2018

A Mixed Methods Study Evaluating A Pediatric to Adult Care Transition Program For Sickle Cell Disease

Ardie Vanessa Pack-Mabien
University of Alabama at Birmingham

A MIXED METHODS STUDY EVALUATING A PEDIATRIC TO ADULT CARE TRANSITION PROGRAM FOR SICKLE CELL DISEASE

by

ARDIE VANESSA PACK-MABIEN

MARIE BAKITAS, COMMITTEE CHAIR
JOHNSON HAYNES, JR.
SIGRID LADORES
WENDY LANDIER
DHEERAJ RAJU

A DISSERTATION

Submitted to the graduate faculty of The University of Alabama at Birmingham,
in partial fulfillment of the requirements for the degree of
Doctor of Philosophy

BIRMINGHAM, ALABAMA

2018

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SCHOOL OF NURSING

ABSTRACT

Sickle cell disease is a potentially life-threatening hereditary hematological disorder. Transition from pediatric to adult care is a challenging process for many adolescents and young adults with sickle cell disease. These challenges involve the adolescent, young adult, family caregiver, health care provider, and health care system. To address the challenges, a limited number of sickle cell centers have developed transition programs to facilitate the transition process. However, research on transition programs is sparse. To address this gap, a mixed methods study was conducted to evaluate transition program participation on successful transition in a purposeful convenience sample of adolescents and young adults at the University of South Alabama. Data was collected using questionnaires, survey instruments, focus groups, telephone interviews, and chart reviews and analyzed quantitatively, using descriptive and inferential statistical analytical methods, and qualitatively, using thematic and content analysis followed by data integration at the interpretative level. The quantitative results demonstrated a statistically significant moderate to strong relationship between the *TR$_X$ANSITION Scale* score and length of time spent in a transition program (r = .53, n = 35, p < .01) and transfer to adult care within 60 days post-termination of pediatric care for the AYA 19 years of age (r = .44, n = 10, p < .01). The qualitative results yielded one overarching theme, participation in a transition program facilitates preparedness for the transfer to adult care supported by four sub-themes: 1) clarifying the process and providing support; 2) promoting

knowledge of sickle cell disease, self-management, and financial obligations; 3) encouraging independence and taking responsibility for one's own care; and 4) lessening emotional concerns and anxieties. The results from data integration were congruent, informative, and descriptive; participants also provided suggestions regarding what could improve preparedness for the transfer to adult care. The suggestions included peer mentoring, support groups, life lesson workshops, and hospital tours. The application of these findings to the transition program at the University of South Alabama have the potential for the refinement of the current program for a more effective process and improved transition experience. Findings could be utilized to generate hypotheses for future research.

Key words: Sickle Cell Disease, Successful Transition, Adolescents and Young Adults, Transition Programs, Transfer to Adult Care, Mixed Methods

ACKNOWLEDGMENTS

I would like to take this opportunity to express my sincere and utmost appreciation to the people who provided me with words of encouragement, emotional support, and prayers throughout this journey. Among these individuals, I must recognize my husband Sylvester of 31 years, youngest daughter Shernell, and mother Leslie whom I refer to as MeMe for always being in my corner and having confidence in my abilities to do well even during my most difficult hours. You gave me the inner strength and motivation I needed to keep moving forward when I didn't have the physical or mental strength to motivate myself. I love you each dearly and could not have made this journey without your constant love, patience, and support. Additionally, I must recognize my devoted four-legged family members: Payton, Pepper, and Jack Daniel. You proved yourselves to be loyal companions on many long nights. Lastly, I would like to thank my pastor, Rev. Dees, for your spiritual guidance, prayers, and most timely text messages with powerful words of inspiration.

There are two very special and outstanding individuals I would like to also acknowledge and express sincere gratitude. First, Dr. Frank, I have nothing but the utmost respect for you as an individual, educator, and researcher. You have been an invaluable mentor, supporter, and friend. It is my personal opinion that you are a true jewel at the University of Alabama at Birmingham, of whom the School of Nursing can be very proud to have as a faculty member. Second, Dr. Haynes, you are more than my

collaborating physician and mentor. You are one of a very limited number of trusted and true friends. Thank you for your constant respect, support, loyalty, and encouragement. I am most appreciative of you for recognizing my strengths, allowing me to develop and flourish professionally and academically, acknowledging my contributions to the sickle cell center, and not capitalizing on my weakness.

Lastly, I would like to acknowledge my dissertation committee chair and mentor, Dr. Marie Bakitas, and committee members, Drs. Wendy Landier, Sigrid Ladores, Dheeraj Raju, and Johnson Haynes, Jr. Thank you for supporting my endeavor to pursue doctoral studies at the University of Alabama at Birmingham. Your comments, advisement, and time throughout this process have been invaluable in the development and completion of my dissertation and related scholarly activities.

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LIST OF ABBREVIATIONS

ACS	Acute Chest Syndrome
AYA	Adolescents and Young Adults
AA	African Americans
ASPHO	American Society of Pediatric Hematology Oncology
APHON	Association of Pediatric Hematology Oncology Nurses
CVA	Cerebrovascular Accident
CT	Chronic transfusion
Df	Degree of Freedom
HbS	Sickle hemoglobin
HbSS	Sickle Cell Anemia-Homozygous Sickle Cell Anemia
HbSC	Sickle C Disease
$HbS\beta^{+}$	Sickle Beta Plus Thalassemia
$HbS\beta^{0}$	Sickle Beta Null Thalassemia
HIPAA	Health Insurance Portability and Accountability Act
HU	Hydroxyurea Therapy
IRB	Institutional Review Board
Ins.	Insurance
MMR	Mixed Methods Research
PACT	Pediatric to Adult Care Transition Program

PHI	Personal Health Information
PI	Principal Investigator
Quan	Quantitative
Qual	Qualitative
RBCs	Red blood cells
R_x	Medication
SCD	Sickle Cell Disease
SCDAA	Sickle Cell Disease Association of America
SCDAA-CBO	Sickle Cell Disease Association of America-Community Based Organization
SCSA	Self-care and Self-Advocacy
SPSS	Statistical Package for the Social Sciences
STAR$_X$	Successful Transition to Adulthood with Therapeutics=Rx for Medications
TP	Transition Program
UAB	University of Alabama at Birmingham
UAB-SON	University of Alabama at Birmingham School of Nursing
USA	University of South Alabama
USA-CSCC	University of South Alabama Comprehensive Sickle Cell Center
USA-SON	University of South Alabama School of Nursing
YSHCNs	Youth with special health care needs

CHAPTER ONE

INTRODUCTION

Successful transition of the adolescent and young adult (AYA) with sickle cell disease (SCD) from pediatrics to adult care is crucial (Amendah, Mvundura, Kavanagh, Sprinz, & Grosse, 2010; DeBaun & Telfair, 2012; Quinn, Rogers, & Buchanan, 2004). However, there are many factors in the lives and medical management of the AYA with SCD that may influence adaptation to this pivotal process (Andemariam et al., 2014; DeBaun & Telfair, 2012; Lebensburger, Bemrich-Stolz, & Howard, 2012). SCD is a hereditary hematological disorder caused by a single point mutation and characterized by the presence of: (a) abnormally shaped erythrocytes or sickle hemoglobin (HbS); (b) severe anemia; (c) intermittent vaso-occlusive pain episodes; and (d) acute and/or chronic end organ damage (DeBaun & Telfair, 2012; Hassell, 2010; Musumadi, Westerdale, & Appleby, 2012).

Because of mandatory newborn screening, early access to health care, and innovative new disease management therapies, 94-98% of the infants born with SCD in the United States are living to adulthood (Quinn et al., 2004; Quinn, Rogers, McCavit, & Buchanan, 2010). This improved survival to adulthood has led health care providers to focus on the transition to adult care as a part of the comprehensive medical management and care of the AYA with a chronic hematological disorder (Bryant, Young, Cesario, & Binder, 2011; DeBaun & Telfair, 2012; Doulton, 2010; Hauser & Dorn, 1999; McPherson, Thaniel, & Minniti, 2009; Wojciechowski, Hurtig, & Dorn, 2002).

Transition programs are a plausible strategy to facilitate this process (Abel et al., 2015; American Academy of Pediatrics, 2002, 2011; Blum, 1995; Blum et al., 1993; Bryant, Porter, & Sobota, 2015; DeBaun & Telfair, 2012; Hankins et al., 2012; McPherson et al., 2009; Smith, Lewis, Whitworth, Gold, & Thornburg, 2011; Telfair, Myers, & Drezner, 1994; Wojciechowski et al., 2002).

Transition is the period of preparation prior to and adjustment immediately after the completion of transfer from pediatric to adult care (Blum et al., 1993; Kennedy & Sawyer, 2008; Rosen, Blum, Britto, Sawyer, & Siegel, 2003). Transition involves a planned, purposeful, and comprehensive approach toward achievement of "autonomous health-related decision-making and self-care" skills necessary to navigate the adult healthcare system (Blum et al., 1993; Ladores, 2015, p. 8). To facilitate the transition process, it is important for health care providers to examine and understand the factors that may influence successful transition to adult care in order to improve the transition experience, inform practice, refine current programs, and develop new programs (Andemariam et al., 2014; Blum et al., 1993; Hankins et al., 2012; Rosen et al., 2003).

This study examined the impact of participation in a transition program on successful transition of the AYA with SCD to adult care. Successful transition was defined using disease-specific indicators and outcome measures. This chapter provides an overview of the: (a) research problem, significance, and problem statement; (b) purpose, specific aims, and research questions; (c) conceptual framework; (d) study design; and (e) definitions of the key terms relative to the research problem.

Research Problem, Significance, and Problem Statement

Although transition is an anticipated event in the lives of AYA with SCD, successful transition to adult care remains problematic (Andemariam et al., 2014; Fortuna, Halterman, Pulcino, & Robbins, 2012; Lebensburger et al., 2012). In this population, as many as one-third of AYAs delay or do not transition to adult care (Andemariam et al., 2014; Bemrich-Stolz, Halanych, Howard, Hilliard, & Lebensburger, 2015; Fortuna et al., 2012; Hankins et al., 2012). This delay or lack of transition is due to both clinical and non-clinical factors (Andemariam et al., 2014; Cancio et al., 2015; Lebensburger et al., 2012). The clinical factors include: (a) hemoglobinopathy status and disease severity; (b) treatment plan; (c) developmental difficulties; (d) cognitive impairment; and (e) delay in psychosocial maturation (Anie & Telfair, 2005; Cancio et al., 2015; Rosen et al., 2003). Non-clinical factors include: (a) dependency of AYA on the parent or caregiver and pediatric health care providers; (b) travel distance for medical care and transition services; and (c) access to skilled health care providers familiar with SCD and the management of disease complications (Andemariam et al., 2014; Lebensburger et al., 2012; Mainous et al., 2015; Okumura et al., 2008). In addition to the factors for an unsuccessful transition, the AYA with SCD face many challenges during the transition process (Bryant et al., 2011; McPherson et al., 2009; Smith et al., 2011; Tuchman, Slap, & Britto, 2008). Challenges faced by the AYA include reluctance to leave pediatrics, mistrust of adult health care providers and the health care system, lack of knowledge about SCD and mastery of self-care and self-advocacy transition skills necessary to navigate the adult health care system (Bryant et al., 2011; Hauser & Dorn, 1999; McPherson et al., 2009; Smith et al., 2011; Tuchman et al., 2008).

To meet the AYA with SCD transition needs of this population, medical experts, policy makers, and health care providers agree that a planned, purposeful, and comprehensive transition process is warranted and must begin early during adolescence (American Academy of Pediatrics, 2002, 2011; Blum et al., 1993; Bryant et al., 2015; National Center for Health Care Transition, 2014; Rosen et al., 2003). This realization led to a limited number of transition programs at sickle cell centers across the United States (Andemariam et al., 2014; Doulton, 2010; Hankins et al., 2012; Smith et al., 2011). One such program is the Pediatric to Adult Care Transition (PACT) program developed at the University of South Alabama Comprehensive Sickle Cell Center (USA-CSCC). The PACT program educates and prepares the AYA with SCD with both disease knowledge and the transition mastery skills of self-care and self-advocacy necessary to navigate the adult health care system. This program provides a multi-disciplinary, comprehensive, individualized, and purposeful approach to facilitate successful transfer and integration of AYA with SCD into the adult health care system.

While professional groups have recognized and endorsed the need for transition programs as a potential strategy to facilitate transition of the AYA has been recognized and endorsed nationally, current programs have not kept pace and lack uniformity (American Academy of Pediatrics, 2002; Andemariam et al., 2014; Blum, 1995; Blum et al., 1993; Bryant et al., 2015; DeBaun & Telfair, 2012; Hankins et al., 2012; Kennedy & Sawyer, 2008; McManus et al., 2013; Rosen et al., 2003; Smith et al., 2011; Telfair et al., 1994; Treadwell, Telfair, Gibson, Johnson, & Osunkwo, 2011). Current transition programs are based on assumptions and best-practice guidelines derived from sparse research findings (American Academy of Pediatrics, 2002, 2011; Blum et al., 1993;

Rosen et al., 2003; Suris & Akre, 2015). Additionally, there remains a dearth of literature on the efficacy of such programs on the transition process (Andemariam et al., 2014; Hankins et al., 2012; Smith et al., 2011). Research on transition programs has primarily focused on adherence to the transfer of care as evidenced by a confirmed adult care appointment and exchange of health information to an adult health care provider, as opposed to the accomplishment of educational, social, and medical disease-specific indicators and outcome measures (Andemariam et al., 2014; DeBaun & Telfair, 2012; Doulton, 2010; Hankins et al., 2012; Smith et al., 2011). Although limited, if the results of the previous research on transition programs could be confirmed, this would provide strong supporting evidence regarding the efficacy of transition program participation on successful transition. In addition, this would provide evidence-based data on defined disease-specific key indicators and outcome measures of successful transition in this population.

This study investigated the impact of participation in a transition program with defined disease-specific indicators and outcome measures that quantify a successful transition. The data generated could be utilized to: (a) provide evaluative evidence and new insight regarding transition programs; (b) refine, inform, and expand current transition programs, practices, and services; (c) develop new strategies to facilitate a more effective transition process; and (d) improve the transition experience of AYA with SCD. In addition, the results could be utilized to generate hypotheses for future research in a larger population of AYA with SCD regarding: (a) participation in a transition program as a strategy to facilitate the transition process; (b) disease-specific indicators

and outcome measures to quantify a successful transition; and (c) associations, interactions, patterns, and trends observed in this study.

Study Purpose, Specific Aims, and Research Questions

The primary purpose of this study was to examine impact of participation in a transition program participation on the AYA's: (a) knowledge of hemoglobinopathy status, therapeutic and prophylaxis medications, and insurance requirements for ongoing access to medical care; (b) mastery of self-care and self-advocacy transition skills necessary to navigate the adult health care system; and (c) transfer to adult care within 60 days post-termination of pediatric care for the AYA 19 years of age. The secondary purpose was to examine and explore clinical and nonclinical factors that may influence adaptation to and coping with the transition process. The clinical and non-clinical factors examined were: (a) hemoglobinopathy status; (b) disease severity; (c) treatment plan; (d) timing in a transition program; and (e) distance to clinic for medical services. Timing in a transition program was examined based on years in the program and number of encounters with the transition nurse coordinator for transition planning and educational services. The specific aims and research questions are:

- Specific Aim 1. Determine the impact of transition program participation on successful transition.
    - Research Question 1: What is the impact of transition program participation on successful transition as evidenced by: (a) knowledge of hemoglobinopathy status, therapeutic and prophylaxis medications, and insurance requirements for ongoing access to health care; (b) acquisition of self-care and self-advocacy skills necessary to self-schedule medical appointments,

communicate medical health history, and inquire about disease management and complications with adult care providers; and (c) transfer to adult care within 60 days post-termination of pediatric care for the AYA 19 years of age?

    - Sub-question 1. What influence do hemoglobinopathy status, disease severity, treatment plan, and distance to clinic for medical services have on the transition process?

- Specific Aim 2. Describe the AYA with SCD thoughts, experiences, concerns, and expectations of their transition program participation on successful transition.
    - Research Question 2: What are the AYA with SCD thoughts, experiences, concerns, and expectations of transition program participation on successful transition?
- Specific Aim 3. Describe the quantitative with qualitative findings and clinical implications on the impact of transition program participation on successful transition that can inform the: (a) refinement of an existing transition program; (b) development of new strategies to facilitate the successful transition; and (c) improvement of the transition experience for this population.
    - Research Question 3: What findings and clinical implications will emerge after comparing the results from the quantitative with qualitative phase of data analysis in order to lend clarity on the impact of participation in a transition program on the successful transition of the AYA with SCD in order to inform the: (a) refinement of an existing transition program, (b) development of new

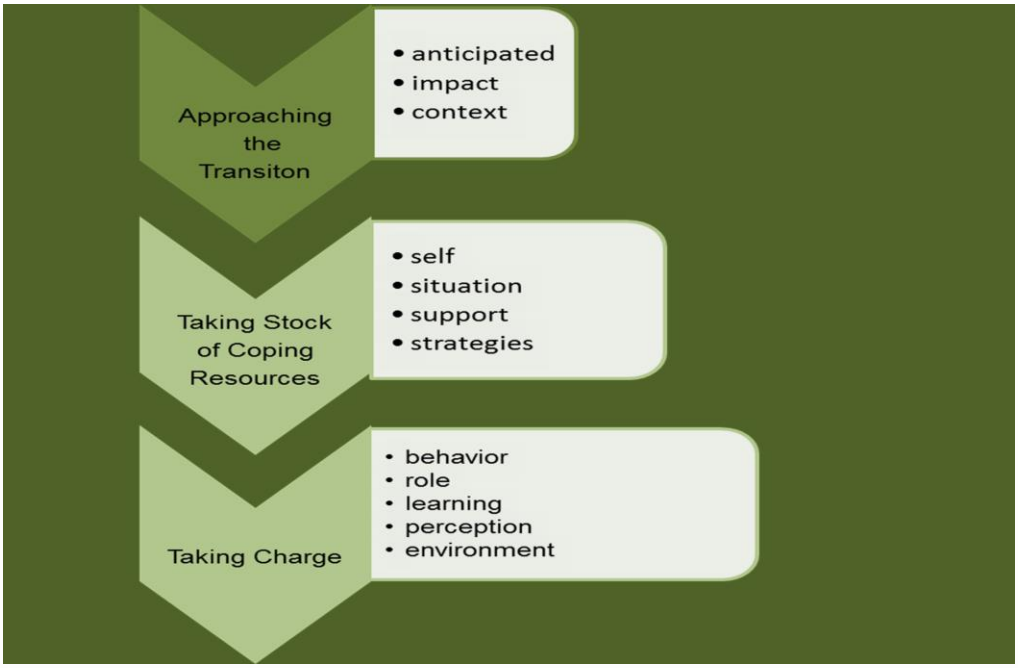
strategies to facilitate a more effective transition, and (c) improvement the transition experience of this population?

Conceptual Framework

Schlossberg's Transition Framework provides a conceptual model to examine the factors that may influence the transition and ability of individuals to take charge with new strategies in order to cope with and adapt to the transition process (Lenz, 2001; Schlossberg, 1981; Schlossberg, Waters, & Goodman, 1995; Winter, 2014). This transition framework is based on the assumption that transition is a process that occurs over time (Schlossberg, 2011; Schlossberg et al., 1995). In addition, Schlossberg's framework has three major concepts: (a) approaching transition; (b) taking stock of coping resources; and (c) taking charge (Schlossberg, 1981, 2011; Schlossberg et al., 1995). The major concepts of Schlossberg's transition framework are presented and visually depicted in Figure 1, adapted from Schlossberg et al. (1995).

Figure 1

Main Concepts of Schlossberg's Transition Framework



Main Concepts of Schlossberg's Transition Framework adapted from Schlossberg, N.K., Waters, E.B., & Goodman, J. (1995). *Counseling adults in transition: Linking practice with theory.* (2nd ed.). New York, NY: Springer.

Approaching transition defines the nature and an individual's perception of the transition: (a) type; (b) relativity; (c) context; and (d) impact (Schlossberg, 1981, 2011; Schlossberg et al., 1995). *Type* refers to the underlying nature of the transition. For example, is the transition an anticipated, unanticipated, or expected event that fails to occur? *Relativity* refers to an individual's appraisal of the meaning regarding the transition. *Context* indicates the personal or interpersonal relationship or physical setting of the transition to the individual. *Impact* reflects an individuals' assessment of how the transition will affect their relationships and routines. *Taking stock of coping resources* identifies four factors considered to be assets and/or liabilities that may influence how an

individual copes with and adapts to the transition: (a) self; (b) situation; (c) support; and (d) strategies (Schlossberg, 1981, 2011; Schlossberg et al., 1995). *Self* encompasses the psychological, personal, and demographic attributes of an individual affected by the transition (Schlossberg, 1981, 2011; Schlossberg et al., 1995). *Situation* refers to the timing, triggers, duration, and concurrent stressors of the transition (Schlossberg, 1981, 2011; Schlossberg et al., 1995). *Support* identifies availability of internal and external environmental factors of support (Schlossberg, 1981, 2011; Schlossberg et al., 1995). *Strategies* refer to measures that an individual utilizes to navigate through or cope with the transition (Schlossberg, 1981, 2011; Schlossberg et al., 1995). *Taking charge* describes an individual's reaction to the transition and occurs with the use of new strategies, acceptance, and integration of the change in routine, expected new behavior, role, learning, environment, and responsibility (Schlossberg, 1981; Schlossberg et al., 1995; Winter, 2014). For example, the expected self-management skills of the AYA require to: a) maneuver through the unfamiliar operating procedures of the adult health care system; b) shoulder adult health responsibilities independent of their caregiver; c) accept accountability for accessing their own medical treatment; and d) communicate effectively with the adult care providers.

Importantly, this transition framework aligns well with the Society for Adolescent Medicine's description of transition as an individualized, flexible, and gradual process that occurs over time with a change in role, responsibility, routine, expected behavior, relationships, and environment (Blum et al., 1993; Rosen et al., 2003).

