 463–471.

<https://doi.org/10.1111/cch.12656>

Hair, J. F., Black, W. C., Babin, B. J., & Anderson, R. E. (2010). *Multivariate Data Analysis: A Global Perspective*: Pearson Education International. New Jersey.

Howell, D. C. (2013). *Statistical methods for psychology* (8th ed.). Belmont CA: Wadsworth Cengage Learning.

J. Okumura, M., Saunders, M., & Rehm, R. S. (2015). The role of health advocacy in transitions from pediatric to adult care for children with Special Health Care Needs: Bridging families, provider, and Community Services. *Journal of Pediatric Nursing*, 30(5), 714–723. <https://doi.org/10.1016/j.pedn.2015.05.015>

Jenerette, C. M., & Murdaugh, C. (2008). Testing the Theory of Self-care Management for sickle cell disease. *Research in Nursing & Health*, 31(4), 355–369. <https://doi.org/10.1002/nur.20261>

Jensen, P. T., Paul, G. V., LaCount, S., Peng, J., Spencer, C. H., Higgins, G. C., Boyle, B., Kamboj, M., Smallwood, C., & Ardoin, S. P. (2017). Assessment of transition readiness in adolescents and young adults with chronic health conditions. *Pediatric Rheumatology*, 15(1), 70. <https://doi.org/10.1186/s12969-017-0197-6>

Johnson, A. D., Pines, E., Seibenhener, S., & Wilburn, S. (2020). Improving transition readiness in young adults with sickle cell disease. *The Journal for Nurse Practitioners*, 16(10), e165-e167. <https://doi.org/10.1016/j.nurpra.2020.07.026>

Kulandaivelu, Y., Lalloo, C., Ward, R., Zempsky, W. T., Kirby-Allen, M., Breakey, V.

- R., Odame, I., Campbell, F., Amaria, K., Simpson, E.A., Nguyen, C., George, T., & Stinson, J.N. (2018). Exploring the needs of adolescents with sickle cell disease to inform a digital self-management and Transitional Care Program: Qualitative Study. *JMIR Pediatrics and Parenting, 1*(2), <https://doi.org/10.2196/11058>
- Lebrun-Harris, L. A., McManus, M. A., Ilango, S. M., Cyr, M., McLellan, S. B., Mann, M. Y., & White, P. H. (2018). Transition planning among us youth with and without special health care needs. *Pediatrics, 142*(4), e20180194. <https://doi.org/10.1542/peds.2018-0194>
- Lebensburger, J., Bemrich-Stolz, & Howard. (2012). Barriers in transition from pediatrics to adult medicine in sickle cell anemia. *Journal of Blood Medicine, 105*. <https://doi.org/10.2147/JBM.S32588>
- Manwani, D., Doyle, M., Davidson, L., Mallea, M., Silver, E., Jackson, J., Ireland, K., Chhabra, R., Morrone, K., Minniti, C., Rastogi, D., Stein, R., Oyeku, S., & Bauman, L. (2020). Transition navigator intervention improves transition readiness to adult care and addresses barriers for youth with sickle cell disease. <https://doi.org/10.22541/au.160253847.75056849/v1> ’
- Matthie, N., Hamilton, J., Wells, D., & Jenerette, C. (2016). Perceptions of young adults with sickle cell disease concerning their disease experience. *Journal of Advanced Nursing, 72*(6), 1441-1451. <https://doi.org/10.1111/jan.12760>
- McClish, D. K., Smith, W. R., Levenson, J. L., Aisiku, I. P., Roberts, J. D., Roseff, S. D., & Bovbjerg, V. E. (2017). Comorbidity, pain, utilization, and psychosocial outcomes in older versus younger sickle cell adults: the PiSCES project. *BioMed*

Research International, 2017, 1-10. <https://doi.org/10.1155/2017/407547>

McManus, M., White, P., Barbour, A., Downing, B., Hawkins, K., Quion, N., Tuchman, L., Cooley, W.C., & McAllister, J. W. (2015). Pediatric to adult transition: A quality improvement model for primary care. *Journal of Adolescent Health*, 56(1), 73–78. <https://doi.org/10.1016/j.jadohealth.2014.08.006>

Melita, N., Diaz-Linhart, Y., Kavanagh, P. L., & Sobota, A. (2019). Developing a problem-solving intervention to improve self-management and transition readiness in adolescents with sickle cell disease. *Journal of Pediatric Nursing*, 46, 26–32. <https://doi.org/10.1016/j.pedn.2019.02.006>

Mennito, S., Hletko, P., Ebeling, M., Amann, L. A., & Roberts, J. (2014). Adolescents with sickle cell disease in a rural community: Are they ready to transition to adulthood? *South Medical Journal*, 107(9), 578–582. <https://doi.org/10.14423/SMJ.00000000000000162>

Molter, B. L., & Abrahamson, K. (2015). Self-efficacy, transition, and patient outcomes in the sickle cell disease population. *Pain Management Nursing*, 16(3), 418–424. <https://doi.org/10.1016/j.pmn.2014.06.001>

Nehring, W. M., Betz, C. L., & Lobo, M. L. (2015). Uncharted territory: Systematic review of providers' roles, understanding, and views pertaining to health care transition. *Journal of Pediatric Nursing*, 30(5), 732–747. <https://doi.org/10.1016/j.pedn.2015.05.030>