Study Design

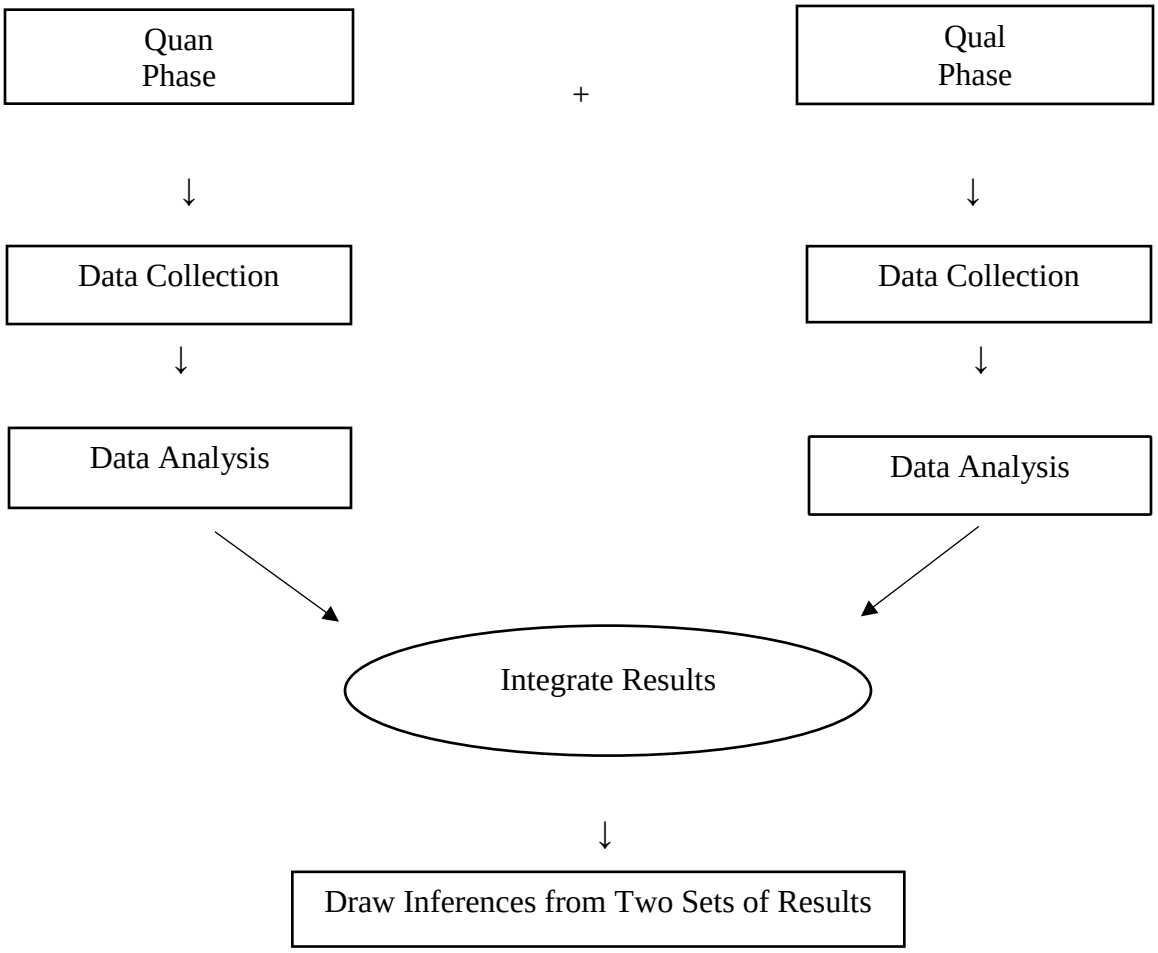
A mixed methods research (MMR) study design was utilized to examine the impact of transition program participation on successful transition. A MMR design collects, analyzes, and integrates quantitative and qualitative data to provide a more comprehensive inquiry into "what works, how, and why" of a research problem and obtain the best answers to a research problem (Creswell & Plano Clark, 2011; Plano Clark & Ivankova, 2016). In addition, MMR addresses the strengths and non-overlapping weaknesses of a single a quantitative or qualitative methodology alone (Creswell & Plano Clark, 2011; Hanson, Creswell, Clark Plano, Petska, & Creswell, 2005; Plano Clark & Ivankova, 2016). For example, the single quantitative methodology examines the relationships and interactions between a research study variables to identify trends and patterns of a research problem, but does not provide an understanding or insight into how or why the trends, interactions, and patterns exist (Creswell & Plano Clark, 2011; Plano Clark & Ivankova, 2016; Polit & Beck, 2012). The single qualitative methodology seeks to identify underlying themes and patterns for an in-depth understanding of a research problem, but lacks generalizability to a larger population (Creswell & Plano Clark, 2011; Plano Clark & Ivankova, 2016; Polit & Beck, 2012). However, when methodologies are combined, these limitations are addressed; enhancing the validity of the findings (Creswell & Plano Clark, 2011; Plano Clark & Ivankova, 2016). MMR also provides researchers with the freedom and flexibility to utilize an array of data collection tools (Creswell & Plano Clark, 2011; Plano Clark & Ivankova, 2016). These tools include questionnaires, surveys, interviews, focus groups,

observations, and audiovisual materials such as photographs and videotapes (Creswell & Plano Clark, 2011).

For the purpose of this study, the concurrent quantitative (quan) + qualitative (qual) MMR study design provided the best scientific method of gathering data from multiple sources: survey instruments, focus groups, telephone interviews, and chart reviews (Creswell & Plano Clark, 2011; Plano Clark & Ivankova, 2016). This design allows researchers the liberty to draw meta-inferences reflective of what was learned from integrating results after data analysis from both methodologies to answer multiple, related, and different aspects of the research questions in order to provide new insight about a complex phenomenon (Creswell & Plano Clark, 2011; Plano Clark & Ivankova, 2016; Polit & Beck, 2012). The research procedures of the concurrent quan + qual MMR study design are depicted visually in Figure 2.

Figure 2

Procedural Diagram of the Concurrent Quan + Qual Research Design



Procedural diagram of the research activities: Concurrent quan + qual study design. Adapted from Plano Clark and Ivankova (2016). *Mixed methods research: A guide to the field*. Thousand Oaks, CA: Sage.

Definition of Key Terms

Sickle cell disease (SCD). An autosomal recessive hematological disorder caused by a single point mutation and characterized by the presence of abnormally shaped erythrocytes or sickle hemoglobin (HbS), chronic hemolysis, anemia, and inflammation; intermittent vaso-occlusive pain episodes, and acute and/or chronic end organ damage

that transcends the lifespan of the affected individual (DeBaun & Telfair, 2012; Hassell, 2010; Musumadi et al., 2012).

Transition. The period of preparation prior to and immediately after the completion of transfer from pediatrics to adult health care that involves the purposeful, planned movement of adolescents and young adults with a chronic physical and/or medical conditions from pediatric-centered to adult-centered health care system (Blum et al., 1993; Kennedy & Sawyer, 2008).

Transfer. The movement of health care and health information between health care systems (Kennedy & Sawyer, 2008).

Transition readiness. The process of making the decision and taking the necessary educational, psychological, social development, and logistical steps by the adolescent, parents, and health care provider to prepare for, begin, continue, and finish the process of transition (Sobota et al., 2014; Telfair, Alexander, Loosier, Alleman-Velez, & Simmons, 2004a).

Adolescents and young adults (AYA). Persons in a developmental period of time that: (a) begins with the onset of puberty which occurs between ages 10 to 12 or 12 to 14 years for females and males respectively; (b) ends at age 19 years for both males and females; and (c) involves the movement from a state of dependency to the acquisition and development of autonomy (Wojciechowski et al., 2002).

Chapter Summary

In summary, the transition of the AYA with SCD from pediatric to adult health care is an anticipated and critical period of time in the medical management of this vulnerable and growing population. However, the transition process remains challenging

for many. To address the challenges encountered during this process, a limited number of transition programs have evolved at sickle cell centers nationally as a plausible strategy to facilitate the successful transition from pediatrics to adult care. However, evaluative evidence-based data on transition programs is sparse, gaps exist, and questions remain regarding efficacy of such programs. In addition, a consensus regarding what constitutes successful transition in this population has not been established. This MMR study investigated the impact of participation in a PACT program on successful transition using disease-specific indicators and outcome measures. The results of this MMR study provides current data regarding transition programs and new insights in order to: (a) refine current and develop new transition programs; b) inform the development of new strategies for a more effective transition process; and c) improve the transition experience of the AYA with SCD.

CHAPTER TWO

REVIEW OF LITERATURE

The review of the literatue relevant to the transition of the adolescent and young adult (AYA) with sickle cell disease (SCD) revealed that, despite the growing consensus and need for a coordinated, proactive, purposeful, and comprehensive transition process; there are many barriers that hinder the timely and successful transition of this population to adult care (American Academy of Pediatrics, 2002; Andemariam et al., 2014; Blum et al., 1993; Bryant et al., 2015; Lebensburger et al., 2012; Rosen et al., 2003; Sobota et al., 2014; Sobota, Neufeld, Sprinz, & Heeney, 2011; Stollon et al., 2015; Telfair, Ehiri, Loosier, & Baskin, 2004b; Wojciechowski et al., 2002). The barriers to successful transition are multi-factorial and relevant to the AYA, parent or caregiver, health care provider, and health care system (Andemariam et al., 2014; Bryant et al., 2011; Hauser & Dorn, 1999; Lebensburger et al., 2012; Mainous et al., 2015; Okumura et al., 2008; Smith et al., 2011; Sobota et al., 2011; Stollon et al., 2015; Telfair et al., 1994; Tuchman et al., 2008). Specifically, the transition barriers relevant to the AYA and parent or caregiver include emotional concerns, fears, and anxieties about the transfer to adult care and lack of preparation by the AYA to assume adult health responsibilities and autonomous decision-making skills (Bryant et al., 2011; Hauser & Dorn, 1999; Smith et al., 2011; Wojciechowski et al., 2002). Barriers relevant to the health care provider include lack of involvement by the pediatric provider in the transition process and limited availability of skilled and trained adult health care providers (Mainous et al., 2015; Okumura et al.,

2008; Telfair et al., 2004a). Barriers relevant to the health care system include inadequate or lack of health insurance, ill-equipped health care system, and inability of transition programs to meet the transitional needs of this population in terms of availability, sophistication, and efficacy (Hauser & Dorn, 1999; Lebensburger et al., 2012; Mainous et al., 2015; Okumura et al., 2008; Porter, Graff, Lopez, & Hankins, 2014; Sobota et al., 2014; Sobota et al., 2011; Telfair, Haque, Etienne, Tang, & Strasser, 2003; Telfair et al., 1994; Wojciechowski et al., 2002).

This chapter presents detailed description of the review, analysis, and synthesis of the literature relevant to the AYA with SCD transition from pediatrics to adult care. The description begins with an overview of the search methods and results, and analysis and synthesis of the literature. The result of the synthesis presents an overview of SCD, definition of transition, relevant historical developments, and the challenges of and barriers to transition. Next, identified gaps in the literature, Schlossberg's Transition Framework, and how this mixed methods design addresses the identified gaps are presented. Then, there is a discussion on mixed methods research (MMR) and concurrent quantitative + qualitative study design. This is followed by an exploration of alternative designs and methods.

Search Methods

The search methods of this comprehensive review of the health sciences literature, conducted to examine the transition of the AYA with SCD from pediatrics to adult care, included five computerized databases: Cumulative Index for Nursing and Allied Health Literature (CINAHL), PubMed, Scopus, Google Scholar, and Google. These search strategies were guided by the use of single and combined key words and phrases

regarding the transition and transfer of children, adolescent, young adult, youth with special health care needs (YSHCNs), chronic illness, and SCD from pediatrics to adult care. Published research studies on the factors that may influence successful transition were also reviewed to support this literature review on the transition process.

The inclusion criteria for selected articles were limited to peer-reviewed, evidence-based, descriptive and observational quantitative, qualitative, and MMR published in the English language between January 1990 and January 2017. The inclusion criteria were also limited to research investigating adolescents ages 13-17 and young adult ages 18-26 years for both males and females and factors that may influence the transition process. Editorial letters, reviews, and commentaries were excluded from the literature review. In addition, research on the transition of adolescents with chronic illnesses other than SCD was not included due to variability in disease pathophysiology, outcome indicators, and confounding variables. Likewise, research on the transition of the AYA from an inpatient facility to a medical home or long-term care facility was excluded. Furthermore, informative and descriptive articles about the learning preferences of AYA and use of health information and technology in the transition process were also excluded. Lastly, research conducted outside of the United States was excluded due to differences in medical management, access to health care, and health outcomes.

To increase the quality and quantity of the literature and identify research not previously found during the initial review, the titles and abstracts of evidence-based research studies and reference lists of key and related articles identified in the primary search were critically appraised for inclusion. Also, a web-based search was conducted

to identify full-text articles not previously identified during the initial review. The web-based search for full-text articles included Got Transition-Center for Health Care Transition Improvement; Sickle Cell Disease Association of America; Alabama Family Got Voices Transition Services; and National Institutes of Health-National Heart, Lung, and Blood Institute. The results of this comprehensive computerized database and web-based review of the literature were compiled, examined, and critically appraised by the researcher.

Outcome Results

The screening process of the full-text articles selection for eligibility, analysis, and synthesis results of this comprehensive literature review on the transition of the AYA with SCD is described and presented visually in a flow diagram (see Appendix D). The computerized database search for the identified keywords and phrases yielded a total of 280 full-text articles. The review of the reference lists from pertinent full-text articles and web-based resources produced an additional 29 full-text articles. From this comprehensive and critical review, a total of 309 full-text articles were identified and screened for eligibility. Duplicate articles (n = 106) were removed. The remaining 203 full-text articles were reviewed and screened to meet the criteria for inclusion. Of these 203 full-text articles, an additional 126 full-text articles did not fully meet eligibility criteria and were excluded from this review. The full-text articles excluded were comprised of those without a named author, editorials, commentaries, and letters. In addition, full-text articles were removed that described the need for quality assurance, case management, transition milestones, and health information technology as an educational tool during the transition process. Likewise, the removed full-text articles

consisted of those articles providing a description of the vital statistics related to SCD. Lastly, full-text articles removed included those related to the transition of the AYA with chronic illness and special health care needs other than SCD and outside the United States. The remaining 77 full-text articles were reviewed and critically appraised for eligibility. This assessment resulted in the removal of an additional 58 full-text articles that did not meet full criteria. The 58 full-text articles removed included: (a) consensus statements, clinical reports, and policies; (b) overview of SCD and transition; (c) narrative description of transition programs; (d) transition readiness assessment tools; (e) age related healthcare cost, utilization, and disease burden; (f) development of transition models and conceptual frameworks; and (g) ethical considerations in the transition process.

Of the remaining full-text articles, 19 descriptive and observational empirical-based research articles were identified as relevant to the transition of the AYA with SCD from pediatrics to adult care and the research questions. Of these 19 studies, 13 quantitative and six qualitative studies with full-text articles were reviewed and appraised for synthesis (Andemariam et al., 2014; Bemrich-Stolz et al., 2015; Bryant et al., 2011; Hankins et al., 2012; Hauser & Dorn, 1999; Mainous et al., 2015; McPherson et al., 2009; Okumura et al., 2008; Porter et al., 2014; Smith et al., 2011; Sobota et al., 2014; Sobota et al., 2011; Speller-Brown et al., 2015; Stollon et al., 2015; Telfair et al., 2004a; Telfair et al., 2004b; Telfair et al., 1994; Tuchman et al., 2008; Wojciechowski et al., 2002). The research studies investigated the natural history and transition experience of this population from the perspective of the AYA, family, and health care providers (n = 10). In addition, the research explored transition readiness and transfer (n = 3), healthcare

providers' participation in the transition process (n = 1), and comfort levels of health care providers in the medical management of the AYA with SCD (n = 2). Lastly, the research included an investigation regarding the efficacy of pilot transition programs of varying formats, structures, and components of successful transition (n = 3): (a) transfer of care (n = 2); and (b) development of increased disease knowledge scores (n = 1). More specifically, the 13 quantitative studies included: (a) non-experimental descriptive studies of the transition experience (n = 6); (b) descriptive, observational, and correlational studies of transition readiness (n = 4); and (c) cross-sectional and national survey of healthcare providers on transition practices, comfort level, education, training, and expectations of the transitioned AYA (n = 3). The quantitative studies also included retrospective chart review, descriptive, and observational pilot studies examining transition programs.

The six qualitative studies included descriptive, phenomenological, and exploratory nonexperimental studies exploring the transition experience, concerns, expectations, attitudes, and barriers from the perspectives of the AYA with SCD, caregivers, and health care providers. The study designs varied relative to the defined study variables, sampling methods, timing, length, and methods of data collection and measurement. For example, the sampling methods utilized were snowball, purposeful, convenience, and random. Furthermore, methods of data collection employed were varied, including surveys, knowledge assessment quiz and questionnaires, transition readiness assessment tools, focus groups, and telephone and face-to-face interviews. However, the studies reviewed were all relevant to the transition of the AYA with SCD and research questions.

Likewise, the web-based search was conducted using the combined key word phrase SCD and transitioning AYA to expand the search results. This search method yielded 15,600 and 30,000 full-text articles, abstracts, commentaries, editorials, dissertations, theses, and resources from Google Scholar and Google, respectively. However, time constraints limited the researcher's ability to fully identify, select, and critically appraise additional full-text articles for this comprehensive web-based search and review. Furthermore, the web-based search performed of Got Transition-Center for Health Care Transition Improvement and the Sickle Cell Disease Association of America for published studies on the transition of AYA yielded 23 articles, of which 16 were full-text articles. Only one of the 16 full-text articles was related specifically to the transition of the AYA with SCD. Although useful in identifying the core elements of transition, resources, and tool kits for health care providers, caregivers, and patients, the web-based search and review of the Center for Health Care Transition Improvement and Sickle Cell Disease Association of America resulted in only two new full-text articles, identified after a thorough review and assessment. The web-based search of Alabama Family Got Voices Transition Services and the National Institutes of Health-National Heart, Lung, and Blood Institute did not result in additional full-text articles for review and assessment. Lastly, research studies conducted outside of the United States were excluded due to differences in healthcare resources, medical advances, and access to health care and medical management.

Analysis and Synthesis of the Literature

Life expectancy for infants born in the United States with sickle cell disease (SCD) has advanced into the fourth and fifth decade of life and beyond (Quinn et al.,

2004; Quinn et al., 2010). As a result of improved survival, the transition of adolescents and young adults (AYA) to adult care is an anticipated event and a critical process (DeBaun & Telfair, 2012; Treadwell et al., 2011). During this transition, adult health care providers expect the AYA with SCD to have knowledge of hemoglobinopathy status, medications, and insurance requirements for ongoing access to medical care, and competence in self-management, self-advocacy, and autonomous living skills (Abel et al., 2015; Blum et al., 1993; DeBaun & Telfair, 2012; Rosen et al., 2003; Telfair et al., 2004a). The AYA with SCD and caregiver express a need for a formalized and purposeful transition process that educates and prepares this population with the knowledge and skillset necessary to navigate the adult health care system (Bryant et al., 2011; Hauser & Dorn, 1999; Porter et al., 2014; Telfair et al., 1994; Wojciechowski et al., 2002). Clinicians recognize transition programs as a plausible strategy to facilitate the AYA's transition to adult care for ongoing chronic disease medical management (American Academy of Pediatrics, 2002, 2011; DeBaun & Telfair, 2012; Quinn et al., 2004; Quinn et al., 2010; Rosen et al., 2003; Telfair et al., 1994; Treadwell et al., 2011).

However, transition programs currently are limited, inconsistent, and driven by assumptions and best-practice guidelines rather than evidence (American Academy of Pediatrics, 2002, 2011; Andemariam et al., 2014; Bryant et al., 2015; Doulton, 2010; Hankins et al., 2012; Rosen et al., 2003; Smith et al., 2011; Sobota et al., 2011; The Center for Health Care Transition Improvement, 2014). Likewise, evidence on the efficacy of such programs is sparse, anecdotal, and the measures of successful transition are limited to the transfer of care rather than the acquisition of disease-specific educational, medical, and psychosocial knowledge (Andemariam et al., 2014; Doulton,

2010; Hankins et al., 2012; Smith et al., 2011). Therefore, it is critical to expand, explore, measure, and understand the essential factors that may influence the transition process using more comprehensive disease-specific key indicators and outcome measures.

Overview of Sickle Cell Disease

SCD is an autosomal recessive hematological disorder notable for a single beta-globin gene mutation at the 6^{th} position of the beta-globin chain on chromosome 11 with the substitution of glutamic acid by valine (Ballas, 2015; Ballas et al., 2010; Quinn, 2013). This disease is characterized by: (a) abnormally shaped erythrocytes or sickle hemoglobin (HbS); (b) recurrent vaso-occlusive pain episodes; (c) chronic hemolysis, severe anemia, and inflammation; and (d) acute and/or chronic end organ damage with a propensity to affect every organ in the body (Ballas, 2015; Ballas et al., 2010; DeBaun & Telfair, 2012; Pack-Mabien & Haynes, 2009). Based on the 2008 U.S. census, SCD is one of the most common genetic disorders in children and affects an estimated 100,000 - 138,000 individuals in the United States, predominantly African Americans and Hispanics (Brousseau, Panepinto, Nimmer, & Hoffmann, 2010b; Hassell, 2010; Yanni, Grosse, Yang, & Olney, 2009). Of these individuals, an estimated 47,400 reside in the southern region of the United States, with an estimated 2,851 living in the state of Alabama (Brousseau et al., 2010b; Hassell, 2010).

There are four commonly seen genotypes of SCD: (a) homozygous sickle cell anemia (HbSS); (b) sickle beta null thalassemia ($HbS\beta^0$ Thalassemia); (c) sickle C disease (HbSC); and (d) sickle beta plus thalassemia ($HbS\beta^+$ Thalassemia) (Ballas et al., 2010; Pack-Mabien & Haynes, 2009; Quinn, 2013). The most commonly seen genotype

is HbSS, which affects one in 365 African Americans, followed by HbSC disease, which affects one in 800 African Americans, and HbSβ^0 and HbSβ^+ Thalassemia, which combined affects one in 1,600 African Americans (Centers for Disease Control and Prevention, 2015; Pack-Mabien & Haynes, 2009; Quinn, 2013). Furthermore, SCD affects one in 16,300 Hispanics in the United States (Centers for Disease Control and Prevention, 2015). In SCD, the life expectancy, disease severity, and degree of anemia are individualized and varies based on genotype (Platt et al., 1994; Serjeant, 2013).

The estimated life expectancy for individuals with HbSS and HbSβ^0 Thalassemia is 42 years for males and 48 years for females (Platt et al., 1994; Serjeant, 2013). For individuals with HbSC disease, the life expectancy is 60 years for males and 68 years for females (Platt et al., 1994). The most common cause of death before 2 years of age is infection (Brousseau, Owens, Mosso, Panepinto, & Steiner, 2010a; Pack-Mabien & Haynes, 2009; Platt et al., 1994; Serjeant, 2013; Thomas, Pattison, & Serjeant, 1982). The most common cause of death after 2 years of age is acute chest syndrome and splenic sequestration (Platt et al., 1994; Serjeant, 2013; Thomas et al., 1982). The most commonly seen disease complications are cerebrovascular accident, sickle retinopathy acute chest syndrome, pulmonary hypertension, acute splenic sequestration, cholelithiasis, acute and chronic renal disease, priapism, dactylitis and leg ulcers (Brousseau et al., 2010a; Cancio et al., 2015; Hamideh & Alvarez, 2013; Pack-Mabien & Haynes, 2009; Platt et al., 1994). Lastly, the management and treatment of SCD and related disease complications include supportive care, red blood cell transfusion, hydroxyurea therapy, and hematopoietic stem cell and umbilical cord blood transplantation (DeBaun & Telfair, 2012; Pack-Mabien & Haynes, 2009; Quinn, 2013).

According to the 2006 Healthcare Cost and Utilization Project Statistical Brief #21, the most recent information available, between 1994 and 2004, SCD accounted for more than 113,000 hospital admissions, incurred more than $1 billion in submitted charges, and cost an estimated $500 million in medical expenses nationwide (Steiner & Miller, 2006). Furthermore, between 2001 and 2005, an average lifetime total health care cost for an individual with SCD was $953,640, of which the greatest proportion attributed to inpatient costs during adolescence and young adulthood (Kauf, Coates, Huazhi, Mody-Patel, & Hartzema, 2009; Mvundura, Amendah, Kavanagh, Sprinz, & Grosse, 2009). More specifically, estimated annual average cost of medical expenses in 2005 was $12,000 for those AYA insured with a federally funded, and $15,000 for those with employer-sponsored (Amendah et al., 2010; Centers for Disease Control and Prevention, 2015; Mvundura et al., 2009). Lastly, the total health care expenditure in 2005 for the AYA with SCD was an estimated $355 million for health care utilization related to hospital admissions, emergency room visits, outpatient services, and prescription drugs (Amendah et al., 2010; Kauf et al., 2009).

Definition of Transition

Transition is the purposeful, coordinated, and comprehensive transfer from pediatrics to adult care that is developmentally and psychologically appropriate without an interruption in access to medical care (Blum et al., 1993). Transition is also a gradual and flexible process coordinated by both pediatric and adult health care providers to address the medical, educational and/or vocational, and psychosocial needs of the AYA with a chronic condition (Ladores, 2015; McPherson et al., 2009; Reiss & Gibson, 2002; Rosen et al., 2003).

The transition of the AYA with SCD has become paramount in the lifelong and ongoing medical management of this chronic and potentially debilitating disease (DeBaun & Telfair, 2012; Hamideh & Alvarez, 2013; Quinn et al., 2010). However, the transition process is often haphazard and challenging for the AYA with SCD (Telfair et al., 2004b; Wojciechowski et al., 2002). As many as one-third of this population delay or do not transition to adult care due in part to the complexity of this chronic disease, concerns and fears of the AYA and caregiver, lack of or inadequate health insurance, limited access to health care services, and an ill-equipped adult healthcare system (Andemariam et al., 2014; Cancio et al., 2015; Fortuna et al., 2012; Lebensburger et al., 2012; Wojciechowski et al., 2002). In addition, this process occurs during a period of time marked by increased occurence and severity of vaso-oclusive pain episodes, recurrent emergency room visits and hospital admissions, and higher health care costs compared to younger children and older adults (Brousseau et al., 2010a; Hamideh & Alvarez, 2013; Kauf et al., 2009).

Furthermore, many lack adequate knowledge about the disease and skill set necessary to navigate the adult health care system (Andemariam et al., 2014; Bryant et al., 2011; Burlew, Telfair, Colangelo, & Wright, 2000; Doulton, 2010; Hankins et al., 2012; Hauser & Dorn, 1999; Lebensburger et al., 2012; Reiss, Gibson, & Walker, 2005; Smith et al., 2011; Tuchman et al., 2008; Wojciechowski et al., 2002). The lack of adequate preparation, disease knowledge, and skill set for adult health responsibilities by the AYA with SCD reflects the critical and growing demand for a more effective transition process and transfer to adult care (Andemariam et al., 2014; Blum et al., 1993; Hankins et al., 2012; Rosen et al., 2003; Treadwell et al., 2011; Wojciechowski et al.,

2002). The participation in a transition program may bridge the gap between pediatric and adult care by facilitating the development of disease-specific knowledge (educational, medical, and psychosocial), acquisition of self-care and self-advocacy skills, and transfer to adult care without interruption of routine medical management and health maintenance (Andemariam et al., 2014; Hankins et al., 2012; Smith et al., 2011). However, the evidence on participation in a transition program in this population is limited (Andemariam et al., 2014; Hankins et al., 2012; Smith et al., 2011).

Relevant Historical Developments

Historically, the complexity of the transition from pediatrics to adult care was first addressed in an open forum by the medical community during the September 1994 International Invitational Conference titled, "Moving On: Transition from Pediatric to Adult Health Care" (Blum, 1995). At this conference, attendees from the medical community explored implications, limitations, and barriers to the transition process, as well as conflicting views of both pediatric and adult healthcare providers about the transition process (Blum, 1995). Additionally, the conference attendees brought to the forefront of the medical community the need to develop, examine, recommend, and implement strategies to improve the transition experience, process, and services for the AYA with a chronic condition (Blum, 1995). Following this conference, numerous consensus statements, clinical reports, and guidelines from leading health organizations have been released with recommendations and best-practice guidelines to aid health care providers in the facilitation of the transition process.

For example, the 2002 joint consensus statement by the American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP), and American

College of Physicians (ACP) highlighted and endorsed the importance of a seamless, efficient, and comprehensive transition to adult care for the AYA with a chronic condition (American Academy of Pediatrics, 2002). Also, the 2003 Society for Adolescent Medicine position paper endorsed transition programs as a means for an effective transition and advocated coordination of such programs by the collaborative efforts of both pediatric and adult health care providers and elimination of factors that impede successful transition (Rosen et al., 2003). This position paper also recommended education of patients, families, and providers on the importance of transition preparation and an increase in the number and training of adult health care providers available to meet the needs of this population (Rosen et al., 2003). In addition, there was a consensus for the development of evidence-based best-practice guidelines (Rosen et al., 2003). Lastly, the position paper identified the need for additional research to examine the transition process (Rosen et al., 2003). Furthermore, the 2011 AAP clinical report provided best-practice guidelines to health care providers to ensure the facilitation of an uninterrupted, high-quality, and developmentally appropriate transition process to adult care beginning early in adolescence (American Academy of Pediatrics, 2011; White, McManus, McAllister, & Cooley, 2012). Finally, the 2015 consensus statement of the Association of Pediatric Hematology/Oncology Nurses and the American Society of Pediatric Hematology/Oncology endorsed the practice of transitioning every AYA with SCD between age 13 and 19 years and transfer to the adult health care system under the coordinated efforts of both pediatric and adult health care providers (Bryant et al., 2015).

Following the release of the consensus statements and clinical reports by medical experts and health organizations, Got Transition, a program of the Center for Health Care

Transition Improvement, identified six core elements essential to the successful transition (American Academy of Pediatrics, 2011; The Center for Health Care Transition Improvement, 2014). The six core elements primarily serve as best-practice guidelines for healthcare providers to improve current transition practices, programs, and services for the AYA with a chronic condition (American Academy of Pediatrics, 2011; The Center for Health Care Transition Improvement, 2014; White et al., 2012). The six core elements define the key components of a model transition program, which include: 1) establishing policy; 2) developing a system for tracking and monitoring; 3) assessing transition readiness routinely; 4) planning and preparing the AYA; 5) transferring of care; and 6) completing transfer of care with integration into the adult health care system (The Center for Health Care Transition Improvement, 2014; White et al., 2012). Lastly, Got Transition, under the umbrella of the Center for Health Care Transition Improvement, developed resources and self-assessment tools for quality assurance that measure progress toward the successful transition and improvement of support services and programs (The Center for Health Care Transition Improvement, 2014). The resources and tools available to health care providers include readiness assessment surveys, individual flow sheets, transfer of care checklists, and post-transfer to adult care feedback surveys (The Center for Health Care Transition Improvement, 2014; White et al., 2012).

In summary, SCD is a chronic and potentially life-threatening hematological disorder. Nevertheless, a growing number of the pediatric population with this disease survive into adulthood with the need for a purposeful and planned transition from pediatric to adult care. However, the transition process is often marked by a host of challenges, increased vulnerability, and higher health care utilization and medical costs.

To address the complexities encountered during this process, the medical community over the last two decades has explored the barriers, implications, perceptions, and limitations of this process. This review of literature identified a consensus on best-practice guidelines and the six core elements of a successful health care transition that will aid healthcare providers in facilitating a more efficient transition process. In addition, healthcare providers and policy makers endorse transition planning and preparation for every AYA with SCD, coordinated by both pediatric and adult health care providers. Likewise, health care providers and policy makers advocate for transition programs as a plausible strategy to facilitate successful transition.

Challenges and Barriers to Transition

There are a host of challenges and barriers to transition of the AYA with SCD that may impede or inhibit successful transition. The challenges and barriers include emotional concerns, fears, and anxieties of the adolescent, young adult, and family caregiver(s), and lack of preparation of the AYA with SCD, health care providers, and health care system.

Emotional Concerns, Fears, and Anxieties

Adolescents and young adults. The identified barriers to transition relevant to the emotional concerns, fears, and anxieties of the AYA are reluctance to leave pediatrics, mistrust of the adult health care provider and health care system, and lack of knowledge about SCD and transition mastery skills necessary to responsibly and independently navigate the adult health care system (Bryant et al., 2011; Hauser & Dorn, 1999; McPherson et al., 2009; Smith et al., 2011; Telfair et al., 2004b; Telfair et al., 1994; Tuchman et al., 2008; Wojciechowski et al., 2002). For example, Bryant et al. (2011), in

a descriptive phenomenological study of the transition experience among a purposive sample of 14 AYA with SCD and Thalassemia, found transition to be a period of adjustment, sadness, abandonment, and apprehension about the identification of an adult provider and transfer to the adult health care system. Similar findings were previously described by Hauser and Dorn (1999), Wojciechowski et al. (2002), and Telfair et al. (2004b) on the transition experience, concerns, and expectations of the AYA with SCD. The researchers of the latter study in a nationwide survey among a cross-sectional sample of 172 AYA with SCD found five primary concerns about the transition experience to adult care. The primary concerns of this national study included: (a) lack of information about the transition process; (b) reluctance to leave their current pediatric provider; (c) unfamiliarity with the new adult care providers; (d) fear of being treated as an adult; and (e) lack of financial means to pay for health care costs.

In a two-part quantitative descriptive investigation of a transition program's impact on disease knowledge scores, concerns, and emotions related to the transition process, Smith et al. (2011) found a broad range of both positive and negative concerns pre- and post-transition in a convenience sample of 33 AYA with SCD. Similar to the qualitative findings of Bryant et al. (2011), Hauser and Dorn (1999), and Wojciechowski et al. (2002), the researchers of this study found AYA are reluctance to leave the familiarity of pediatric care. Additionally, the study identified AYA's concerns, fears, and anxieties about establishing a relationship with a new and unfamiliar provider, finding an adult provider with expertise in SCD management, and having limited experience with autonomous decision-making, self-management skills, and adult health responibilities. Furthermore, the findings of Smith et al. (2011) are similar to the

previous quantitative findings of Telfair et al. (1994), who explored the transfer concerns of adolescents (*n* = 36) and young adults (*n* = 60) with SCD. In this study, the researchers found mixed emotions and transfer concerns relative to successful transition. The concerns were related to treatment as an adult with SCD, means of payment for medical care, adult health care providers' knowledge, understanding, and management of SCD, and reluctance in leaving the long-term relationship with the pediatric care program.

Family caregiver(s). The literature review also revealed that family caregiver(s) harbored a mistrust of the adult health care system, expressed a lack of confidence in the adult health care provider's ability to manage SCD, and were concerned about the development of self-management skills, autonomy, and adherence with medical care by the AYA once pediatric care was terminated (Hauser & Dorn, 1999; Porter et al., 2014; Telfair et al., 1994). For example, Porter et al. (2014) recruited convenient and purposeful sample of (*n* = 12) families of the AYA with SCD from a comprehensive pediatric SCD program to explore the perspectives of the adolescent (*n* = 11), their siblings (*n* = 11), and caregivers (*n* = 12) on the transition to adult care. In this descriptive qualitative study, the researchers found three core themes surrounding the concerns of caregivers: (a) lack of preparation on behalf of the AYA in the development of disease knowledge and self-management skills; (b) adult providers' lack of knowledge about SCD; and (c) lack of available and identifiable adult health care providers. Similar findings were previously reported in the qualitative research of Telfair et al. (1994), who explored concerns, issues, and expectations in a cross-sectional survey of adolescents (*n* = 36), young adults (*n* = 60), and caregivers (*n* = 25). In this study, the researchers found five primary concerns of the caregivers: (a) leaving the familiarity of pediatrics; (b) AYA

ability to assume adult health responsibilities; (c) adult health care providers' lack of understanding SCD; (d) adult health care providers' lack of belief in the AYA report of pain severity and appropriate pain management; and (e) anxiety related to the transfer of care process.

In addition, caregivers were also reluctant to "let go" or assume a more supportive rather than a central role, thus not allowing the AYA to take on a more independent and self-sufficient role as a young adult (Blum et al., 1993; Lebensburger et al., 2012; Porter et al., 2014; Rosen et al., 2003; Telfair et al., 1994). For example, in a descriptive study by Speller-Brown et al. (2015) of parents and AYA with SCD ages 14 to 21 years, dyads (n = 60) sought to examine and measure perceptions of transition readiness and transfer to adult care. The researchers found that parental involvement in health care and perception of preparedness to assume complete responsibilities had a strong positive correlation with the development of transition readiness regarding autonomy and adult health responsibilities but had a negative correlation with perceived readiness to transfer to adult care. Similarly, Telfair et al. (1994) in a cross-sectional survey of caregivers (n = 25) over a five-month period found 11 (44%) of caregivers were concerned about the acquisition of autonomy and adult health responsibilities needed to seek medical care and manage the disease independent of the caregiver.

Lack of preparation. The literature also showed that AYA with SCD were often not adequately prepared for the transition to adult care and often had difficulty accepting adult health responsibilities and autonomy for self-management and seeking medical management independently (Burlew et al., 2000; McPherson et al., 2009; Newland, 2008; Pinckney & Stuart, 2004; Sobota et al., 2014; Speller-Brown et al., 2015; Wojciechowski

et al., 2002). For example, Sobota et al. (2014) conducted a pilot study to assess and describe both knowledge and psychological readiness for transition among a convenience sample of AYA with SCD ages 18 to 22 years (n = 33). In this study, the researchers assessed five knowledge skill sets (medical, educational, health benefits, social support, and independent living) over a period of two years and three areas of psychological readiness for transition (feelings, stress, and self-efficacy). Findings indicated that 23 (73%) of AYA did not know their baseline hemoglobin level, 12 (36%) did not understand the different types of available health insurance, 17 (52%) did not know about the resources available at community-based SCD programs, 5 (15%) did not know how to self-schedule an appointment with a health care provider, and 7 (21%) had not attended an appointment with a health care provider independent of a parent or caregiver. The findings of Sobota et al. (2014) are similar to the previous quantitative findings of McPherson et al. (2009), which examined transition readiness in a sample of 70 AYA with SCD ages 14 - 20 years as well as the qualitative findings of Hauser and Dorn (1999) and Wojciechowski et al. (2002) who found that AYA with SCD transfer to adult care with little or no education, direction, or preparation on the transition process.

Health Care Providers

Lack of involvement in transition. Although the need for health care provider involvement in the coordination and facilitation of successful transition has been acknowledged, another barrier identified in the literature review was the lack of physician participation in the transition process (Sobota et al., 2011; Telfair et al., 2004a; Wojciechowski et al., 2002). In a national cross-sectional survey of pediatric and adult health care providers from multiple disciplines (n = 72), Telfair et al. (2004a) sought to

investigate providers' involvement in the transition process, their expectations of the transitioned young adult with SCD, and their perspective on the need for transition programs. The researchers found 73 (67%) of the respondents were involved in the transition of AYA with SCD, and many expected the transitioned young adult to exhibit adult health responsibilities similar to the more recent quantitative findings of Sobota et al. (2011). The researchers of this latter study sought to describe the transition practices of pediatricians at a comprehensive sickle cell center's outpatient pediatric clinic. The respondents of this study acknowledged the need for transition programs to aid in the development of adult health responsibilities in this population. Reasons cited for the need of such programs included: (a) education of AYA about the transition process and expectations; (b) acquisition of individualized transitional needs; (c) mechanism to address barriers to transition; (d) promotion of autonomy and adult health responsibilities; and (e) communication between pediatrics and adult health care providers in a timely and efficient manner. Of interest, in comparing the provider responses, Telfair and colleagues found that nurse practitioners (86%) were more likely to be involved in the transition process than other health care providers who responded to the survey.

Availability of skilled and trained adult health care providers. Another barrier to successful transition identified in the literature was the health care providers' lack of medical training and education, limited exposure to individuals with SCD, and overall discomfort expressed by general internists regarding the medical management of SCD and related disease complications (Mainous et al., 2015; Okumura et al., 2008; Telfair et al., 2004a). Mainous et al. (2015) conducted a survey for the Council of Academic

Family Medicine Educational Research Alliance related to the treatment of SCD by practicing family physicians in the United States. In this study, the researchers surveyed 3,158 physicians, with a response rate of 1,060 (34%), to assess comfort with and concerns about managing patients with SCD and related complications and their willingness to collaborate with a sickle cell specialist or hematologist in SCD management. Mainous et al. (2015) found that 848 (80%) of the family physicians surveyed reported not feeling comfortable with the overall management of SCD. These results are similar to previous quantitative findings by Okumura et al. (2008), in which the researchers found that one-third of health care providers in a randomized sample of 1,288 U.S. general internists and pediatricians were not comfortable providing care for young adults with SCD. However, Mainous et al. (2015) found that 67.8% of the surveyed physicians were willing to manage individuals with SCD in collaboration with a sickle cell specialist or hematologist. The researchers also found a significant difference in comfort level among physicians who provided care for individuals with SCD compared to those who did not in their current practice or previous training. There was also a significant difference in comfort level related to the age of the physician with physicians under the age of 50 being more comfortable in the treatment and management of the individual with SCD compared to the physicians over 50 years old.

Health Care System

Inadequate or lack of health insurance. The literature also revealed that many AYA lose insurance benefits available to them when they turn 18 or 19 years of age and are subsequently uninsured or under-insured (Boulet, Yanni, Creary, & Olney, 2010; DeBaun & Telfair, 2012; McManus et al., 2013; O'Sullivan-Oliveira, Fernandes, Borges,

& Fishman, 2014; Okumura et al., 2008; Sobota et al., 2011; Tuchman et al., 2008). This decline in access to ongoing health insurance was demonstrated by Fortuna et al. (2012) in an examination of the data from the National Ambulatory Medical Care and National Hospital Ambulatory Medical Care Survey between 1998 and 2008 of health care visits by young adults ages 18 to 30 years with a chronic condition. Fortuna et al. (2012) found that limited or no health insurance was a risk factor for an unsuccessful or delayed transition, similar to the qualitative and more recent findings of Bemrich-Stolz et al. (2015). The researchers of the latter study sought to identify barriers to transition by exploring the transition experiences of adult patients (n = 10) ages 18 and older with SCD. The researchers found the AYA with SCD were not prepared for the transfer of care to the adult health care system related to the mistrust of the adult care provider and health care system and concurrent stressors of employment, personal relationships, and lack of adequate health insurance. In addition, the researchers found the AYA with SCD had negative experiences during the transition process related to three common themes: (a) living with sickle cell disease as an adult, subdivided into five categories; (b) emotions experienced during transition such as a feeling of abandonment by the pediatric provider; and (c) lack of self-efficacy and self-care skills. The five subcategories of living with SCD as an adult included: (a) mistrust of physicians; (b) access to care; (c) insurance; (d) employment; and (e) relationships. The insurance category was further divided into three subcategories of common themes: (a) loss of insurance; (b) physician acceptance of insurance; and (c) limitations on the number of prescription refills covered by health insurance.

Ill-equipped health care system. The current health care system has relatively few comprehensive sickle cell centers nationwide that provide comprehensive, quality healthcare, and psychosocial support services, and most are located in urban areas impacting access to transition programs (Andemariam et al., 2014; Bemrich-Stolz et al., 2015; Hankins et al., 2012; Mennito & Clark, 2010; Quinn, 2013; Smith et al., 2011; Telfair et al., 2003; Williams et al., 2015). Furthermore, many young adults 19 years of age and older have no source of routine comprehensive care or social services support necessary to facilitate transition to the adult health care system (Callahan & Cooper, 2006; Dickerson, Klima, Rhodes, & O'Brien, 2012; Lotstein, Kuo, Strickland, & Tait, 2010). There are also notable differences between the AYA with SCD in urban versus rural areas regarding access to and utilization of health care services such as an adult hematologist or sickle cell provider (Sobota et al., 2011; Telfair et al., 2003). In addition, there are geographic disparities in health care services for routine outpatient management, transition, and psychosocial services, as well as utilization of local emergency rooms and urgent care centers with individuals living in urban areas having better access to a greater number of services (Andemariam et al., 2014; Telfair et al., 2003; Williams et al., 2015). Such findings were demonstrated in a retrospective review of the data retrieved from the Sickle Cell Disease Registry in the State of Alabama by Telfair et al. (2003). Researchers of this study examined the relationship between socioeconomic factors and geographic distribution to the utilization of medical services over a two-year period at four tertiary centers in a cross-sectional sample of 662 individuals with SCD in the state of Alabama. The socioeconomic factors examined were community distress, physical functioning, and medical problems. In the examination of these socioeconomic factors,

Telfair and colleagues found individuals with SCD residing in urban areas have higher annual income, lower community distress and medical problem index, and higher utilization of medical services at a comprehensive sickle cell center or tertiary care center compared to those individuals in rural areas. Furthermore, the decreased frequency of routine outpatient clinic visits for medical and preventive health care services has been associated with distance traveled in excess of 20 to 30 miles and is considered a risk factor for an unsuccessful transition (Andemariam et al., 2014; Fortuna et al., 2012; Mayer, 2008; Telfair et al., 2003; Williams et al., 2015).

Transition Programs

A conceivable approach to address challenges, barriers, and factors for an unsuccessful transition may be a transition program that educates the AYA with SCD in preparation for the change in routine, expected behaviors, roles, responsibilities, environment, and learning (Andemariam et al., 2014; Doulton, 2010; Hankins et al., 2012; Smith et al., 2011; Sobota et al., 2014; Telfair et al., 1994; Williams et al., 2015). The Pediatric to Adult Care Transition (PACT) program at the University of South Alabama Comprehensive Sickle Cell Center (USA-CSCC) implemented in 2012 is an example of such programs. This program provides activities and services that educate the AYA with SCD about the disease and prepares them with the transition mastery skills of self-care and self-advocacy through the collaborative efforts of both pediatric and adult health care providers. The transition activities and services consist of educational sessions with age-appropriate and hemoglobinopathy-specific workbooks and videos on SCD, medications and treatment options, insurance requirements, and transition process. Additionally, referrals are made to the social worker at the local community-based

organization for assistance with transportation, access to vocational rehabilitation services, and tutorial programs. The transition activities and services are orchestrated by a transition nurse coordinator who serves as a liaison between the patient, caregiver, social workers, pediatrics and adult care providers. Likewise, the transition nurse coordinator conducts disease knowledge and transition readiness assessments during the routine pediatric clinic visits in preparation for the transfer of care. Finally, the transition nurse coordinator schedules and facilitates participants' transfer of care to the newly identified adult health care providers and conducts a post-transfer assessment.

However, evaluation of such transition programs for the AYA with SCD is limited, since there are relatively few transition programs in the United States. Only three studies were identified from the literature search (Andemariam et al., 2014; Hankins et al., 2012; Smith et al., 2011). The three studies identified sought to examine the impact of a transition-pilot program at varying levels of developments on two components of the transition process, transfer of care and disease knowledge (Andemariam et al., 2014; Hankins et al., 2012; Smith et al., 2011).

In a retrospective review of 47 AYA with SCD who participated in a three-phase transition program over the course of five years, Andemariam et al. (2014) examined both clinical and nonclinical factors for an unsuccessful transition and transfer to adult care among study participants. Andemariam et al. (2014) found that 68% of the participants in this program successfully transferred to adult care, which was defined as attendance of at least one adult care appointment within 12 months after termination of pediatric care, whereas 32% did not transfer successfully and were lost to medical follow-up, similar to previous findings by Hankins et al. (2012) and Fortuna et al. (2012). The

factors found to be influencing contributors to an unsuccessful transition included: (a) hemoglobinopathy status with markers of milder disease severity and no chronic transfusion therapy; (b) age greater than 21 years at the time of transitioning; and (c) travel distance from home greater than 20 to 30 miles to the healthcare center. In addition, Andemariam et al. (2014) found that the risk for an unsuccessful transition was higher at 9 (50%) among individuals with HbSC and HbSβ^+ Thalassemia (n =18) compared to 6 (21%) among individuals with HbSS and HbSβ^0 Thalassemia (n = 29), p = .04. The researchers also found the risk for an unsuccessful transition was higher at 14 (42%) among individuals not on a chronic transfusion regimen (n = 33) compared to only one of (n = 14) individuals on a chronic transfusion regimen at 7% , p = .02.

In a retrospective analysis, Hankins et al. (2012) examined the feasibility of a one-day transition pilot program, overall participation, and effects of such a program on the transfer of care without interruption to an adult hematologist. In this study, Hankins et al. (2012) invited 83 adolescents, of which 34 (41%) agreed to participate, and found that 25 of the 34 (74%) participants completed the transfer to adult care without interruption and within three months, compared to only 16 of the 49 (33%) nonparticipants (p = .0002) and 11 out of 75 (15%) patients at this sickle cell center prior to the implementation of this pilot program (p < .0001). At the conclusion of this one-day transition pilot program, all of the study participants, their parents, and health care providers rated the program as helpful or very helpful.

In a descriptive clinical investigation, Smith et al. (2011) examined the initial impact of participation in a transition program incorporated within the context of routine clinic visits on knowledge about SCD, expressed transition concerns, and emotional

response to the transition process. This pilot program consisted of lectures and written materials covered over the course of 12 educational sessions presented by a child life specialist. The researchers recruited 35 AYA ages 15-18 years of whom 33 (94%) agreed to participate. After the completion of three out of the 12 educational sessions of this pilot program, Smith et al. (2011) conducted an assessment of SCD knowledge score of the program participants. The researchers found that SCD knowledge scores increased by 8% compared to baseline scores with the mean number of correct answers on the SCD quiz of 9.52 of 12 (95% CI: 8.76-10.27, $p = 0.07$). Smith et al. (2011) also hypothesized that earlier onset of participation at 13 years of age and an increase in the number of completed educational sessions in the transition program would have resulted in improved SCD knowledge scores. An interesting finding was the mixture of both negative and positive concerns and emotions about transition by the study participants both before and after program participation. The concerns and emotions about the transition process found were related primarily to the transfer of medical care to a new and unfamiliar health care provider; these were similar to the concerns reported in qualitative studies on the perspectives of AYA with SCD regarding the transition experience conducted by Bryant et al. (2011), Hauser and Dorn (1999), Sobota et al. (2014), and Wojciechowski et al. (2002).