Patino, C. M., & Ferreira, J. C. (2018). Internal and external validity: Can you apply research study results to your patients? *Jornal Brasileiro de Pneumologia*, 44(3),

183–183. <https://doi.org/10.1590/s1806-37562018000000164>

- Piel, F. B., Steinberg, M. H., & Rees, D. C. (2017). Sickle cell disease. *New England Journal of Medicine*, *376*(16), 1561–1573. <https://doi.org/10.1056/nejmra1510865>
- Porter, J. S., Lopez, A. D., Wesley, K. M., Magdovitz-Frankfurt, P., Anderson, S. M., Cole, A. R., Boggs, J., & Hankins, J. S. (2017). Using qualitative perspectives of adolescents with sickle cell disease and caregivers to develop health care transition programming. *Clinical Practice in Pediatric Psychology*, *5*(4), 319–329. <https://doi.org/10.1037/cpp0000212>
- Porter, J. S., Wesley, K. M., Zhao, M. S., Rupff, R. J., & Hankins, J. S. (2017). Pediatric to adult care transition: Perspectives of young adults with sickle cell disease. *Journal of Pediatric Psychology*, *42*(9), 1016–1027. <https://doi.org/10.1093/jpepsy/jsx088>
- Reiss, J. G., Gibson, R. W., & Walker, L. R. (2005). Health care transition: Youth, family, and provider perspectives. *Pediatrics*, *115*(1), 112–120. <https://doi.org/10.1542/peds.2004-1321>
- Sarri, G., Bhor, M., Abogunrin, S., Farmer, C., Nandal, S., Halloway, R., & Revicki, D. A. (2018). Systematic literature review and assessment of patient-reported outcome instruments in sickle cell disease. *Health and Quality of Life Outcomes*, *16*(1). <https://doi.org/10.1186/s12955-018-0930-y>
- Sawicki, G. S., Lukens-Bull, K., Yin, X., Demars, N., Huang, I. C., Livingood, W., Reiss, J., & Wood, D. (2011). Measuring the transition readiness of youth with special health care needs: validation of the TRAQ—Transition Readiness Assessment

Questionnaire. *Journal of pediatric psychology*, 36(2), 160–171.

<https://doi.org/10.1093/jpepsy/jsp128>

Schwartz, L. A., Brumley, L. D., Tuchman, L. K., Barakat, L. P., Hobbie, W. L.,

Ginsberg, J. P., Daniel, L.C., Kazak, A.E., Bevan, L., & Deatrick, J. A. (2013).

Stakeholder validation of a model of readiness for transition to adult care. *JAMA*

Pediatrics, 167(10), 939. <https://doi.org/10.1001/jamapediatrics.2013.2223>

Setia M. S. (2016). Methodology Series Module 3: Cross-sectional Studies. *Indian*

journal of dermatology, 61(3), 261–264. [https://doi.org/10.4103/0019-](https://doi.org/10.4103/0019-5154.182410)

5154.182410

Speller-Brown, B., Patterson Kelly, K., VanGraafeiland, B., Feetham, S., Sill, A.,

Darbari, D., & Meier, E. R. (2015). Measuring transition readiness: A

correlational study of perceptions of parent and adolescents and young adults with sickle cell disease. *Journal of Pediatric Nursing*, 30(5), 788–796.

<https://doi.org/10.1016/j.pedn.2015.06.008>

Speller-Brown, B., Varty, M., Thaniel, L., & Jacobs, M. B. (2019). Assessing disease

knowledge and self-management in youth with sickle cell disease prior to

transition. *Journal of Pediatric Oncology Nursing*, 36(2), 143–149.

<https://doi.org/10.1177/1043454218819447>

Stevens, J. P. (2009). *Applied multivariate statistics for the social sciences* (5th ed.).

Mahwah, NJ: Routledge Academic.

Tabachnick, B. G., & Fidell, L. S. (2019). *Using Multivariate Statistics*, 7th ed. Pearson.

Treadwell, M., Johnson, S., Bitsko, M., Gildengorin, G., Medina, R., Barreda, F., Major,

- K., Telfair, J., & Smith, W. R. (2016). Self-efficacy and readiness for transition from pediatric to adult care in sickle cell disease. *International Journal of Adolescent Medicine and Health*, 28(4), 381–388. <https://doi.org/10.1515/ijamh-2015-0014>
- Tuchman, L. K., Schwartz, L. A., Sawicki, G. S., & Britto, M. T. (2010). Cystic fibrosis and transition to adult medical care. *Pediatrics*, 125(3), 566–573. <https://doi.org/10.1542/peds.2009-2791>
- Weissberg-Benchell, J., & Shapiro, J. B. (2017). A review of interventions aimed at facilitating successful transition planning and transfer to adult care among youth with chronic illness. *Pediatric Annals*, 46(5). <https://doi.org/10.3928/19382359-20170421-01>
- Wood, D. L., Sawicki, G. S., Miller, M. D., Smotherman, C., Lukens-Bull, K., Livingood, W. C., Ferris, M., & Kraemer, D. F. (2014). The Transition Readiness Assessment Questionnaire (TRAQ): Its Factor Structure, Reliability, and Validity. *Academic Pediatrics*, 14(4), 415–422. <https://doi-org.ezp.waldenulibrary.org/10.1016/j.acap.2014.03.008>