In summary, previous research supports the efficacy of transition programs as a strategy to facilitate successful transfer of care. However, evidence is sparse and limitations exist. The limitations include: a) small and convenience sample sizes ($n < 50$); b) lack within and between group comparisons; c) selection bias with a purposeful sample; and d) absence of a conceptual framework to guide development and

implementation of studies (Andemariam et al., 2014; Hankins et al., 2012; Smith et al., 2011). Research findings were also limited to quantitative studies (Andemariam et al., 2014; Hankins et al., 2012; Smith et al., 2011), and lack defined disease-specific key indicators and outcome measures of successful transition, as well as the utilization of validated and reliable measurement instruments. Despite these limitations, the previous research's use of the purposeful and convenience sample worked well to inform future researchers about the defined population and problem under investigation. However, questions remain on the efficacy of transition programs and what constitutes successful transition. Additionally, gaps exist in the literature on the impact of program participation on successful transfusion and how these programs may influence the transition process.

Identified Gaps in the Literature

Gaps exist in the literature related to successful transition of the AYA with SCD (DeBaun & Telfair, 2012; Treadwell et al., 2011). The gaps include unanswered questions regarding disease-specific educational, medical, and psychosocial indicators and outcome measures of successful transition (Andemariam et al., 2014; DeBaun & Telfair, 2012; Hankins et al., 2012; Smith et al., 2011; Treadwell et al., 2011). Previous research investigated only two components of transition: disease knowledge scores and adherence with the transfer of care as evidenced by a confirmed adult care appointment and the exchange of health information with an adult health care provider (Andemariam et al., 2014; DeBaun & Telfair, 2012; Hankins et al., 2012; Smith et al., 2011). In addition, previous research did not investigate self-care, self-advocacy, and autonomous decision-making skills as outcome measures of successful transition (Andemariam et al., 2014; Hankins et al., 2012; Smith et al., 2011). Furthermore, previous research examined

diverse programs of varying content, availability of resources, organizational format, and level of development in relation to the six core elements of successful health care transition which may affect study findings (Andemariam et al., 2014; Hankins et al., 2012; Smith et al., 2011). Lastly, previous research did not provide clear insight into the impact of participation in transition programs from the perspective of the AYA with SCD who have experienced this process.

In addition, fundamental questions about the impact of participation in a transition program on successful transition have not been definitively answered that address the key indicators and outcome measures of successful transition for the AYA with SCD. The following questions are largely unanswered by previous research. (a) What are the key indicators and outcome measures of successful transition in the AYA with SCD? (b) Does an increase in SCD knowledge scores correlate with successful transition? (c) Does participation in a transition program correlate with successful transition? (d) Does hemoglobinopathy status, disease severity, plan of treatment, distance to clinic in miles, and timing of the onset of transition have an influence successful transition? Clearly, further research is warranted that examines, analyzes, measures, and promotes understanding of the impact of participation in a transition program on the successful transition with disease-specific key indicators and outcome measures (American Academy of Pediatrics, 2002; Andemariam et al., 2014; Blum et al., 1993; DeBaun & Telfair, 2012; Hankins et al., 2012; Rosen et al., 2003; Smith et al., 2011; Suris & Akre, 2015). Further research is also warranted to ensure clarity on what constitutes successful transition and what best defines an effective transition process in the SCD clinical setting.

Schlossberg's Transition Framework

Nancy K. Schlossberg's Transition Framework is a holistic model for analyzing and understanding adaptation to transition and provides a conceptual guide for examining, exploring, and assessing the transition of the AYA with SCD from pediatrics to adult care (Lenz, 2001; Schlossberg, 1981; Schlossberg et al., 1995; Winter, 2014). This framework assumes transition is an anticipated process that occurs over time with a change in routine, expected behavior, role, learning, and responsibility (Schlossberg, 2011; Schlossberg et al., 1995). Another assumption and strength of this framework is its broad view regarding the variability of an individual's perception of the transition and availability of potential resources for coping and adaptation (Lenz, 2001; Schlossberg, 2011; Schlossberg et al., 1995; Winter, 2014). This framework has three main concepts: (a) approaching transition; (b) taking stock of coping resources; and (c) taking charge of the transition with new strategies (Schlossberg, 1981, 2011; Schlossberg et al., 1995).

Approaching transition defines the nature and an individual's perception of the transition: (a) type; (b) relativity; (c) context; and (d) impact (Schlossberg et al., 1995). In addition, *approaching transition* provides an understanding of the best approach available for an individual to cope with and adapt to the transition. *Taking stock of coping resources* identifies four factors considered to be assets and/or liabilities that may influence how individuals cope with and adapt to the transition: (a) self; (b) situation; (c) support; and (d) strategies (Schlossberg, 1981; Schlossberg et al., 1995). *Self* encompasses the individual personal and demographic attributes (Schlossberg, 1981, 2011; Schlossberg et al., 1995). *Situation* refers to the timing, triggers, duration, and concurrent stressors (Schlossberg, 1981, 2011; Schlossberg et al., 1995). *Support*

identifies the availability of internal and external environmental factors of support such as the family, community services, and institutional (Schlossberg, 1981, 2011; Schlossberg et al., 1995). *Strategies* refer to measures individuals use to navigate through or cope with the transition (Schlossberg, 1981, 2011; Schlossberg et al., 1995). Schlossberg refers to these factors as "*The 4 S System,"* which are also described as variables or factors that may influence the transition process (Schlossberg et al., 1995, p. 26). In addition, *taking stock of coping resources* assumes that individuals approach transition differently depending on the ratio of assets to deficits pre- and post-transition and allow for changes in the ratio of assets and/or liabilities as an individual's situation, interactions, and reactions change over time (Schlossberg, 1981). *Taking charge* describes an individual's reaction to the transition and occurs with the use of new strategies and acceptance of and integration with the change in routine, expected new behavior, role, learning, and responsibility (Schlossberg, 1981; Schlossberg et al., 1995; Winter, 2014).

Although utilization of Schlossberg's Transition Framework has been limited in the field of nursing and adolescent care, this framework does provide a conceptual guide to explain, explore, and promote understanding of the transition of AYA (Chickering & Schlossberg, 1995; Lenz, 2001; Patton & Davis, 2014; Schlossberg, 1981, 2011; Schlossberg et al., 1995; Winter, 2014). In the field of adolescent care, Schlossberg's Transition Framework was used to guide an investigation and description of the transition experiences (pre, during, and post) of a young child from the home into state care and displaced African-American college students following Hurricane Katrina (Patton & Davis, 2014; Winter, 2014). Despite its limited use in this field, this transition

framework does provide a guide to capture and describe both clinical and non-clinical factors that may influence the ability of the AYA to cope with and adapt to the changes associated with the transition process to adult care (Chickering & Schlossberg, 1995; Lenz, 2001; Patton & Davis, 2014; Schlossberg, 1981, 2011; Schlossberg et al., 1995; Winter, 2014). The utilization of this transition framework in research investigating the transition of the AYA with SCD would: (a) address gaps in the health sciences literature on its usefulness in research involving the care of adolescents and young adults; (b) explore and explain the transition process theoretically, conceptually, and in practice; and (c) expand knowledge on the transition experience in this population (Chickering & Schlossberg, 1995; Schlossberg, 2011; Schlossberg et al., 1995; Winter, 2014). Lastly, this transition framework provides health care providers and researchers with a comprehensive model to examine, inform, and expand current transition practices and programs to improve the transition experience of this population (Schlossberg, 1981; Schlossberg et al., 1995).

In summary, the transition of the AYA with SCD involves a process of moving from dependency to independence with disease knowledge, adult health responsibilities for self-care and self-advocacy, new relationships with adult care providers, and adaptation to the differences between the pediatric and adult health care system (Blum et al., 1993). Schlossberg's Transition Framework describes transition as a gradual process that results in a change in routine, new pattern of behavior, role, learning, and responsibilities (Schlossberg, 1981; Schlossberg et al., 1995). This framework provides a starting point to examine and understand the complexities of the transition process by acknowledging the nature of the transition, factors that contribute to or impede the

transition process, and the individual's ability to take charge of new strategies to cope with and adapt to the transition (Schlossberg, 1981, 2011; Schlossberg et al., 1995).

How This Mixed Methods Research Study Addressed the Identified Gaps

This MMR study addressed the remaining questions and identified gaps in the literature by focusing on the impact of participation in a transition program on successful transition and investigating all components of the transition process with disease-specific key indicators and outcome measures. In this MMR study, the key indicators and outcome measures of successful transition were conceptualized as: (a) development of disease knowledge related to hemoglobinopathy status, prophylaxis and therapeutic medications, and ongoing access to insurance; (b) acquisition of self-care and self-advocacy skills; and (c) transfer to adult care within 60 days post-termination of pediatric care for the AYA 19 years of age. It also examines potential factors such as hemoglobinopathy status, disease severity, treatment plan, timing in a transition program, and distance to clinic for medical services in order to provide new insight into the factors that may influence adaptation to and coping with the transition process. In addition, this study investigates the transition experience throughout the transition period by examining the process, pre- and post- transition to inform the development of new strategies to facilitate the process and improve the transition experience for the AYA with SCD. Furthermore, it provides additional, evidence-based data to support and supplement the previous findings regarding the efficacy of transition programs. Lastly, utilizing MMR provides a more complete and in-depth understanding of the impact of participation in a transition program on successful transition answers the questions "what works, how, and why."

In summary, current transition programs are based on assumptions, best-practice guidelines, and principles for a successful transition. Little is known about the type, format, and key components of a model transition program (Andemariam et al., 2014; Hankins et al., 2012; Smith et al., 2011). Defined quality outcome measures of successful transition are needed to evaluate the transition process in this population (Andemariam et al., 2014; DeBaun & Telfair, 2012; Hankins et al., 2012; Rosen et al., 2003; Sobota et al., 2011; Suris & Akre, 2015). In addition, questions remain and gaps exist in the literature on the impact of participation in transition programs as a potential strategy to facilitate a more effective transition process (Abel et al., 2015; Andemariam et al., 2014; Betz & Redcay, 2005; Hankins et al., 2012; Quinn, 2013; Smith et al., 2011; Tuchman et al., 2008). Therefore, the focus of this MMR study was to examine an existing transition program to: (a) contribute to the current evidence; (b) define disease-specific indicators of successful transition; (c) refine current transition programs; (d) inform transition practices and future programs; and (e) develop new strategies to improve the transition experience in this population.

Mixed Methods Study Design

Mixed methods research is a scientific method in which researchers use quantitative and qualitative methodologies to collect and analyze data in a single study to provide a holistic examination and comprehensive understanding of a complex real-life problem (Johnson, Onwuegbuzie, & Turner, 2007; Plano Clark & Ivankova, 2016; Polit & Beck, 2012). This approach utilizes all possible methods of inquiry, data collection and analysis, and integration of multiple sources to provide the best and most robust answer to and comprehensive understanding of a research problem (Creswell & Plano

Clark, 2011; Plano Clark & Ivankova, 2016). At the same time, this approach allows the researcher to capitalize on the strengths and non-overlapping weaknesses of the quantitative and qualitative methods and reduces the possibility for an alternative explanation of the results to produce more credible and generalizable study findings (Plano Clark & Ivankova, 2016). Furthermore, from the pragmatists' perspective, MMR draws on many ideas, values both objective and subjective knowledge, and utilizes multiple approaches to address the research problem and tells the whole story with credible and validated findings (Creswell & Plano Clark, 2011).

Concurrent Quantitative + Qualitative Study Design

The concurrent quantitative (quan) + qualitative (qual) study design is an MMR approach that can be used to evaluate effects of an intervention (Creswell & Plano Clark, 2011; Hanson et al., 2005; Ivankova, 2015; Johnson et al., 2007; Plano Clark & Ivankova, 2016). This study design collects, analyzes, and integrates both data sources concurrently with equal priority to address different and related aspects of the research problem in a complementary manner (Creswell & Plano Clark, 2011; Plano Clark & Ivankova, 2016). In addition, it compares and synthesizes results of both methodologies in an attempt to confirm, corroborate, and validate study findings and conclusions (Creswell & Plano Clark, 2011; Hanson et al., 2005; Johnson et al., 2007; Plano Clark & Ivankova, 2016).

However, data integration of the quantitative and qualitative results with this study design may prove to be challenging, as results may yield conflicting findings and make it difficult to draw meaningful conclusions (Ivankova, 2015; Plano Clark & Ivankova, 2016). In addition, this design requires extensive time and resources for

approval of the institutional review board, access to potential study participants, data collections and analysis from multiple sources as well as expenses for printing study related materials and transcribing focus groups and interviews (Creswell & Plano Clark, 2011). Nevertheless, an advantage of this study design is that joint collection and analysis of multiple data sources can help defray related expenses and time commitment to answer a research question (Plano Clark & Ivankova, 2016). In addition, the integration of the two sets of results: (a) answers research questions that cannot be answered by any other means; (b) expands knowledge; and (c) produces more complete and validated conclusions through the utilization of multiple and complementary data sources and divergent views (Creswell & Plano Clark, 2011; Plano Clark & Ivankova, 2016). Finally, this study design allows researchers to draw meta-inferences reflective of what was learned from integrating results from both methodologies to answer multiple, related, and different research questions about the impact of participation in a transition program on successful transition.

This research study answers multiple questions using quantitative and qualitative data sources to aid health care providers refine current transition programs and develop new programs, inform the development of new strategies to facilitate successful transition, and improve the transition experience of the AYA with SCD. In addition, it addresses the gaps in the literature and sparse findings of previous research on the efficacy of transition programs. Furthermore, it recognizes the importance of investigating all components of successful transition based on disease-specific indicators and outcome measures related to SCD. Lastly, this study contributes to the current

literature on the factors that may influence adaptation to and coping with the transition process.

In summary, MMR allows researchers the freedom to collect and analyze data with rigor, integrate findings, and draw inferences using quantitative and qualitative methods and provides a comprehensive investigation and better understanding of complex real-life phenomena, solve problems, and expand knowledge about issues of importance (Johnson et al., 2007; Plano Clark & Ivankova, 2016; Polit & Beck, 2012). Additionally, the concurrent quan + qual design is an MMR approach that permits researchers to collect, analyze, and integrate multiple data sources concurrently with equal priority to answer multiple, different, and related research questions in a timely and efficient manner (Plano Clark & Ivankova, 2016; Polit & Beck, 2012). Although the concurrent quan + qual design has its advantages and disadvantages, this design provides a holistic approach to best answer the "what, how, and why" relative to the impact of participation in a transition program on successful transiton.

Alternative Research Design

An alternative research design to MMR is a single quantitative or qualitative study design. A single quantitative or qualitative research study design would provide an approach to investigate the impact of participation in a transition program on successful transition. However, there are limiting factors noted with both the single quantitative and qualitative methodology. The quantitative approach focuses on well-developed concepts to examine cause-effect relationships with reliable and precise methods of measurement but does not provide insight into how and why the cause-effect relationship exists (Polit & Beck, 2012). In contrast, the qualitative approach provides a rich understanding,

heightened awareness, and dialogue about a phenomenon to discover underlying patterns and themes for a defined study population but lacks results that are generalizable to a larger population or different setting (Creswell, 2013; Polit & Beck, 2012). Consequently, neither the single quantitative nor qualitative study designs are sufficient alone to capture the trends, interactions, nor details of the complexities and influencing factors associated with the transition of the AYA with SCD. However, a MMR study design: (a) allows for a more complete analysis of the complexities of transition; (b) addresses "what works, how, and why"; (c) examines different but related research questions; (d) confirms study results with multiple data sources; and (e) enhances the validity of the study findings to draw meta-inferences and conclusions (Creswell & Plano Clark, 2011; Hanson et al., 2005).

Chapter Summary

In summary, this literature synthesis demonstrated that the AYA with SCD transition from pediatric to adult care is a major process in the lifelong medical management of this chronic disease. Quantitative and qualitative studies have investigated and documented the transition process and experience. From these studies, a multitude of clinical and non-clinical factors, barriers, and challenges were described that influenced the AYA's successful transition. To address these issues encountered during the transition process, health care providers and policy makers acknowledged and endorsed transition planning and preparation for every AYA with SCD. As a result, transition programs were developed nationwide as a plausible strategy for a more efficient and timely transition process. However, current programs are limited and based on a consensus of best-practice guidelines and assumptions. In addition, the evidence is

scant and not definitive regarding the efficacy of such programs on successful transition. To address these gaps, further research is warranted to provide evidence-based data with disease-specific educational, medical, and psychosocial indicators and outcome measures of successful transition. Suggestions for further research are identified to provide additional insight into this complex process, contribute to the advancement of knowledge in the health sciences literature, inform current and new transition programs, and improve transition experience for a more effective and timely process in this population.

CHAPTER THREE

METHODS

A descriptive, observational, cross-sectional concurrent quantitative (quan) + qualitative (qual) study was employed to address the specific aims and related research questions regarding the impact of transition program participation on successful transition of the adolescent and young adult (AYA) with sickle cell disease (SCD). Additionally, factors were assessed that may influence adaptation to and coping with the transition process. The impact of transition program participation was examined for the number of years in the program and encounters with the transition nurse coordinator. The number of years and encounters were examined for two categories: < 3 and ≥3 years. The factors examined were hemoglobinopathy status, disease severity, treatment plan, and distance to clinic. Additionally, distance to clinic was examined within the context of miles traveled to the USA-CSCC for two categories: <30 and ≥ 30 miles one way. The specific aims and related research questions were:

- Specific Aim 1). Determine the impact of transition program participation on successful transition.
- Research Question 1). What is the impact of transition program participation on successful transition as evidenced by: (a) knowledge of hemoglobinopathy status, therapeutic and prophylaxis medications, and insurance requirements for ongoing access to health care; (b) acquisition of self-care and self-advocacy

skills necessary to self-schedule medical appointments, communicate medical health history, and inquire about disease management and complications with the adult care provider; and (c) transfer to adult care within 60 days post-termination of pediatric care for the AYA 19 years of age?

    - Research Sub-question 1. What influence do hemoglobinopathy status, disease severity, treatment plan, and distance to clinic in miles for medical services have on successful transition?

- Specific Aim 2). Describe the AYA with SCD thoughts, experiences, concerns, and expectations of their transition program participation on successful transition.
    - Research Question 2). What are the AYA with SCD thoughts, experiences, concerns, and expectations of transition program participation on successful transition?
- Specific Aim 3. Describe the quantitative with qualitative findings and clinical implications on the impact of transition program participation on successful transition of AYA with SCD that can inform the: (a) refinement of an existing transition program; (b) development of new strategies to facilitate the successful transition; and (c) improvement of the transition experience for this population.
    - Research Question 3): What findings and clinical implications will emerge after comparing the results from the quantitative with qualitative phase of data analysis in order to lend clarity on the impact of participation in a transition program on the successful transition of the AYA with SCD in order to inform the: (a) refinement of an existing transition program, (b) development of new

strategies to facilitate a more effective transition, and (c) improvement the transition experience of this population?

This chapter presents a detailed description of the methodologies utilized to address the specific aims and related research questions under investigation. This description begins with an overview of the research design, setting and sample, inclusion and exclusion criteria, and procedures for recruitment and advertisement. Next, there is an account of the procedures used in the informed consent process, protection of human subjects, and data collection. Afterward, a discussion is provided of the instruments and methods used for data collection, data management, and analysis. The description of the procedures and methods employed for data collection of the concurrent quantitative + qualitative study begins with the quantitative phase then the qualitative phase. Finally, this chapter presents a discussion of ethical issues in relation to human subject research involving the adolescent and minority participants and methods used to address rigor and credibility of this study are presented.

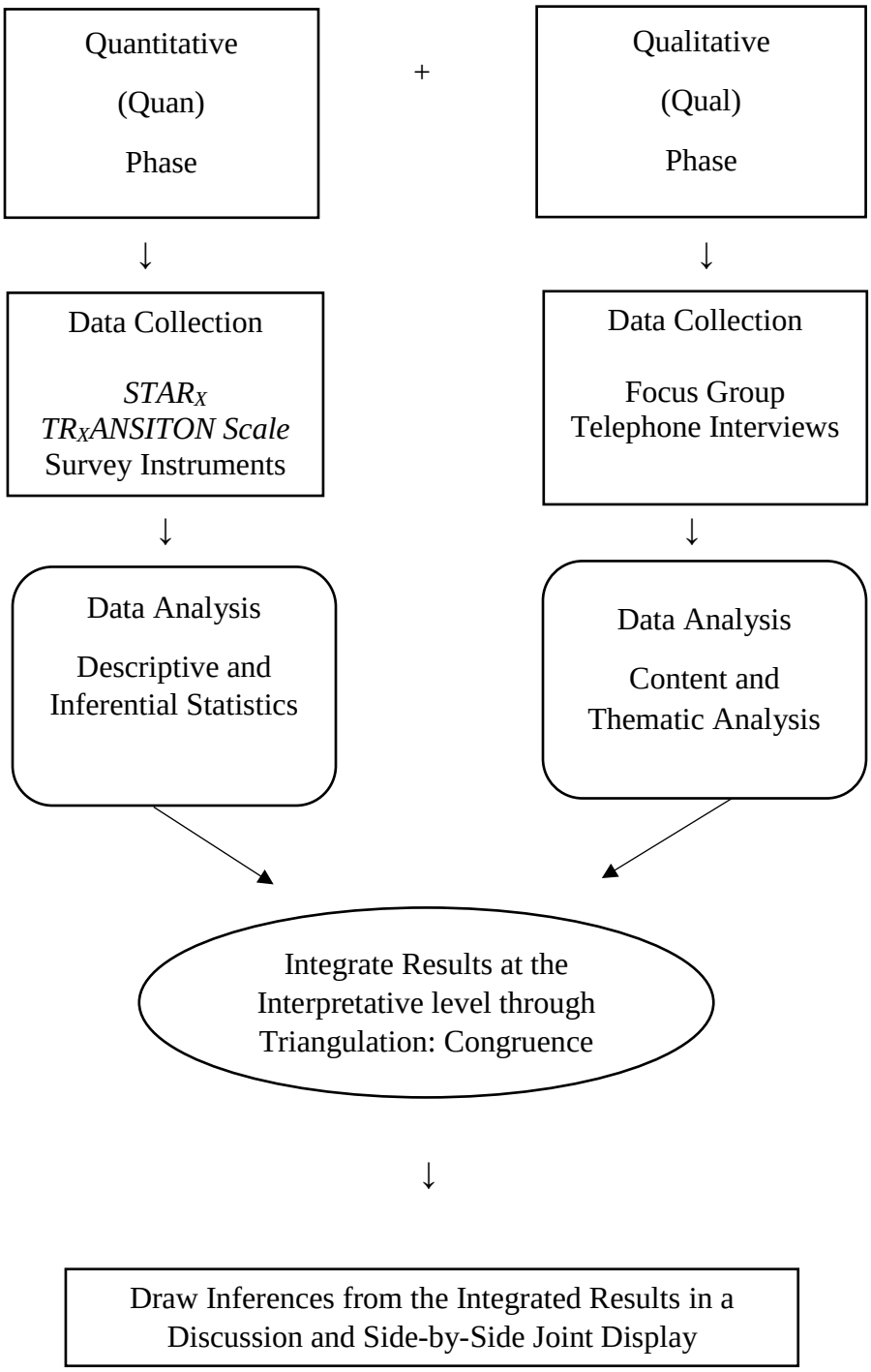
Research Design

The descriptive observational study observes, describes, and documents aspects of a phenomenon without manipulation and serves as a starting point to generate hypotheses for future research in a larger population (Polit & Beck, 2012; Vogt, 2005). The cross-sectional study provides a snap-shot of a phenomenon within a population at a particular or fixed point in time to describe the status or existing relationships among variables of interest (Polit & Beck, 2012; Vogt, 2005). The concurrent quantitative (quan) + qualitative (qual) design

collects and analyzes both quantitative and qualitative data simultaneously yet separately with equal priority (Creswell & Plano Clark, 2011; Plano Clark & Ivankova, 2016). In this design, the results of both data sets are integrated after the completion of data analysis (Creswell & Plano Clark, 2011; Plano Clark & Ivankova, 2016; Polit & Beck, 2012). The research activities of the concurrent quan + qual design used in this study are depicted in Figure 3.

Figure 3

Diagram of the Research Activities Used in This Concurrent Quan + Qual Study



Procedural diagram of the research activities: Concurrent quan + qual study design. Adapted from Plano Clark and Ivankova (2016). *Mixed methods research: A guide to the field*. Thousand Oaks, CA: Sage.

This descriptive, observational, cross-sectional concurrent quan + qual study sought to examine the impact of participation in a transition program on successful transition of the AYA with SCD as well as factors that may influence adaptation to and coping with the transition process using questionnaires, survey instruments, focus groups, and interviews. The purpose was to provide new insight and a pathway to improve existing transition practices and programs, develop new strategies to facilitate a more effective transition process, and generate hypotheses for future research in a larger population.

Setting

After Institutional Review Board (IRB) approval was obtained at the University of Alabama at Birmingham and University of South Alabama, this study was conducted at the University of South Alabama (USA)-Comprehensive Sickle Cell Center (CSCC) and Sickle Cell Disease Association of America, community based-organization (SCDAA-CBO) with administrative approval and support (see Appendices A-B). The USA-CSCC was recognized in 1988 by the National Institutes of Health as one of the nation's major centers for SCD. This CSCC is the primary care site for both adult and pediatric individuals with SCD who reside in the coastal and southern regions of Alabama and bordering states of Mississippi and Florida. As such, the USA-CSCC provides consultation services for the diagnosis, management, and treatment of approximately 775 children and adults with SCD. In addition, it offers follow-up services for the State of Alabama newborn screening program in nine counties. Moreover, it has a pediatric to adult care transition (PACT) program that was implemented in 2012 and an eligible sample pool AYA with SCD, ranging in age from

13 to 21 years. Lastly, the USA-CSCC partners with the local SCDAA-CBO to provide psychosocial support services to individuals affected by SCD.

Sample

A criterion, purposeful, maximum variation convenience sample of AYA with SCD (n = 70) was recruited as potential study participants. The convenience and criterion sample works well for recruiting individuals from a particular setting to represent a population currently experiencing or that has experienced the research problem under investigation (Creswell, 2013; Polit & Beck, 2012). Likewise, the purposeful maximum variation sample allows the selection of a population to purposefully inform the researcher about the research problem or question under investigation with a wide range of variation in backgrounds and viewpoints (Creswell, 2013; Polit & Beck, 2012).

In this study, every current and recently transitioned participant of the Pediatric to Adult Care Transition (PACT) program (n = 70) at USA-CSCC was targeted, screened, and recruited as potential study participants. From this cohort, 9% (n = 6) did not meet study eligibility requirements, 36% (n = 25) did not present to the pediatric or adult outpatient sickle cell clinics during the recruitment and enrollment period, and 6% (n = 4) did not consent to participate for unknown reasons. Nevertheless, 36% of the current (n = 25) and 15% of recently transitioned (n = 10) participants of this transition program were successfully recruited and consented to participate in this study. The combined accrual rate was a total of 50% (n = 35).

Inclusion Criteria

The criteria for inclusion consisted of the AYA with SCD ages 13-21 and participant of a transition program either current or recently transitioned to adult care ≤ 24 months with the ability to read, complete a self-report survey independently or surrogate assistance, and speak English.

Exclusion Criteria

The criteria for exclusion consisted of the AYA with SCD with a cognitive, visual, and/ or hearing impairment deemed incapable of the decision-making capacity by the pediatric or adult care provider at USA-CSCC to give informed consent, assent, and complete the research activities with accommodation or corrective devices.

Procedures

Recruitment

The procedures for recruitment began with a formal meeting with the pediatric and adult medical providers, transition coordinator, pediatric and adult nursing staff, and social worker at the study site. This meeting was conducted to discuss the purpose of the research and present a brief overview of the study design and methods of data collection. Afterward, several meetings were held with the transition and pediatric sickle cell nurse coordinators to primarily identify and screen every participant of the PACT program for eligibility and recruitment. Once identified, every participant of this program was approached by the transition and pediatric sickle cell nurse coordinator in the privacy of the exam room. The procedures for recruitment and enrollment occurred between February 7th thru June 30th 2017 using advertisement approved by the IRB at UAB and USA.

Advertisement

Advertisement was circulated in two forms. First, an announcement was placed in the USA-CSCC semi-annual newsletter distributed by standard delivery mail to every SCD patient who receives care at this center (see Appendix E). The newsletter was also distributed during the recruitment and enrollment period to every adult and pediatric participant of the PACT program and parents by the transition and pediatric nurse coordinators at the outpatient clinics. Secondly, a single page informational flyer was distributed and discussed with every participant of the PACT program by the transition nurse coordinator (see Appendix E). It was distributed by mail electronically and standard delivery by the U.S Postal Services and discussed during a routine clinic visit at the adult and pediatric outpatient clinics and after-school activities sponsored by the USA-CSCC. Likewise, it was posted on the display board at the Learning Resource and Development Center at the administrative office of the USA-CSCC, where participants of the PACT program meet for various activities. Additionally, it was displayed at the local SCDAA-CBO office in the foyer and after-school tutorial classrooms. Finally, the case manager of the SCDAA-CBO distributed the flyer at community events held for pediatrics clients during the period of recruitment and enrollment.

Prior to distribution, the flyer was critiqued by the principal investigator (PI), dissertation chair, members of the dissertation committee with pediatric expertise, and the director of the USA-CSCC. The critique of the flyer consisted of an appraisal for clarity, reading level no greater than 8th grade, content, and sensitivity to the cultural, language, age, and ethnic diversity of the AYA with SCD living in South Alabama and southern coastal regions of Mississippi and Florida. The flyer provided a brief overview of the

research study purpose and aim, procedures, risks and benefits, and contact information of the PHI.

Informed Consent and Protection of Human Subjects

Informed consent.

Informed consent involved the AYA ages 13-21 as potential study participants. Therefore, the process for informed consent included the AYA age ≥18 and assent of minors under the age of 18 years and at least one parent or caregiver's consent (see Appendix F). The informed consent process involved full written and verbal disclosure to each potential study participant with a detailed description of the research purpose, procedures, risks, potential benefits, and selection process. This description also entailed the responsibilities and time commitment required of the study participants for the completion of the demographic questionnaire, survey instruments, focus groups, interviews, and feedback on a narrative report of the study findings when applicable. There was a statement describing the use of audio-recorders during the focus groups, interviews, and location of the research activities. Furthermore, potential study participants were informed of the researcher's responsibilities, commitment, and strategies to maintain confidentiality. Contact information was provided for the principal investigator (PI) and IRB. Finally, the methods and frequency of communicating the final details of the focus groups, interviews, courtesy reminders, and notification by the researchers were described. Contact information of the study participants was obtained during this process including home mailing address, email address, and home, cellular, and alternative numbers when applicable.

The process of informed consent was conducted by two trained research assistants to address the potential for undue coercion. The research assistants were undergraduate honor nursing students at the University of South Alabama, School of Nursing. Each received Health Insurance Portability and Accountability Act (HIPAA) and National Institutes of Health Office of Extramural Research Protection of Human Subject training. During the informed consent process, the research assistant utilized age-specific scripts developed by the researcher to ensure consistency during the process (see Appendix F). Potential study participants were allowed to read and review the informed consent document. After the document was read in its entirety and time was allotted for questions to be addressed, an additional 15 minutes was given to allow for potential study participants to re-read and review the document in the privacy of the exam room and when applicable to discuss with the parent(s), caregiver(s), or significant other.

Signatures were then obtained from the study participants and the research assistant collecting the informed consent documents. A copy was given to the study participants. The signed original informed consent documents were stored as hard copies in a locked file cabinet and electronic and electronic versions in a password protected computer file folder under double lock-and-key system at the USA-CSCC. The documents will be kept in storage at the USA-CSCC for the required seven years with access limited to the PI, dissertation chair, key members of the dissertation committee, and research team.

Protection of human subjects.

Research practices were employed throughout the study with the highest level of ethical and moral integrity with respect to the protection of human subjects and their

rights with special considerations given for this vulnerable and ethnically underserved population. Extreme care was taken throughout the full written and verbal disclosure of the research activities and informed consent process with respect to person, beneficence, and justice. Similarly, confidentiality was maintained to assure privacy and in observance of the policies of institutional and federal governing and regulatory bodies.

To ensure these measures, the informed consent documents were adapted to a reading level no greater than 8th grade for ease of use and to insure clarity and understanding, using the Microsoft 2013 readability statistics program (Polit & Beck, 2012). Additionally, the voluntary nature of participation and right to withdraw informed consent at any time without consequences for the ongoing medical treatment or any other expressions of prejudice was fully discussed during the informed consent process. Furthermore, a one-time compensation was extended to the AYA for $20 and only one transporting parent of the non-driving AYA to and from the focus groups for $15 in the form of a Visa pre-paid gift card for a maximum number of two gift cards per household. The maximum total amount of this one-time compensation given per study participant was $35 for travel conducted outside of the routine clinic visit and related to the research activities of the study.

In addition, authorization of the PI, dissertation chair, dissertation committee, and key members of the research team to access, use, and disclose personal health information (PHI) was included in the informed consent process. PHI was encrypted with a randomly selected and unique identification number assigned for every study participant. For additional protection, PHI was kept under a double lock-and key -system with access limited by password to authorized personnel of the dissertation committee

and research team only. Likewise, PHI computer and electronic databases created and utilized were maintained under a double lock-and key-system, password accessible, and limited to only authorize members of the dissertation committee and research team. The elements and types of PHI consisted of: name, zip code to calculate travel distance, date of birth, telephone numbers, and medical records numbers. PHI was collected utilizing a modified version of the demographic questionnaire previously employed in a study by Porter et al. (2014) involving a convenience sample of AYA with SCD (n = 11), siblings (n = 11), and their parents (n = 12) at a comprehensive sickle cell center by. Permission with authorization to modify the questionnaire was obtained from the creator (see Appendix C).

Specific Aim and Research Question 1

Quantitative data collection and measurement instruments.

To address specific aim and research question 1, quantitative data were collected by trained research assistants using two valid and reliable survey instruments to measure successful transition created by Cohen et al. (2015) and Ferris et al. (2012) at the University of North Carolina at Chapel Hill School of Medicine-Kidney Center. Permission was obtained from the original creators for the use of the survey instruments (see Appendix C). Additionally, data was collected using the modified and paper study demographic questionnaire previously utilized by Porter et al. (2014). Permission was also obtained for the use and modification of this instrument. This questionnaire was utilized to capture the factors described in the literature and Schlossberg's Transition Framework that may influence an individual's ability to cope with and adapt to the transition process (Andemariam et al., 2014; Lebensburger et al., 2012; Schlossberg,

1981, 2011; Schlossberg et al., 1995). The data captured included: (a) participation in a transition program for the number of years and encounters; (b) hemoglobinopathy status, disease severity, and treatment plan; (c) distance to clinic in miles for medical care; and (d) timing between termination of pediatric care and the first adult care medical appointment (Andemariam et al., 2014; Schlossberg, 1981, 2011; Schlossberg et al., 1995). Additionally, age, gender, and race; socioeconomic status and type of health insurance; highest completed level of education, overall health status, home telephone and mailing address, and cellular phone numbers were captured. After informed consent was obtained, data was collected by the research assistants during a routine adult or pediatric clinic visit in the privacy of the examination room. Once collected, the data was reviewed for clarity and confirmed by a review of the medical records by the PI and trained research assistants.

Instruments. The instruments used to quantitatively measure successful transition were *Successful Transition to Adulthood with Therapeutics=Rx for medications ($STAR_x$)* and *$TR_xANSITION$ Scale* (see Appendix G) (Cohen et al., 2015; Ferris et al., 2015; Ferris et al., 2012; Johnson et al., 2015). Both instruments were completed by study participants at the conclusion of routine pediatric or adult sickle cell clinic visits in the privacy of the examination room.

$STAR_x$ is a brief, reliable, and valid instrument previously utilized to measure successful transition of AYA ages 16-25 with chronic illness inclusive of SCD, private and public insurer from various socioeconomic status and clinical settings (Cohen et al., 2015; Ferris et al., 2015). This instrument provides an assessment of disease knowledge and self-management skills in a multi-dimensional and complementary manner (Cohen et

al., 2015; Ferris et al., 2015). This instrument consists of 18 items answered on a Likert scale with responses ranging from (never, very hard, or nothing) to (always, very easy, or a lot), and an additional response for not applicable with a possible score range of 0 to 90 (Cohen et al., 2015; Ferris et al., 2015). The items measure six domains of successful transition: (a) medication management; (b) provider communication; (c) patient engagement with the healthcare provider; (d) disease knowledge; (e) adult health care management responsibilities; and (f) utilization of support services and resources (Cohen et al., 2015; Ferris et al., 2015). Furthermore, the six domains are divided into three categories: self-care with nine items, disease knowledge with three items, and self-advocacy with six items. Lastly, this instrument demonstrates desirable psychometric properties (Ferris et al., 2015).

The psychometric properties of the *STAR$_x$* instrument include a desirable internal consistency with an overall alpha coefficient ($\alpha = 0.80$) and temporal stability ($\beta = 0.704$) (Cohen et al., 2015; Polit & Beck, 2012; Urdan, 2010). In this study, the instrument also demonstrated a desirable internal consistency with an overall alpha coefficient ($\alpha = .896$). Furthermore, this instrument allowed for both retrospective and current data collection, offered anonymity, diminished interview bias, and demonstrated readability ease and comprehension with a Flesch-Kincaid 4.4 grade level reading index (Cohen et al., 2015; Ferris et al., 2015; Polit & Beck, 2012). Although this instrument yielded information that would have been impossible to gather by any other means, a disadvantage of this instrument is the issue of accuracy and validity of the obtained data, given an individual's desire to be viewed in a favorable manner by over- and/or under-reporting (Ferris et al., 2012; Polit & Beck, 2012). To address this potential weakness, the *TRxANSITION Scale*

was also utilized to quantitatively measure successful transition (Ferris et al., 2012; Johnson et al., 2015).

The *TRxANSITION Scale* is a validated, complementary, and multi-dimensional semi-structured tool consisting of 33 items to measure disease knowledge and the transition mastery skills of self-care and self-advocacy (Ferris et al., 2012; Johnson et al., 2015). This instrument measures disease knowledge regarding the type of chronic illness, current medications, and insurance for ongoing access and maintenance, and transition skills for self-advocacy and autonomous decision-making skills (Cohen et al., 2015; Ferris et al., 2012; Johnson et al., 2015). The items on this instrument are divided into three sections: self-care, disease knowledge, and self-advocacy. Moreover, the items on the instrument specifically assess an individual's ability to complete self-management skills such as self-scheduling medical appointments and contacting a newly identified adult health care provider with specific questions or concerns about disease management (Ferris et al., 2012). Furthermore, the items on this instrument are scored on a range of 0 - 1: (a) 0 for inadequate knowledge or skills; (b) 0.5 for partial knowledge or skills; and (c) 1 for adequate knowledge or skills with a possible score range of 0 to 10 (Ferris et al., 2012). The *TRxANSITION Scale* was administered and scored utilizing the *TRxANSITION Scale Answer and Scoring Guide* created at the University of North Carolina at Chapel Hill School of Medicine-Nephrology. Permission was obtained to use and modify this user guide for the purposes of this study (see Appendix C). The answer and scoring guide was modified for the AYA with SCD (see Appendix G) by the PI, director of the USA-CSCC and dissertation committee member, and pediatric hematology/oncology committee member. The score on the *TRxANSITION Scale* for

knowledge of genotype and current medication using the modified version of the answer and scoring guide was confirmed with a review of the study demographic questionnaire and medical record used by the creators of this guide (Ferris et al., 2012). The review process revealed no conflicting results. Lastly, *TRxANSITION Scale* demonstrates desirable psychometric properties.

The psychometric properties of the *TR$_X$ANSITION Scale* include a good inter-rater reliability for internal consistency exemplified by an acceptable and desirable Cohen's kappa = 0.71 (Cohen et al., 2015; Ferris et al., 2015; Polit & Beck, 2012; Urdan, 2010). Each item on the *TR$_X$ANSITION* Scale had a moderate to strong correlation with their respective domain (r = .42 - .85) and weak to strong correlation with the total score (r = .18- .62) (Ferris et al., 2012; Johnson et al., 2015). Additionally, the domains had a reported moderate to strong correlation with the total score (r = .34 - .74) (Ferris et al., 2012; Johnson et al., 2015). In this study population, the *TRxANSITION Scale* also demonstrated a desirable internal consistency with an overall alpha coefficient (α = .871). The content of this instrument was validated by national experts and health care providers in the field of transition and adolescent medicine during the developmental phase and pilot testing of two previous versions (Ferris et al., 2012). Importantly, this instrument was piloted in a total of 185 AYA ages 12-22 years in a variety of chronic illnesses inclusive of SCD (Ferris et al., 2015; Ferris et al., 2012; Johnson et al., 2015).

Prior to the use and administration of the survey instruments, answer and scoring user guide, and study demographic questionnaire, training sessions were conducted with

the research assistants in order to provide an overview of the procedures to be utilized with each instrument to ensure consistency in data collection. Additionally, a hard copy of the training materials and procedures for data collection was provided to the research assistants at the completion of the training session and maintained at the pediatric and adult outpatient sickle cell clinics throughout the data collection process.

The instruments, survey items, and corresponding defined outcome measures of successful transition in this study are presented in Table 1.

Table 1

Instruments, Items, and Corresponding Defined Outcome Measures

Instrument & Item		Defined Outcome Measures
STAR$_X$	*TR$_X$ANSITION* Scale	
10-12	1-7, 27-29, & 31-33	knowledge of hemoglobinopathy status, therapeutic and prophylaxis medications, and insurance requirements for ongoing access to health care
1-9 & 13-18	14-20	acquisition of self-care and self-advocacy skills necessary to self-schedule medical appointments, communicate medical health history, and inquire about disease management and complications with adult care providers

Note. *STARx* = Successful Transition to Adulthood with Therapeutics=*Rx* for medications.

Quantitative data management.

Once the quantitative data were gathered, the PI and research assistants each reviewed every instrument for legibility, entry errors, and missing data upon completion of data collection. Next, the survey instruments were logged and randomly assigned unique identification numbers. These numbers were transcribed, organized, and stored in a codebook for each study participant. Afterward, the data were entered into an Excel spreadsheet. Upon completion, a preliminary review of the Excel spreadsheet was conducted for entry errors and deletions. Next, the data were imported into the Statistical Package for the Social Sciences (SPSS) for quantitative data analysis.

Quantitative data analysis.

Quantitative data analysis consisted of descriptive and inferential statistical analyses using the SPSS version 24 to quantitatively answer each specific aim and related research question(s). The descriptive statistical analyses were conducted in order to describe and summarize the characteristics of the study sample and check study variables for any violations of the assumptions for the underlying population distribution (Pallant, 2013; Urdan, 2010). Inferential statistical analyses were conducted to describe and report the relationships, trends, patterns, and interactions between study variables to draw conclusions and make inferences (Pallant, 2013; Urdan, 2010). Analytical methods used to analyze the quantitative data were viewed and discussed thoroughly with the consulting statistician on the research team. In discussions with the statistician, the small sample size, avoidance of a type I or II error when conducting multiple comparisons analyses, and limitations associated with assessing the meaning and significance of the findings using the traditional alpha, ($p < .05$) were addressed and a decision was

finalized. It was decided to use effect sizes in order to determine magnitude and false p-values in order to avoid a type I or II error in addition to the traditional alpha ($p < .05$) as a criteria for interpreting the meaning of the results (Levine & Hullett, 2002; Pallant, 2013; Urdan, 2010). It was also decided that the effect sizes .1 = small, .3 = medium, and .5 = large would be the criteria used when interpreting the magnitude of the effect (Cohen, 1988). Lastly, it was decided, because of the multiple comparison analyses of this study between the variables, Benjamini and Hochberg's Method was a practical approach to discover the false p-value (Benjamini & Hochberg, 1995; Polit & Beck, 2012; Urdan, 2010).

First, descriptive statistical analysis was conducted for age, hemoglobinopathy status, gender, annual household income, overall general health status, highest level of education completed, and health insurance status to provide a descriptive profile of the study sample characteristics and background. Next, the categorical variables (hemoglobinopathy, disease severity, treatment plan, and distance to clinic for medical services) were examined for frequency and percent. Likewise, the continuous variables (participation in a transition program, total *STARx* and *TRxANSITION Scale* scores, and transfer to adult care within 60 days post termination of pediatric care of the AYA 19 years of age) were examined for the mean, median, standard deviation, range of scores, skewness and kurtosis. The descriptive statistics for participation in a transition program were conducted for number of years and encounters with the transition nurse coordinator for transition educational, planning, and preparation for transfer to adult care services. Afterward, a test of normality was conducted in order to assess and describe the distribution of the total scores for *STARx* and *TRxANSITION Scale* for the entire study

sample in order to avoid the probability of a Type I or Type II error. Using the traditional Cronbach alpha coefficient ($\alpha < .05$) to assess for statistically significant finding, Kolmogorov-Smirnov statistics suggested no violation of the assumption of normality. After an appraisal of the false p-values, the results indicated normality of the distribution of the scores. As a result, the decision was made by the consulting statistician, dissertation chair, and PI to use non-parametric analytical methods when available in order to examine the relationships between the study variables, differences in the mean total *STARx* and *TRxANSITION Scale* scores, and degree of variance between the different groups of the independent variables (factors). Non-parametric analytical methods are useful with a small population and do not make assumptions or stringent requirements about the underlying normality regarding the distribution of the population (Pallant, 2013; Urdan, 2010). The analytical methods used to examine the relationships, trends, and patterns between the study variables included Pearson' bivariate correlation coefficient, Mann-Whitney U test, Chi-square test for Independence, and standard multiple regressions..

Correlation coefficient analytical approach was used to examine the relationships, both strength and direction, between the independent variables and outcome measures of successful transition. Using this analytical method, an analysis was conducted to examine the relationship between the independent variables, participation in a transition program, hemoglobinopathy status, disease severity, treatment plan, and distance to clinic, and the total *STARx* and *TRxANSITION Scale* scores. Likewise, an analysis was conducted to examine the relationship between the independent variables and the transfer to adult care within 60 days post-termination of pediatric care for the AYA19 years of

age. In both analyses, timing in a transition program was examined for both number of years in the program and encounters orchestrated by transition nurse coordinator for transitional educational sessions, planning, and preparation services through the program.

Afterward, general linear models were conducted to examine the linear relationships and statistical differences between and within the independent variables and the defined outcome measures of successful transition, and to determine if there was a change in variance when a set of independent variables (factors) were entered into the model. The groups for each of the factors are described and listed in Table 2.

Table 2

Factors and Groups

Factors	Groups
Hemoglobinopathy status	HbSS HbSβ ^{0} Thalassemia HbSC HbSβ $^{+}$ Thalassemia
Disease severity[a]	Acute chest syndrome Cerebrovascular accident No acute chest syndrome or cerebrovascular accident Both acute chest syndrome and cerebrovascular accident
Treatment plan	Hydroxyurea Chronic transfusion No hydroxyurea or chronic transfusion Both hydroxyurea and chronic transfusion
Timing in a transition program Years	< 3 ≥ 3
Encounters	< 3 ≥ 3
Distance to clinic[b]	< 30 miles ≥ 30 miles

Note. [a] Disease severity was defined by a medical history positive for acute chest syndrome, cerebrovascular accident, or combination of both self-reported by the adolescent and young adult and/or parent(s) or caregiver(s) and confirmed by a review of the medical records by the principal investigator or research assistants. [b] The distance to clinic was the total miles traveled one way to the USA-CSCC from the reported place of residency by the study participant.

Because the expectancy frequency in any cell of the groups within the factors were less than five, groups were combined for a cell count of at least an expected frequency of five or more in at least 80 percent of each cells (Pallant, 2013; Urdan, 2010). Hemoglobinopathy status was combined into two groups based on the degree of

disease severity and anemia for the reported and confirmed genotype of the study participants: 1) HbSS and HbSβ^0 Thalassemia and 2) HbSC and HbSβ^+ Thalassemia. Disease severity was combined based on a positive or negative medical history for acute chest syndrome, cerebrovascular accident or combination of both. Treatment plan was defined and combined based on a positive or negative medical history for hydroxyurea, chronic transfusion or combination of both. Of note, both disease severity and treatment plan were self-reported by the AYA and caregiver(s) or parent(s) and confirmed by a review of the medical records by the PI.

Mann-Whitney U test, an alternative to the one-way between groups analysis of variance (ANOVA), was conducted to compare and determine if there was a difference in the mean total *STARx* and *TRxANSITION Scale* scores between each group of the independent variables (factors): participation in a transition program, hemoglobinopathy status, disease severity, treatment plan, and distance to clinic. Likewise, this analytical approach was conducted to compare and determine if there was a mean difference in the transfer to adult care within 60 days post-termination of pediatric care of the AYA 19 years of age for each factor. Lastly, it was conducted to determine if there was a difference in the mean total *STARx* and *TRxANSITION Scale* scores between the current and recently transitioned to adult care participants of a transition program.

Next, Chi-square test for independence was performed to explore the relationship between the factors and the outcome measure transfer to adult care within 60 days post-termination of pediatric care for the AYA 19 years of age. From this analytical approach, observations were made of the Chi-square value, degree of freedom (*df*), and significance level to conclude if there was a statistically significant difference in the total *STARx* and

TRxANSITION Scale scores across the groups (Pallant, 2013; Urdan, 2010). Because the lowest expected frequency in every cell (100%) was less than five, computed 2 by 2 tables, and a small sample of recently transitioned ($n = 10$), Fisher's exact probability, one sided, $p < .05$ and false p values were used to examine for statistical significant results. Additionally, Phi coefficient statistics were observed in reporting the magnitude of the computed associations. The null hypotheses utilized for this analytical approach included:

- H_0 = there is no statistically significant relationship between participation in a transition program for the number of years and the defined outcome measures of successful transition.
- H_0 = there is no statistically significant relationship between participation in a transition program for the number of encounters and the defined outcome measures of successful transition.
- H_0 = there is no statistically significant relationship between hemoglobinopathy status and the defined outcome measures of successful transition.
- H_0 = there is no statistically significant relationship between disease severity and the defined outcome measures of successful transition.
- H_0 = there is no statistically significant relationship between treatment plan and the defined outcome measures of successful transition.
- H_0 = there is no statistically significant relationship between distance to clinic and the defined outcome measures of successful transition.

Afterward, a standard multiple linear regression analysis was conducted in order to examine, isolate, and quantify the total predictive effect of an independent (predictor) variable on the dependent variable while controlling the effect of the other predictors (Urdan, 2010). This analytical approach was used to assess the predictive nature of participation in a transition in relation to the number of years and encounters, hemoglobinopathy status, disease severity, treatment plan, and distance to clinic on each of the defined outcome measures of successful transition. Statistical results for significance, strength, directions, and interactions were examined using a traditional statistical significance $\alpha < .05$ followed by an appraisal of the computed false discovery p-value using Benjamini and Hochberg's Method (Urdan, 2010). In addition, magnitude of practical relevance was recorded and determined by effect size, Cohen's *d* for the standard multiple regression (Levine & Hullett, 2002; Polit & Beck, 2012; Urdan, 2010). The combined use of a traditional statistical significance, false discovery p-value, and measure of effect size provided vital information related to the reliability and importance of the statistical results (Benjamini & Hochberg, 1995; Urdan, 2010). To determine and assess practical significance of the predictive nature of the independent variables on the dependent variable, the coefficient of determination R^2 and adjusted *R* were used in order to provide the percentage of variance explained (Urdan, 2010). This information was utilized to evaluate and assess total effect of independent variables on the dependent variable (Urdan, 2010). Because of the small sample size and to avoid an over-estimate of the degree of variance explained by the predictors, the adjusted *R* was used in the appraisal and reported in the results (Pallant, 2013) .

The research questions, independent variables and listed groups, defined outcome measures of successful transition, and corresponding statistical methods to analyze data are presented in Table 3.

Table 3

Research Questions, Study Variables, and Corresponding Analytical Methods

Research questions	Study Variables				Analytical Methods
	Independent		Dependent		
	Predictors/ Factors	Groups	Indicators	Measures	
What is the impact of transition program participation on successful transition? What influence do HS, disease severity, treatment plan, timing in a transition program, and distance to clinic for medical services have on the process and successful transition?	Participation in a transition program	Years Enc.	Disease knowledge •HS •prophylaxis medications •ongoing access and maintenance of insurance Self-care and self-advocacy skills: •self scheduled appointments •communicate with health care provider •engagement with adult provider *STARx* *TRxANSITION* Scale Transfer to adult care within 60 days post-termination of pediatric care	*STARx* *TRxAN.* Scale Chart reviews	Bivariate descriptive Pearson correlation coefficient General linear modeling Mann-Whitney U test Chi-square test for Independence Multiple linear regression

	HS	HbSS HbSC HbSβ^0 Thal. HbSβ^+ Thal.
	Disease severity	ACS CVA
	Treatment plan	HU therapy CT
	Distance to clinic	<30 ≥30

Note. ACS = acute chest syndrome; CVA = cerebrovascular accident; CT = chronic transfusion; Enc. = Encounters; HU = hydroxyurea; HS = hemoglobinopathy status; Thal. = Thalassemia

Specific Aim and Research Question 2

Qualitative data collection.

To address specific aim and research 2, qualitative data were collected using focus groups and telephone interviews divided into two categories, current and recently transitioned study participants. Focus groups were conducted to explore and provide an in-depth understanding of and insight into the impact of participation in a transition program before, during, and after transition to adult care from different viewpoints in a timely manner (Polit & Beck, 2012). Because the distance to clinic in miles for medical services for many of the AYA with SCD served at the USA-CSCC can be as far as 100 miles, telephone interviews were also used to collect qualitative data from study participants unable to attend the focus groups to broaden the scope of data collection. Both methods of data collection were used to compare and contrast across two categories, current and recently transitioned AYA with SCD (Krueger & Casey, 2015). The two

categories, current and recently transitioned consisted of the AYA ages: 13-18 (n = 8) and 19 to 21 (n = 3), respectively. The focus groups and telephone interviews were supervised by the PI and facilitated by the same trained research assistants who collected the quantitative data. Both the focus groups and telephone interviews consisted of 5-6 open-ended questions, lasted approximately 60 minutes, and were audio-recorded using two digital recorders in the event that one recorder malfunctioned. The questions posed during the focus groups and telephone interviews addressed pre- and post-transition topics related to the specific aim and research question. In addition, the questions were guided by Schlossberg's Transition Framework to explore and address the factors that may influence adaptation to and coping with successful transition (Schlossberg, 1981; Telfair et al., 1994). Additionally, the questions were derived from an interview guide previously utilized by Porter et al. (2014) to explore the perspectives of adolescents and family on the transition to adult care in a convenience sample of AYA (n = 11) ages 14 to 18 recruited from a comprehensive pediatric sickle cell program. Permission was obtained for the use and modification of the interview guide for the purpose of this study from the original author (see Appendix G). The modified focus group and interview guide content was validated by an expert panel that consisted of a pediatric hematology oncology nurse practitioners, sickle cell disease specialist, and dissertation chair. Finally, the questions were facilitated by the research assistants using the age-appropriate focus group and telephone interview scripts to ensure accuracy and trustworthiness of the qualitative data (see Appendix G) (Creswell, 2013; Polit & Beck, 2012).

Prior to the focus groups and telephone interviews, study participants received a letter in the mail through the United States Postal Services. Additionally, flyers were

distributed in the pediatric and adult outpatient clinics during regular scheduled medical appointment and courtesy telephone calls were made by the research assistants two weeks, one week, and 24 hours prior to the appointment. The focus groups were held during spring break for the local and surrounding school system, colleges, and universities over a one-week period. The focus groups took place at the local SCDAA Mobile Chapter, CBO in the conference room with the doors closed in order to ensure privacy (Polit & Beck, 2012). During the pre-transition focus group, the parent and caregiver(s) who provided transportation were asked to remain in the lobby of the SCDAA to ensure transportation would be available at the conclusion. After the completion of the focus groups, study participants (current and recently transitioned) unable to attend due to distance traveled greater than 30 miles were contacted by telephone to participate in an interview over the telephone. Those agreeing (current participants, $n = 2$ and recently transitioned participants, $n = 1$) to take part were given an agreed-upon date and time for a telephone interview with the research assistant. Following this conversation, a telephone call from the facilitating research assistant was conducted 24 hours prior to the interview to confirm and remind study participants of the scheduled interview. However, only two telephone interviews were completed, current ($n = 1$) and recently transitioned ($n = 1$). The third scheduled telephone interview was not conducted due to technical difficulties with the telephone connection on more than one occasion followed by a disconnection of the cellular services at the given contact number. The telephone interviews were conducted from the USA-CSCC Clinical Research Office, with the doors to the office closed for privacy.

Qualitative data management.

Management of the qualitative data began with the timely, independent, and verbatim transcription of the audio-recording from the focus groups and telephone interviews by the principal investigator (PI). Once completed, the transcripts were read, reviewed, and compared with the audio-recordings of both methods of data collection word-by-word on multiple occasions to critically assess and ensure accuracy of the transcripts prior to and in preparation for data analysis.

Qualitative data analysis.

Qualitative data analysis was conducted using conventional content and thematic analytical approach to provide a rich description of the expressed thoughts, experiences, and concerns of the AYA with SCD regarding their experiences on the impact of participation in a transition program on successful transition.

First, the PI organized the data from the focus groups and telephone interviews by reading and browsing through the entire transcripts of both. During this initial reading, notes were taken in order to capture first impressions of the data. Next, the transcripts were read and re-read on multiple occasions to critically appraise the data for relevancy, new discovery, and similarities. Afterward, the key words, phrases, patterns, and statements of what was conveyed in the transcripts were highlighted, reviewed, and organized to create a narrative report from the current and recently transitioned focus groups and telephone interviews.

The narrative reports and entire transcripts were sent independently to the dissertation chair and pediatric hematology/oncology dissertation committee members for review and appraisal. This process was done independent of each other following the

same format as the PI. Next, the PI and these members of the dissertation committee met on more than one occasion in order to discuss and collaborate on the final narrative report, both current and recently transitioned. The narrative reports contained an interpretive description and summary of findings from the transcripts of the focus groups and telephone interviews. The narrative reports consisted of a cover sheet with detailed instructions for review and completion. Prior to distribution, the narrative reports were evaluated for readability using Microsoft 2013 readability statistical program (Polit & Beck, 2012). The narrative report for those currently in transition, ages 13-18 was limited to a two-page document with a Flesch reading ease of 70.2 and Flesch- Kincaid grade level of 8.0 for reading and understanding by adolescents. The narrative report of those recently transitioned, ages 19-21 was limited to a four-page document with a Flesch reading ease of 72.5 and Flesch-Kincaid grade level of 7.0 for reading and understanding by young adults. Once the narrative reports were finalized, reports were sent by the United States Postal services to the self-reported and confirmed home mailing address listed on the study demographic questionnaire (current and recently transitioned) for feedback in order to confirm or disconfirm the accuracy of the statements. The mailing address of the study participants were confirmed by the research assistants with a review of the medical records. A self-addressed stamped envelope was enclosed with the narrative reports for study participants to return the reviewed narrative reports. After a four-week period, there were a total number of (n = 6) narrative reports returned that were equally distributed between the current and recently transitioned participants. From this cohort, feedback confirmed the findings of the narrative report describing the impact of participation in a transition program on successful transition from the perspective of

the AYA. Additionally, there were no new, different, or contradictory findings presented in the returned narrative reports.

After this process was completed, highlighted key words, compelling phrases, and exemplary quotes from the transcripts were then clustered into themes by the PI. Afterward, the dissertation chair and two other members of the dissertation committee with expertise in qualitative data analysis independently read, re-read, and analyzed the transcripts following the same process of coding and confirming the findings for the development of themes. Next, these members of the dissertation committee and the PI collaborated over the telephone and email on multiple occasions to review, confirm, and discuss the accuracy, relevancy, and meaning of the findings and themes. Finally, the PI, dissertation chair, and members of the dissertation committee reflected on the data in order to confirm or disconfirm the developed theme and sub-themes (Creswell, 2013; Marshall & Rossman, 2011; Polit & Beck, 2012). During this process, detailed records were kept of the decision-making process and data analysis, deduction, and interpretation that transpired between the members of the dissertation committee. Transparency and full disclosure of the PI personal bias, preferences, and perceived ideas about transition program participation was maintained throughout the entire process of data analysis.

Specific Aim and Research Question 3

Data integration.

To address specific aim and research question 3, the results of the quantitative and qualitative data analyses were integrated and compared for similarities and differences at the interpretive level using triangulation to strengthen the validity of the findings through convergence of the quantitative and qualitative results (Bryman, 2006; Creswell & Plano

Clark, 2011; Plano Clark & Ivankova, 2016; Sandelowski, 2000). The two sets of data were synthesized to identify existing trends, relationships, and interactions. Afterward, possible explanations of why and how the identified trends, relationships, and interactions existed were explored and determined in order to answer the related research question. Next, a master list of the descriptive and inferential findings as well as identified themes was created for review. Then, a matrix was created from the master lists to assess for both convergent and divergent findings between the quantitative and qualitative data. This was followed by an interpretation of the findings to draw conclusions and meta-inferences about the impact of participation in a transition program and factors that may influence adaptation to and coping with the transition process (Creswell & Plano Clark, 2011; Plano Clark & Ivankova, 2016). Throughout this process, the PI and members of the dissertation committee met on multiple occasions through telephone calls and emails to examine, compare, discuss, and interpret the findings (Creswell & Plano Clark, 2011). Once this process was completed, a joint side-by-side comparison table was created of the findings in order to present a comprehensive picture of how the quantitative and qualitative results interacted, agreed, and conflicted with each other.

Ethical Issues in Research Involving Minorities and Adolescents

Individuals from minority backgrounds may lack access to needed medical treatment for their disease and thus may be vulnerable, creating the potential for exploitation, coercion, or undue influence (Emanuel, Crouch, Arras, Moreno, & Grady, 2003; Lott, 2005). Likewise, the adolescent is a vulnerable population with special considerations by the researcher in relation to ethical issues, informed consent and assent

of minors, and protection of human subjects (Emanuel et al., 2003). This MMR study targeted the participation of the AYA with SCD virtually all of whom are from minority backgrounds (Hassell, 2010). However, the protection of human subjects participating in this study was encompassed throughout every aspect of the research process, beginning with trust, respect of person, beneficence, and justice to minimize, avoid, and prevent harm (Knight, Rossa, & Umana-Taylor, 2009; Polit & Beck, 2012; Shamoo & Resnik, 2009). The research team was committed to an awareness of and compliance with both legal and ethical standards mandated by local and federally governed institutions and exercised the highest level of ethical and moral principles in the conduct of each phase (Knight et al., 2009; Shamoo & Resnik, 2009). Furthermore, each member of the research team completed formalized training on the protection of human subjects involved in research.

However, there were some ethical issues relevant to this MMR study that deserved special considerations extending beyond respect for person, beneficence, and justice (Shamoo & Resnik, 2009). These ethical issues included protection of a vulnerable population, consent of minors and their decision-making capacity, as well as exploitation and undue coercion (Knight et al., 2009; Shamoo & Resnik, 2009). An additional issue of concern was bias on behalf of the PI who functions as a nurse practitioner in the medical management of the targeted population and plays a vital role in the PACT program at the USA-CSCC.

To address both ethical issues and special considerations, general strategies of the research team included: (a) protection of personal health information (PHI); (b) respect for autonomy and dignity; and (c) informed consent process of the study participants ≥

age 18, assent of minors, and parental informed consent (Knight et al., 2009; Shamoo & Resnik, 2009). Also, the research team explicitly communicated the voluntary nature of participation, right to withdraw consent, and refusal without penalty, as well as assessed study participants' level of decision-making capacity, avoided coercion and unfair compensation, and provided full disclosure of the potential for researcher bias (Knight et al., 2009; Shamoo & Resnik, 2009).

First, rigorous measures were undertaken to prevent the disclosure of sensitive PHI that could cause potential harm, stigmatization, or embarrassment that may be experienced by the AYA with SCD particularly during and soon after the transition to adult care (Jenerette & Brewer, 2010; Knight et al., 2009; Shamoo & Resnik, 2009). The AYA with SCD and parent(s) or caregiver(s) were assured that strict measures would be taken for the protection of identity and confidentiality of responses to survey questionnaires, focus groups, and interviews. To secure the protection of identity, study participants' responses, and PHI, data were collected by HIPAA-trained research assistants during the regular business hours of the pediatric and adult sickle cell clinic and maintained under double lock and key at the USA-CSCC clinical research and administrative office. Furthermore, study participants and parent(s) or caregiver(s) were informed that any information or knowledge gained from this study would be reported as an aggregate in generalized term, and without personal identifiers to improve the current transition program, expand knowledge on the transition process, and develop new strategies to improve the transition experience (Shamoo & Resnik, 2009).

Secondly, respect and interest in each and every study participant as an individual was exercised throughout every phase of this study. For example, parent(s) or

caregiver(s) were addressed by their formal names, and assenting minors were included in the decision-making process (Adderley-Kelly & Green, 2005). In addition, time and privacy were given to each study participants and parent(s) or caregiver(s) to complete the surveys without any coercion or influence (Adderley-Kelly & Green, 2005). Furthermore, great care was taken to listen, be attentive, respect study participants' concerns, and answer questions related to the research purpose, aim, and activities. For instance, the focus groups were conducted at the Sickle Cell Disease Association of America- Mobile Chapter, community-based organization office where study participants could feel comfortable and freely answer questions (McDonagh & Bateman, 2012). Likewise, questions posed during the focus groups and interviews were repeated to ensure clarity on behalf of the study participants. Lastly, time was given to study participants to fully express themselves in response to the focus group and interview questions.

Each study participant was treated fairly throughout the implementation of this study. For example, informed consent and assent for minor forms were developmentally appropriate in language, content, and reading level. In addition, all current and former participants of the PACT program who meet inclusion criteria were provided information on the study and given an opportunity to participate by the transition nurse coordinator at the USA-CSCC. Furthermore, the study participants' time was respected by first limiting the number of surveys completed to two brief, reliable, and validated instruments. Second, a reasonable amount of time was provided to complete the surveys and assess for difficulty in completing the surveys. Third, surrogate assistance was allowed if indicated or requested (McDonagh & Bateman, 2012). Likewise, assenting minors and adolescents

under age 18 were actively engaged during the decision-making and informed consent process (McDonagh & Bateman, 2012). Lastly, the study participants' right to refuse to participate or answer any question on the survey instruments and during the focus groups and interviews was restated during the informed consent phase (McDonagh & Bateman, 2012).

Thirdly, clear, concise, culturally sensitive full disclosure, both verbal and written, in language that includes all of the elements of informed consent was given during the informed consent phase. In addition, the research assistants spoke with a calm and slow voice, used clear wording with a literacy level less than 8th grade, as well as took time to fully explain and assess understanding of the informed consent, instructions on the completion of the questionnaires, and reading of focus group and interview questions (Polit & Beck, 2012).

Fourthly, in accordance with the Code of Ethics for Nurses, this vulnerable population was included and treated the same as any other study participant while being mindful of the special circumstances that might interfere with their ability to make autonomous decisions (Beattie & VandenBosch, 2007). The ability to make an informed consent was assessed by reviewing the medical records and identify potential cognitive impairment in consultation with the medical staff and social worker at the USA-CSCC (Shamoo & Resnik, 2009). The decision-making capacity component of the informed consent process was based on three principles: (a) ability to understand what is being asked of them; (b) comprehension of the idea that permission is being sought independently; and (c) ability to make choices free from outside constraints (Emanuel et al., 2003).

Although members of a vulnerable population may consent to participation in a research study as a means to obtain financial gains, access to healthcare or medical treatment otherwise not affordable, the use of incentives continues to be a gray area both ethically and morally (Shamoo & Resnik, 2009; Tait, Voepel-Lewis, & Malviya, 2003). However, the compensation of study participants of this study was consistent with the average wage for similar jobs without undue inducement, exploitation, and coercion (Dickert, 2009; Emanuel et al., 2003). A minimal and one-time incentive was given in the amount of $20 to the study participant, and $15 to the parent(s) or caregiver(s) who provided transportation for the non-driving study participant to the focus groups if applicable. This one-time incentive was distributed in the form of two separate Visa pre-paid gift cards for a combined and potential total amount of $35 for their time commitment and distance traveled from home to the location of the focus group. A detailed description of this process was outlined in the informed consent (Emanuel et al., 2003; Lott, 2005). Lastly, study participants were reminded of the study purpose and that there were no immediate benefits from participation. However, it was disclosed that current and future participants of the PACT program might potentially benefit from the knowledge gained to refine the current transition practice and program at USA-CSCC.

Lastly, researchers' bias, such as subjectivity and reflectivity, could have threatened this study's ability to reveal valid and reliable data (Polit & Beck, 2012). To address this threat, the key indicators and outcome measures utilized to quantify successful transition were tightly controlled and well-defined. Valid and reliable instruments were used for the collection of high quality data (Polit & Beck, 2012). The survey instruments were administered by two trained research assistant and guided by a

survey script. In addition, the PI consulted and collaborated with the dissertation chair and committee members about data collection, study findings, and every decision involved in conducting this study. Furthermore, the PI reflected on and critically appraised her role as the PI and health care providers of the targeted study population, personal biases, and preconceived opinions about the impact of transition program participation. However, objectivity analysis of the study findings were maintained throughout the research activities by consulting with the dissertation chair and committee members during data analysis, interpretation, and discussion of the study findings. Additionally, to ensure objectivity and avoid undue influence on study participants, the PI was not directly participate in participants' recruitment; informed and assent of minor consent process, and data collection.

In summary, research involving adolescents with a chronic illness is necessary to explore the decision-making process of this population and create culturally sensitive interventions to improve health outcomes (Miller, Bakas, Buelow, & Habermann, 2013; van Staa, Jedeloo, Latour, & Trappenburg, 2010). However, extensive planning and ethical considerations on behalf of the research team to address the potential for exploitation, coercion, or undue influence of the vulnerable and ethnic minority populations are of the utmost importance. This MMR study was conducted in its' entirety with the utmost respect for person, beneficence, justice, and ethical considerations of the AYA with SCD.

Rigor and Credibility

Efforts were made throughout each phase of this study to ensure and enhance scientific rigor and credibility of the study findings. The efforts began with the use of

explicit inclusion and exclusion criteria, valid and reliable instrumentation, and clear guidelines for the procedures of data collection. A purposeful sampling strategy was utilized to richly inform the PI and dissertation committee on the transition program participation. Peer view, debriefing, and confirmability were conducted throughout the qualitative phase of data analysis. The results were reviewed for accuracy, relevancy, and meaning by three members of the dissertation committee throughout data analysis. Additionally, an audit trail was maintained of the research activities and decision made by the PI and dissertation committee. Likewise, triangulation of the data was obtained through the convergence of multiple data sources to insure inferences drawn from the study results of both data sets. Moreover, a highly qualified senior researcher and equally qualified team of consulting researchers were involved during every decision-making phase of this study. The dissertation chair and consulting team of researchers included doctor of philosophy advanced practice nurses and research scientists (n = 3) with clinical experience and expertise in the areas of the health sciences ranging from palliative care, hematology/oncology, and general pediatrics. The dissertation committee comprised of researcher also included a highly skilled and knowledgeable internal medicine physician and noted sickle cell specialist (n = 1) and a qualified statistician with experience and expertise in quantitative, statistical analytical methods.

As part of the process, the PI contemplated, reflected on, and disclosed both personal experiences and worldviews on the transition of AYA with SCD to the dissertation chair and committee members of the research team. It was the view of the principal investigator with more than 20 years of caring for the study population that transition is a complex and difficult process that occurs during a vulnerable period

influenced by a multitude of factors. In addition, the facilitation of successful transition is viewed as a shared responsibility between the AYA, caregiver, and health care provider. This philosophy was communicated and discussed with the dissertation chair and committee members of the research team early in the planning phase and it was used to thoughtfully guide the implementation phase.

Finally, the narrative reports of the current and recently transitioned (n = 6) developed from the transcripts of the focus groups and telephone interviews were used by the PI to ensure a clear understanding and concise description of the true essence of the health care transition from the perspective of the AYA with SCD. The reports were sent accordingly to each study participants who took part in the focus groups and telephone interviews (n = 13).

Chapter Summary

In summary, this chapter presented the methodologies employed in this descriptive, observational, cross-sectional concurrent quantitative + qualitative study to examine and promote understanding of the impact of participation in a transition program on successful transition of the AYA with SCD and factors that may influence this process. This included the rationale for and description of the study design, sample, setting, instrumentations, and methods of data collection. It also provided details of the procedures used for obtaining informed consent and assent of minors. An overview of the strategies and special considerations employed for the protection of human subjects and research involving the minority and adolescent population with a chronic illness are addressed. Lastly, the rationale and methods used for data management and analysis are presented.

This MMR study addressed gaps in the literature on transition programs with defined outcome measures of successful transition beyond disease knowledge scores and transfer of care. Additionally, it provided insight into the factors that may influence adaptation to and coping with the transition process. The findings could be utilized to refine current transition progams and practices, develop new strategies to facilitate a more effective process, and improve the transition experience of the AYA with SCD at the USA-CSSC. Lastly, the findings could likewise be used to generate hypotheses for future research on the transition process and program at a larger sickle cell center to develop new and model transition programs.

CHAPTER FOUR

RESULTS

This chapter presents the results of this observational, descriptive, cross-sectional concurrent quantitative (quan) + qualitative (qual) study evaluating the impact of participation in a transition program on successful transition and factors that may influence adaptation to and coping with the process. The chapter begins with an overview of the screening and enrollment accrual of study participants and the mean differences between the study and non-study participants. Next, there is a description of the study sample sociodemographic characteristics. This is followed by descriptive statistics and information about the study variables, test of normality, and reliability of the survey instruments. Then, there is a detailed description of the findings from each component of the concurrent quan + qual data analyses in relation to the specific aims and related research questions. Finally, a discussion and side-by-side comparison table is presented to describe and display the similarities between the results of the quantitative and qualitative data analyses.

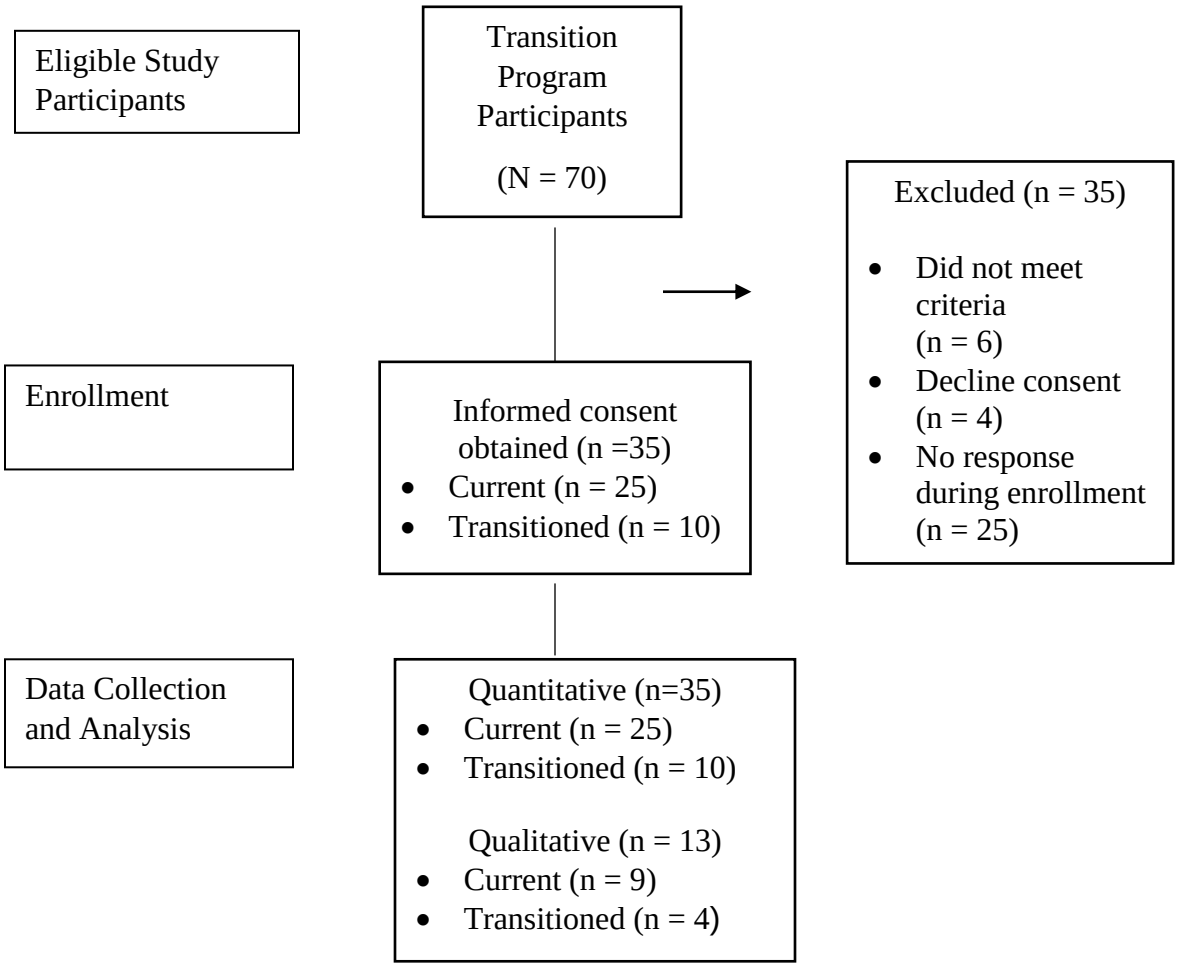
Screening and Enrollment Accrual

From a purposeful maximum variation convenience sample of adolescents and young adults (AYA) with sickle cell disease (SCD) seen in the pediatric and adult outpatient clinics at the University of South Alabama Comprehensive Sickle Cell Center (USA-CSCC), 45 current and 25 recently transitioned to adult care participants of the Pediatric to Adult Care Transition (PACT) program were identified as potential study

participants. Of the potential study participants identified, 35were excluded from the study because they did not meet the inclusion criteria (*n* = 6), declined informed consent (*n* = 4), or did not respond to recruitment efforts by the research assistants during the period of enrollment and accrual (*n* = 25). Thirty-five consented to participate in the study for an accrual rate of 50%. Within this sample, 25 participants were current and ten were recently transitioned to adult care participants. The results from screening and enrollment accrual of the study sample are presented in Figure 4.

Figure 4

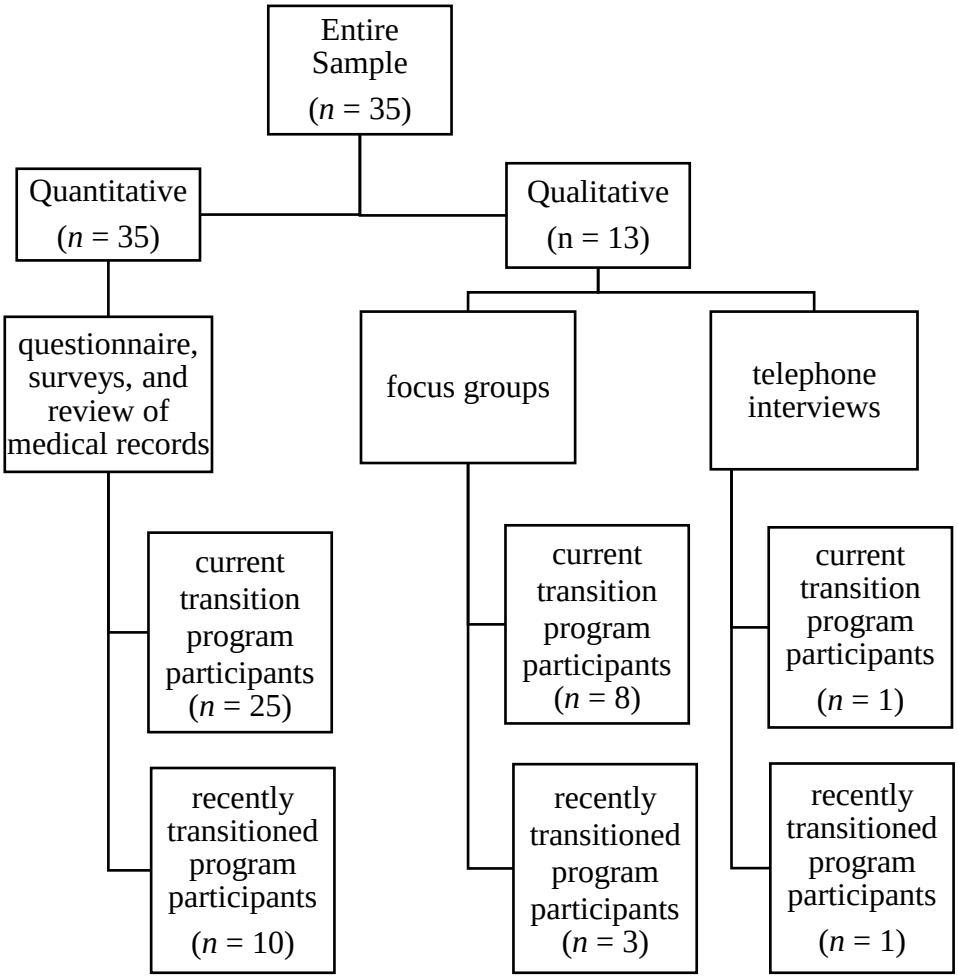
Screening and Enrollment Accrual: Participation Flow Throughout the Study



From this sample, 35 consenting current and recently transitioned to adult care AYA with SCD ages 13-21 participated in the quantitative phase and participated in both the quantitative and qualitative phases. The sample composition for the research activities of each phase of this concurrent quan + qual study are presented in Figure 5.

Figure 5

Sample and Research Activities for Each Phase of the Concurrent Quan + Qual Study



To compare the differences between the study and non-study participants, an independent sample *t*-test was conducted for hemoglobinopathy status, disease severity, treatment plan, timing in a transition program, and distance to clinic. Timing in the

transition program was examined for the number of years in the program and encounters with the transition nurse coordinator. Distance to clinic was examined within the context of the total miles traveled one way to the USA-CSCC, less than < 30 and ≥ 30 miles from the place of residency. In this assessment, the differences between the two groups were assessed for statistically significant mean differences using t-test for Equality of Means. Statistically significant results were determined using the traditional alpha, $p < .05$, false p-value, and calculated effect size using the formula, $d = \bar{X}_1 - \bar{X}_2 \div$ ŝ (Urdan, 2010). The criteria used to interpret the magnitude of the effect meaning was: .2 = small, .5 = medium, and .8 = large proposed by Cohen (1988). The results indicated there was not a significant difference observed in hemoglobinopathy status, treatment plan, number of years in the transition program, or distance to clinic between the study and non-study participants. However, there was a statistically significant difference observed in the number of encounters with the transition nurse coordinator between the study (*M* = 3.29, *SD* = 1.384) and non-study participants (*M* = 2.63, *SD* = 1.330; *t* (2.025), *p* = .047, two-tailed). The magnitude of the differences in the means (mean difference = .657, 95% *CI*: .010 to 1.305) was small (*d* = .17).

There was also a statistically significant difference observed in the AYA whose disease severity was worsened by a medical history positive for acute chest syndrome, cerebrovascular accident, or combination of both between the study participants (*M* = 2.86, *SD* = .355) and non-study participants (*M* = 2.23, *SD* = .1.003; *t* (3.497), *p* = .001, two-tailed). The magnitude of the differences in the means (mean difference = .629, 95% *CI*: .266 to .991) was small (*d* = .22). Upon assessing the false discovery p-value, the

only statistically significant difference observed between the study and non-study participants was disease severity. The results are summarized in Table 4.

Table 4

Mean Statistical Differences Between Study and Non-Study Participants, M [SD]

Characteristics	Participants (N = 35)	Non-participants	*t*-value	*p*-value	Cohen's *d*	false *p*-value
Hemoglobinopathy status	1.97 [1.20]	2.03 [1.15]	-.203	.83	.18	.99
Disease severity	2.86 [.355]	2.23 [1.00]	3.497	.001*	.22	0.006*
Timing in a transition program						
• # of years	2.80 [1.53]	2.74 [1.42]	.162	.87	.18	0.87
• # of encounters	3.29 [1.38]	2.63 [1.33]	2.025	.047*	.17	0.14
Treatment plan	2.20 [1.10]	2.40 [.881]	-.837	.41	.17	.82
Distance to clinic	24.34 [26.9]	20.69 [18.8]	.657	.51	.18	.76

Note. M = means; SD = standard deviation.
* $p < .05$, there is a significant difference in the mean scores on the dependent variable for each of the two groups.

Sample Sociodemographic Characteristics

The sample was comprised of 35 AYA of African American ethnicity distributed equally between males (51%; n = 18) and females (49%; n = 17). The mean age of this sample was 16.82, SD = 2.567 and ranged from 13 -21 years. The hemoglobinopathy status was comprised of and distributed across all four major genotypes: HbSS, HbSC, HbSβ^0 Thalassemia and HbSβ^+ Thalassemia with 57% HbSS (n = 20), followed by 26% HbSC (n = 9), 15% HbSβ^+ Thalassemia (n = 5), and 3% HbSβ^0 Thalassemia (n = 1). Among this sample, there were 43% (n = 15) whose disease severity was worsened by a

medical history positive for acute chest syndrome (ACS), cerebrovascular accident (CVA), or combination, 51% (*n* = 18) negative for ACS or CVA, and 3% positive for only CVA. There were 43% (*n* = 15) with a treatment plan consisting of Hydroxyurea (HU) therapy alone, 9% (*n* = 3) consisting of both HU and chronic transfusion (CT), and 3% (*n* =1) CT therapy alone. At the beginning of this study, the mean number of years participating in the transition program at the sickle cell center was 3.20, *SD* = 1.605, and the mean number of encounters with the transition nurse coordinator for services offered by the program was 3.29, *SD* = 1.384. For this sample, the mean distance to clinic in miles one way was 24.34, *SD* = 26.986 each way. However, there was a subset, 31% (*n* = 11) of this sample whose distance to clinic was more than 30 miles. The annual household income was below the poverty line for the state of Alabama in 63% (n = 22), and greater than or equal to the poverty line 37% (*n* = 13) of the participants. Every participants had a health insurer with 66% Medicaid (*n* = 23), followed by 20% private payer (*n* = 7), 9% Medicare (*n* = 3), and 6% combination of private payer and Medicaid or Medicare (*n* = 2). Private payer insurer was limited to Blue Cross Blue Shield of Alabama for reasons unknown. The level of education extended from 7th grade to at least some college education completed. Lastly, the self-reported overall health status was very good in 37% (*n* = 13), good in 40% (*n* = 14), and fair in 23% (*n* = 8).

In the qualitative phase of this mixed methods study, 13 AYA of African American ethnicity participated equally distributed between males at (54%; *n* = 7) and females (46%; *n* = 6). In this subset, the mean age was 16.69, *SD* = 2.720 and ranged from 13–21 years. The hemoglobinopathy status was comprised of and distributed across the all four major genotypes, of which, 62% (*n* = 8) was HbSS, followed 15% (*n* = 2)

HbSC, 15% (*n* = 2) HbSβ^+ Thalassemia, and 8% (*n* = 1) HbSβ^0 Thalassemia. Disease severity was worsened in 39% (*n* = 5) of this subset with a medical history that was positive for ACS or combination of ACS and CVA. However, 51% (*n* = 18) of this subsets' disease severity was not worsen by a medical history of ACS or CVA. In the management of SCD and its' complications, 69% (*n* = 9) of this subset had a plan that consisted of HU therapy. At the beginning of this study, the mean number of years participating in the transition program at the sickle cell center was 3.00 *SD* = 1.683, and the mean number of encounters with the transition nurse coordinator for services offered by the program was 3.38, *SD* = 1.261. The mean distance to clinic in miles one way was 22.00, *SD* = 24.28 each way. However, the distance to clinic was more than 30 miles in 31% (*n* = 11). Fifty-four percent (*n* = 7) of the sample had an annual household income below the poverty line for the state and 46% (*n* = 6) was greater than or equal to the poverty line. Every participant had health insurance with Medicaid 69% (*n* = 9) followed by private payer insurer 23% (*n* = 3) limited to Blue Cross Blue Shield for reasons unknown, and Medicare 8% (*n* = 1). The level of education extended from 7th grade to some college completed, of which, 31% (*n* = 4) were high school graduates and 15% (*n* = 2) had at least some college. The overall health status was described as good to very good in 77% (*n* = 10) and fair in 23% (*n* = 3) of the sample. The sample sociodemographic characteristics are presented in Table 5.

Table 5

Sample Sociodemographic Characteristics as N (%) and M [SD]

Characteristic	Quan. (N = 35)	Qual. (N = 13)	CTPP (N = 25)	RTPP (N = 10)
Age	16.69 [2.58]	16.69 [2.72]	15.36 [1.63]	20.00 [.94]
Gender				
Female	17 (49)	6 (46)	11 (44)	6 (60)
Male	18 (51)	7 (54)	14 (56)	4 (40)
Hemoglobinopathy				
HbSS	20 (57)	8 (62)	15 (60)	5 (50)
HbSC	9 (26)	1 (8)	6 (24)	3 (30)
HbSβ^0 Thal.	1 (3)	3 (23)		1 (10)
HbSβ^+ Thal.	5 (14)	1 (8)	4 (16)	1 (10)
Disease severity[a]				
ACS	15 (43)	4(31)	12 (48)	3 (30)
CVA	1 (3)			1 (10)
ACS and CVA	1 (3)	1 (8)	13 (52)	1 (10)
No ACS / CVA	18 (51)	8 (62)		5 (50)
Treatment plan				
HU	15 (43)	9 (69)	11 (44)	4 (40)
CT	1 (3)			1 (10)
HU and CT	3 (9)		3 (12)	
No HU / CT	16 (46)	4 (31)	11 (44)	5 (50)
Distance to clinic	24.34 [26.99]	22.00 [24.28]	25.04 [24.78]	22.60 [33.30]
< 30 miles	24 (69)	9 (69)	16 (64)	8 (80)
≥ 30 miles	11 (31)	4 (31)	9 (36)	2 (20)
Timing in a program				
# of years	2.80 [1.53]	3.00 [1.68]	2.72 [1.60]	4.40 [.84]
# of encounters	3.29 [1.38]	3.38 [1.26]	3.12 [1.48]	3.70 [1.10]
Medical insurance				
PP	7 (20)	3 (23)	4 (16)	3 (30)
Medicaid	23 (66)	9 (69)	17 (68)	6 (60)
Medicare	3 (9)	1 (8)	3 (12)	
PP + M/M	2 (6)		1 (4)	1 (10)

Annual income[b]				
< poverty level	22 (63)	7 (54)	16 (64)	6 (60)
≥ poverty level	13 (37)	6 (46)	9 (36)	4 (40)
Education completed				
< 7th grade	3 (9)	1 (8)	3 (12)	
7th to 9th grade	10 (27)	5 (39)	10 (40)	
10th to 11th grade	8 (23)	1 (8)	8 (32)	
HS graduate	10 (29)	4 (31)	4 (16)	6 (60)
Some college	4 (11)	2 (15)		4 (40)
Overall health status [c]				
Fair	8 (23)	3 (23)	6 (24)	2 (20)
Good	14 (40)	6 (46)	9 (36)	5 (50)
Very Good	13 (37)	4 (31)	10 (40)	3 (30)

Note. [a] Disease severity as defined by a medical history of ACS, CVA, or both and plan of treatment were self-reported by study participants and confirmed by a review of the medical records by the principal investigator. [b] Annual household income was self-reported by either the parent or caregiver of the AYA and examined within the context of the state of Alabama poverty line for a household of four ($24, 300), obtained from the US Census Bureau Quick Facts: Alabama retrieved from https://www.census.gov/quickfacts. [c] Overall health status was self-reported by the AYA. *M* = means; *SD* = standard deviation; CTPP = current transition program participants; RTPP = recently transitioned program participants; Thal. = Thalassemia; ACS = acute chest syndrome; CVA = cerebrovascular accident; HU = hydroxyurea therapy; CT = chronic transfusion; PP = private payer; M/M = Medicaid or Medicare; g = grade level; HS = high school.

Descriptive Statistics for the Study Variables

The descriptive statistics computed for the study variables included the central tendency measures for the frequency and percent for the independent variables: participation in a transition program, hemoglobinopathy status, disease severity, treatment plan, and distance to clinic in miles. Additionally, transition program participation was assessed for the number of years and encounters with the transition nurse coordinator. The central tendency for distance to clinic in miles was computed for < 30 or ≥ 30 miles one way. The descriptive statistics computed for the independent study variables are presented in Table 6.

Table 6

Descriptive Statistics of the Independent Variables: Continuous and Categorical

	Sample			
	Quan. (*N* = 35)	Qual. (*N* = 13)	CTPP (*N* = 25)	RTPP (*N* = 10)
Continuous Variables	*M* [*SD*]			
Timing in a program				
# of years	2.80 [1.53]	3.00 [1.68]	2.72 [1.60]	4.40 [.84]
# of encounters	3.29 [1.39]	3.38 [1.26]	3.12 [1.48]	3.70 [1.06]
Distance to clinic	24.34 [26.99]	22.00 [24.28]	25.04 [24.78]	22.60 [33.30]
Categorical Variables	*N* (%)			
Hemoglobinopathy status				
HbSS	20 (57)	8 (62)	15 (60)	5 (50)
HbSC	9 (26)	1 (8)	6 (24)	3 (30)
HbSβ^0 Thal.	1 (3)	3 (23)		1 (10)
HbSβ^+ Thal.	5 (14)	1 (8)	4 (16)	1 (10)
Disease severity				
ACS	15 (43)	4(31)	12 (48)	3 (30)
CVA	1 (3)			1 (10)
ACS and CVA	1 (3)	1 (8)	13 (52)	1 (10)
No ACS/CVA	18 (51)	8 (62)		5 (50)
Plan of treatment				
HU	15 (43)	9 (69)	11 (44)	4 (40)
CT	1 (3)			1 (10)
HU and CT	3 (9)		3 (12)	
No HU or CT	16 (46)	4 (31)	11 (44)	5 (50)
Distance to clinic[a]				
< 30 miles	24 (69)	9 (69)	16 (64)	8 (80)
≥ 30 miles	11 (31)	4 (31)	9 (36)	2 (20

Note. [a] Distance to clinic was calculated from the place of residency to the University of South Alabama Comprehensive Sickle Cell Center. The place of residency was self-reported and retrieved from the demographic questionnaire. ACS = acute chest syndrome; CVA = cerebrovascular accident; CT = chronic transfusion; HU = hydroxyurea therapy; Thal. = Thalassemia.

The central tendency measures of distribution (mean, minimum-maximum (range), and standard deviation) are presented for the dependent variable defined outcome measures of successful transition: total *STAR$_X$* and *TR$_X$ANSITION Scale* scores and transfer to adult care within 60 days post-termination of pediatric care for the AYA 19 years of age. In this sample, the mean total *STARx* score was 58.514, *SD* = 8.55 and *TR$_X$ANSITION Scale* was 10.37, *SD* = 3.45. Transfer to adult care within 60 days post-termination of pediatric care for the AYA 19 years of age occurred in 50% (*n* = 5) of the recently transitioned sample, and the mean number of days between the termination of pediatric care and the transfer to adult care was 95.60 days, *SD* = 93.86. The descriptive statistics computed for the dependent variable defined outcome measures are presented in Table 7.

Table 7

Descriptive Statistics of the Dependent Variables

	Total Scores		
	Mean [SD]	Minimum	Maximum
STAR$_X$	58.14 [8.55]	34	73
TR$_X$ANSITION	10.37 [3.45]	5	17
	N (%)		
N = 10 Transfer to adult care (Number of days)	95.60 [93.86]	5	289
Transfer to adult care ≤ 60 days	5 (50%)		

Note. *STAR$_X$* = Successful Transition to Adulthood with Therapeutics=*Rx* for Medication Transition Readiness Questionnaire.

Test of Normality

A test of normality was conducted to describe the distribution of scores for the defined outcome measures of successful transition for the study sample. The scores of the outcome measures, total scores for the *STAR$_X$* and *TR$_X$ANSITION* Scale were assessed for normality using Kolmogorov-Smirnov statistics. From the results, significant values for *STAR$_X$* (p = .041) and *TR$_X$ANSITION Scale* (p = .200) suggest no violation of the assumption of normality. In order to avoid a type I error, false p-values were computed using Benjamini and Hochberg's method and the distribution of the scores were re-appraised for normality. The non-significant values *STAR$_X$* (p = .082) and *TR$_X$ANSITION* Scale (p = .200) indicates normality for the distribution of the total scores of both instruments. The results of the test for normality are presented in Table 8.

Table 8

Normality of the Distribution of Scores for STAR$_X$ and TR$_X$ANSITION Scale (N=35)

Total Score	Kolmogorov-Smirnov[a]			
	Statistic	*df*	Sig.	False *p*-value
STAR$_X$	.151	35	.041	.082
TRxANSITION Scale	.096	35	.200*	.200

Note. [a] Lilliefors significance correction.
* The lower level of a true significance.

Reliability of the Survey Instruments

Because the reliability of a measurement instrument to consistently measure the underlying construct can differ for study populations, reliability statistical analyses were conducted to assess internal consistency of the *STARx* and *TRxANSITION Scale* measurement instruments for the entire study sample (N = 35). Both instruments were

used to quantitatively measure the defined outcome measures of successful transition: development of disease, medication, and insurance knowledge and acquisition of self-care and self-advocacy skills.

According to Cohen et al. (2015) and Ferris et al. (2015), the *STAR$_X$* measurement instrument has a preferred internal consistency, with a Cronbach alpha coefficient reported of .80, and items on the instrument displayed a moderate to strong correlation with the total score. Internal consistency of the *TR$_X$ANSITION Scale* was explored by Ferris et al. (2012) using item and total score correlations. The researchers examined the correlation of each item with the scores of its respective domain and overall total *TR$_X$ANSITION* Scale. From the analyses, each item had a moderate to strong relationship with their respective domain and weak to strong correlation with total score. Additionally, the domains had a reported moderate to strong relationship with the total score.

In this study, the *STAR$_X$* self-report measurement instrument also had a preferred internal consistency with a Cronbach alpha coefficient of .87. The inter-item (n = 18) correlation of this instrument was weak to strong and ranged from (r = .01 - .70) with the exceptions of item #4 (how often did you make your own appointment) and #17 (how hard or easy is it to take care of yourself). Of the two items, there was no observed correlation (r = .00). There was a weak to moderate correlation (r = .02 - .67) between the remaining items and total score. The *TR$_X$ANSITION Scale* measurement had acceptable internal consistency with a Cronbach alpha coefficient of .73. When assessing the "alpha if item deleted" statistics for the domains of this instrument not used to capture the underlying construct, successful transition (adherence, nutrition, issues of

reproduction, trade/school, and ongoing support), it was revealed that removing the items did not alter the reliability (r = .70 -.79) of the measurement instrument. In assessing the relationship between the total *TRXANSITION Scale*, items, and domain specific to this study, knowledge of the type of illness, medications, and insurance as well as self-care, self-advocacy skills, and identifying a new provider, there was a strong correlation (r = -.70). Similar to the findings of Ferris et al. (2012), there was a positive correlation between the domains specific to this study and total *TRXANSITION Scale* score ranging from moderate to strong (r = .45 - .75). The assessments of the both instruments' internal consistency findings are presented in Tables 9 - 16.

Table 9

Internal Consistency of the Measurement Instruments (N = 35)

Instrument	# of Items	Cronbach Alpha
STARX	18	.87
TRXANSITION Scale	33	.73

Table 10

Correlation Matrix: Inter-items of $STAR_X$ (N = 18)

Items																	
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
1	-	.54	.36	-.02	.33	.01	.40	.28	.39	.70	.46	.54	.40	.50	.36	.40	.40	.37
2		-	.14	.04	.70	-.13	.37	.55	.16	.30	.37	.22	.28	.39	.41	.78	.52	.16
3			-	.30	.11	-.09	.29	.-07	.29	.38	.28	.20	.06	.34	.25	.-05	.11	.16
4				-	.12	.21	.11	-.08	.31	.03	.14	.08	.14	.24	.37	.02	.00	.06
5					-	-.21	.45	.55	.32	.13	.17	.12	.27	.31	.49	.63	.44	.13
6						-	.14	-.15	.04	.05	.21	.11	-.36	.08	.33	-.13	.08	.11
7							-	.16	.20	.16	.19	.08	.17	.19	.48	.18	.36	-.04
8								-	.39	.25	.38	.15	.21	.20	.18	.48	.39	.23
9									-	.37	.49	.14	.24	.54	.47	.14	.33	.27

10	-	.62	.52	.27	.55	.37	.29	.20	.46
11		-	.37	.23	.32	.46	.29	.35	.43
12			-	.30	.29	.27	.16	.09	.34
13				-	.35	.18	.32	.15	.22
14					-	.51	.25	.48	.38
15						-.	.23	.63	.28
16							-	.38	.12
17								-	.38
18									-

Note. Items 1-9 and 13-18 capture self-care and self-advocacy skills and 10-12 capture knowledge of disease and medications.

Table 11

Correlation Matrix: Items and Total $STAR_X$ Score (N = 18)

Items	Total $STAR_X$ Score
1	.67
2	.67
3	.48
4	.27
5	.59
6	-.02
7	.30
8	.51
9	.50
10	.37
11	.62
12	.62
13	.38
14	.63
15	.62
16	.46
17	.59
18	.52

Table 12

Correlation Matrix: TRXAN. Scale-Disease Knowledge: Items, Subscale, and Scale

Items				Scores	
	1	2	3	Subscale	Scale
1	-	.28	.01	.55	.15
2		-	.06	.65	.12
3			-	.67	.41
Subscale				-	.39
Scale					-

Note. Items 1-3 of the *TRXANSITION* Scale capture disease knowledge. R_x = medication; *TRXAN. = TRXANSITION Scale*.

Table 13

Correlation Matrix: TRXANSITON Scale-R_x Knowledge: Items, Subscale, and Scale

Items					Scores	
	4	5	6	7	Subscale	Scale
4	-	.57	.31	.43	.69	.43
5		-	.49	.26	.75	.51
6			-	.63	.83	.53
7				-	.73	.52
Subscale					-	.64
Scale						-

Note. Items 4-7 of the *TRXANSITION Scale* capture medication knowledge. R_x = medication.

Table 14

Correlation Matrix: TRXANSITION Scale-Ins. Knowledge: Items, Subscale, and Scale

Items					Scores	
	27	28	29	30	Subscale	Scale
27	-	.30	-.08	.26	.48	.47
28		-	.49	.36	.84	.70
29			-	.41	.70	.52
30				-	.70	.58
Subscale					-	.83
Scale						-

Note. Items 27-30 of the *TRXANSITION Scale* capture insurance knowledge. Ins. = insurance; R_x = medication.

Table 15

Correlation Matrix: TRXANSITION-SCSA: Items, Subscale, and Scale

Items							Scores	
	14	15	16	17	18	19	Subscale	Scale
14	-	.67	.35	.29	.00	.09	.52	.34
15		-	.62	.48	.31	.35	.78	.57
16			-	.68	.55	.74	.87	.66
17				-	.36	.71	.80	.78
18					-	.73	.66	.45
19						-	.81	.72
Subscale							-	.82
Scale								-

Note. Items 14-19 capture self-care and self-advocacy skills on the *TRXANSITION* measurement instrument. SCSA = self-care and self-advocacy.

Table 16

Correlation Matrix: TRXANSITION-SCSA AC Provider: Items, Subscale, and Scale

Items			Scores	
	32	33	Subscale	Scale
32	-	.52	.90	.61
33		-	.85	.45
Subscale			-	.61
Scale				-

Note. Items 32-33 capture engagement and communication with adult care provider. AC = adult care; SCSA = self-care and self-advocacy.

Specific Aim and Research Question 1

Specific Aim 1

- *Determine the impact of transition program participation on successful transition.*

Research Question 1

- *What is the impact of transition program participation on successful transition as evidenced by: (a) knowledge of hemoglobinopathy status, therapeutic and prophylaxis medications, and insurance requirements for ongoing access to health care; (b) acquisition of self-care and self-advocacy skills necessary to self-schedule medical appointments, communicate medical health history, and inquire about disease management and complications with the adult care provider; and (c) transfer to adult care within 60 days post-termination of pediatric care of the AYA 19 years of age?*

Sub-question 1

- *What influence do hemoglobinopathy status, disease severity, treatment plan, and distance to clinic in miles for medical services have on successful transition?*

To address specific aim and research question 1, a Pearson's bivariate correlation analysis was conducted to examine the relationship between participation in a transition program and the defined outcomes measures of successful transition: total *STAR$_X$* and *TR$_X$ANSITION Scale* scores and transfer to adult care within 60 days post-termination of pediatric care for the AYA 19 years of age. In this analysis, participation in a transition

program was examined for the number of years in the transition program and encounters with the transition nurse coordinator for transition services. Additionally, an analysis was conducted to examine the relationship between the factors: hemoglobinopathy status, disease severity, treatment plan, distance to clinic, and the defined outcome measures of successful transition. The relationships and direction of the movement (positive or negative) observed between the variables. The strength of the relationships was appraised using the correlation coefficient parameters: weak < .20, moderate between >.20 and ≤.50, and strong = >.50 (Pallant, 2013; Urdan, 2010).

From this analysis, a moderate to strong positive statistically significant relationship was observed between the number of years participating in a transition program and the total *TR$_X$ANSITION Scale* score (r = .53, n = 35, p < .002), transfer to adult care (r = .75, n = 35, p = .05) and transfer to within 60 days post-termination of pediatric care for the AYA 19 years of age (r = .44, n = 35, p = .000). However, no statistically significant difference in the relationship observed between number of years participating in a transition program and total *STAR$_X$* score. Additionally, there were no statistically significant differences observed in the relationships between participation in a transition program for the number of encounters, hemoglobinopathy status, disease severity, treatment plan, distance to clinic; and the outcome measures of successful transition. However, there was a weak negative correlation between distance to clinic and total *STAR$_X$* (r = -.17) and *TR$_X$ANSITION Scale* scores (r = -.24). Of interest, there was a moderately strong negative statistically significant relationship observed between the independent variables, hemoglobinopathy status and timing in a transition program for the number of encounters with the transition nurse coordinator for educational and

transitional services (r = -.44, p = 0.01). Lastly, there was a moderately weak positive statistically significant relationship between hemoglobinopathy status and treatment plan (r = .43, p = 0.01). These statistical findings are presented in Table 17.

Table 17

Pearson's Bivariate Correlation: Relationships Between the Study Variables

	Timing[a]		HS	DS	TP	DTC[b]	Total *STAR$_X$*	Total *TR$_X$AN.*	Adult care	Trans. ≤ 60 days
Timing[a]	Years	Enc.								
Years	-	.24	.10	.11	-.023	.-.023	.048	.53**	.75*	.44*
Enc.		-	-.44**	-.24	-.33	-.35	.050	.17	.30	.06
HS			-	.10	.43*	-.06	.004	.16	.55	.03
DS				-	.10	.24	-.06	.23	-.39	.14
TP					-	.01	-.15	.15	-.11	-.14
DTC[b]						-	-.17	-.24	.02	.13
Total *STAR$_X$* Score							-	.28	.20	.07
Total *TR$_X$AN* Score								-	.11	.39*
Adult Care									-	.70*
Trans. < 60 days										-

Note. Enc. = encounters; DS = disease severity; DTC = distance to clinic; HS = hemoglobinopathy status; TP = treatment plan; *TR$_X$AN = TR$_X$ANSITION Scale.*

[a] Timing in a transition program was examined within the context of number of years and encounters by the study sample. [b] Distance to clinic data was captured and examined for the total number of miles traveled one way to USA-CSCC.

* = significant at the 0.05 level (two-tailed). ** = significant at the 0.01 level (two-tailed).

General Linear Models, Nonparametric Alternatives

General linear models, non-parametric alternative analytical procedures were conducted to examine the mean differences between and within the independent variables (factors/groups) on the defined outcome measures of successful transition: total *STAR$_X$* and *TR$_X$ANSITION* Scale scores and transfer to adult care within 60 days post-termination of pediatric care for the AYA 19 years of age. The non-parametric procedures used to examine the associations and variability between the study variables included Mann-Whitney U Test, and Chi-square test for independence. A standard multiple regression analysis was also conducted to assess for variances seen in the dependent variables explained by the independent variables (predictor) while controlling the other variables interest. The factors and groups examined using these analytical methods are listed in Table 2. The descriptive statistics for the study variables are presented in Tables 6 and 7.

A Mann-Whitney U Test was performed to examine the difference between two independent groups on the total *STAR$_X$ and TR$_X$ANSITION Scale* and transfer to adult care ≤ 60 days post-termination of pediatric care for the young adult 19 years of age. Additionally, differences were also computed between the current and recently transitioned to adult care participants and the outcome measures of successful transition. From this analysis, the Z value, level of significance using the traditional alpha and false p-value, and effect size using Cohen criteria (.1 = small, .3 = medium, and .5 = large) were appraised to determine statistical meaning and magnitude of the difference.

From this analysis in relation to the total *STAR$_X$* mean score, the results indicated that there was not a statistically significant difference between the factors and the

outcome measures of successful transition. However, there was an effect size difference ranging between very small to medium (r = 0.08-0.29) in the total $STAR_X$ mean score between: 1) HbSS and HbSβ^0Thalassemia (M = 17.29, n = 21) and HbSC and HbSβ^+Thalassemia (M = 19.07, n = 14), with a very small effect, U = 132.00, z = -.506, p = .61, r = .09; 2) medical history positive for either ACS, CVA, or both (M = 18.79, n = 17), and negative for ACS or CVA (M = 17.25, n = 18), with a very small effect, U = 139.50, z = -.446, p = .66, r = .08; 3) treatment plan consisting of either HU, CT, or both (M = 15.29 n = 19) and not consisting of HU or CT (M = 21.22, n =16), with a medium effect, U = 100.50, z = -1.709, p = .09, r = .30; 4) distance to clinic <30 (M = 19.17, n = 24) and ≥30 miles (M = 15.45), with a small effect, U =104.00, z = -.997; p = .32, r = .17; 5) time in a timing in a transition program for number of encounters < 3 (M = 18.27, n = 11) and ≥3 (M = 17.88, n = 24) encounters, with a very small effect, U = 129.00, z = -.107, p = .915, r = .02; and 6) time in a timing in a transition program for number of years ≥ 3 (M = 19.23, n = 20)< 3 (M = 16.37, n = 15) and < 3 (M = 16.37, n = 15) ≥ 3 years (M = 19.23, n = 20), U = 125.50, z =-.818, p = .41, with a small effect, r = .14. However, the mean rank total $STAR_X$ score was higher in study participants whose with length of time timing in a transition program for years ≥3 (M = 19.23, n = 20) when compared to than <3 years (M = 16.37, n = 15), U = 104.00, z = -.997, p = .32, r = .02. Likewise, scores were higher with the study participants whose distance to clinic < 30 (M = 19.17, n = 24) when than compared to ≥30 miles (M = 15.45, n = 11), U = 104.00, z = -.997, p = .32, r = .17. Lastly, scores were higher with the study participants whose treatment plan consisting of HU, CT or both (M = 21.22, n = 16) when compared to a

treatment plan not consisting of HU or CT (*M* = 15.29, *n* = 19), *U* = 100.50, *z* = -1.709, *p* = .09, *r* = .29. The results are presented and models (1-6) summarized in Table 18.

Table 18

Two Independent Groups' Differences on the Total STARx Score: Models 1 - 6 (N = 35)

	N	Mean rank	Median	*U*-value	*Z*-value	*p*-value	False *p*-value	Cohen's *d*
Time in program: number of encounters				129.00	-.107	.92	.91	.02
<3	11	18.27	60.00					
≥ 3	24	17.88	60.00					
Time in program: number of years				125.50	-.818	.41	.93	0.14
<3	15	16.37	60.50					
≥3	20	19.23	59.00					
Hemoglobinopathy status				132.00	-.506	.61	.91	0.09
HbSS and HbSβ^0 Thal.	21	17.29	60.00					
HbSC and HbSβ$^+$ Thal.	14	19.07	61.00					
Disease severity:				139.50	-.446	.66	.80	0.08
MH positive for ACS, CVA or both	17	18.79	60.00					
MH negative for ACS and CVA	18	17.25	60.00					
Treatment plan:				100.5	-1.709	.09	.93	0.29
TP consisting of either HU, CT, or both	19	15.29	59.00					
TP not consisting of HU or CT	16	21.22	62.00					
Distance to clinic[a]				104.00	-.997	.31	.54	0.17
< 30 miles	24	19.17	60.50					
≥30 miles	11	15.45	59.00					

Note. [a] Distance to clinic was examined within the context of the total miles traveled one way from the place of residency to the USA-CSCC. ACS = acute chest syndrome; CVA = cerebrovascular accident; HU = hydroxyurea; MH = medical history; Thal. = Thalassemia; TP = treatment plan; CT = chronic transfusions.

In relation to the total *TRXANSITION* Scale mean score, the results indicated that there was a statistically significant difference with the length of time in the transition program ≥ 3 years (M = 21.55, n = 20) as compared to < 3 years (M = 13.27, n = 15), U = 79.00, z = -2.372, p = .02, with a medium effect size (r = .40). Additionally, a statistical significant difference was observed in the *TRXANSITION* Scale mean score of the study participants with a treatment plan consisting of HU, CT, or combination (M = 14.76, n = 19) as compared to a treatment plan not consisting of HU or CT (M = 21.84, n = 16), U = 90.50, z = -2.041, p = .04, with a medium effect size (r = .34). However, after an appraisal of the false discovery p value, there was not a statistically significant difference in the total *TRXANSITION* Scale score for both timing in a transition program and treatment plan. Lastly, there was not a statistically significant differences in the total *TRXANSITION* Scale mean scores between: 1) HbSS and HbSβ^0Thalassemia (M = 16.79, n = 21) and HbSC and HbSβ^+Thalassemia (M = 19.82, n = 14), U = 121.50, z = -.860, p = .40, r = .15 with a small effect size; 2) medical history positive for either ACS, CVA, or combination of both (M = 16.68, n = 17), and negative for either ACS or CVA (M = 19.25, n = 18) U = 130.50, z = -.744, p = .46, r = .13 with small effect size; and 3) distance to clinic < 30 (M = 20.00, n = 24) and ≥30 miles (M = 13.64, n = 11), U = 84, z = -1.709, p = .90, r = .30,with a medium effect size. However, the mean rank *TRXANSITION Scale* score was higher with HbSC and HbSβ^+Thalassemia (M = 19.82) than HbSS and HbSβ^0Thalassemia (M = 16.79). Additionally, the mean rank score was higher with the medical history negative for either ACS or CVA (M = 19.25) than positive for ACS, CVA, or combination of both (M = 16.68). Lastly, higher mean rank

score can be seen with distance to clinic < 30 (*M* = 20.00) than ≥30 miles (*M* = 13.64).

The results are presented and models (1 - 6) summarized in Tables 19.

Table 19

Two Independent Groups' Differences on the Total TR$_X$AN. Score: Models 1 - 6 (N = 35)

	N	Mean rank	Median	*U*-value	*Z*-value	*p*-value	False *p*-value	Effect size
Time in a program related to number of encounters				112.00	-.712	.48	.48	.12
< 3	15	16.18	9.00					
≥3	20	18.83	10.50					
Time in a program related to number of years				79.00	-2.372	.20*	.12	.40
<3	11	13.27	8.50					
≥3	24	21.55	12.00					
Hemoglobinopathy status[a]				121.50	-.860	.39	.60	.15
HbSS and HbSβ^0 Thal.	21	16.79	9.000					
HbSC and HbSβ$^+$ Thal.	14	19.82	11.25					
Disease severity				130.50	-.744	.46	.56	.13
MH positive for ACS, CVA, or both	17	16.68	9.500					
MH negative for ACS or CVA	18	19.25	10.50					
Treatment plan				90.50	-2.041	.04*	.12	.34
TP positive for HU, CT. or both	19	14.76	8.500					
TP negative for HU or CT.	16	21.84	11.75					
Distance to clinic[a]				84.00	-1.709	.09	.18	.30
<30 miles	24	20.00	11.00					
≥30 miles	11	13.64	8.500					

Note. [a] The distance to clinic was examined for the total miles traveled one way from the place of residency to the USA-CSCC. ACS = acute chest syndrome; CT = chronic transfusion, CVA = cerebrovascular accident; HU = hydroxyurea; MH = medical history; Thal. = Thalassemia; TP = treatment plan.

In relation to the recently transitioned and current participants, the results indicated the total *TRXANSITION Scale* score was statistically significant higher with the recently transitioned (M = 27.75, n = 10), as compared to the current participants (M = 14.10, n = 25), U = 27.50, z = -3.568, p = .00, with a large effect size (r = .60). However, in relation to the total *STARX* scores, the results indicated there was not a statistically significant difference observed between the recently transitioned (M = 19.40, n = 10) and current participants (M = 17.44, n = 25) , U = 111.00, z = -.512, p = .61, with a very small effect size (r = .09). The results are presented and models (1-2) summarized in Table 20.

Table 20

Differences on Participants' Total STARX and TRXAN. Scores: Models 1-2 (N = 35)

	N	Mean Rank	Median	*U-value*	*Z-value*	*p-value*	False *p-value*	Effect size
STARX				111.00	-.512	.61	.61	.09
Current participants	25	17.44	60.00					
Recently transitioned participants	10	19.40	60.50					
TRXANSITION Scale				27.50	-3.568	.00	.00	.60
Current participants	10	14.10	8.50					
Recently transitioned participants	25	27.75	14.00					

Note. *TRXAN.* = *TRXANSITION* Scale.

Next, chi-square test for independence (with Yates's continuity correction) was performed using Fisher's exact probability cross tabulation to determine if there was an observed relationship between the factors and the outcome measure, transfer to adult care within 60 days post-termination of pediatric care for the young adult 19 years of age.

Because the lowest expected frequency in every cell (100%) was less than five and a small sample of (n = 10) recently transitioned study participants, Fisher's exact probability was used to examine the level of significance using the traditional alpha, $p <$ .05. Additionally, Phi coefficient statistics were observed in reporting the magnitude of the computed associations. The null hypotheses utilized for this analytical approach were:

- H_0 = there is no statistical relationship between hemoglobinopathy status and transfer to adult care within 60 days post-termination of pediatric care for the AYA 19 years of age.
- H_0 = there is no statistical relationship between disease severity and transfer to adult care within 60 days post-termination of pediatric care for the AYA 19 years of age.
- H_0 = there is no statistical relationship between treatment plan and transfer to adult care within 60 days post-termination of pediatric care for the AYA 19 years of age.
- H_0 = there is no statistical relationship between participation in a transition program for number of years and the transfer to adult care within 60 days post-termination of pediatric care for the AYA at 19 years of age.
- H_0 = there is no statistical relationship between participation in a transition program for number of encounters and the transfer to adult care within 60 days post-termination of pediatric care for the AYA at 19 years of age.

- H_0= there is no statistical relationship between distance to clinic in miles and the transfer to adult care within 60 days post-termination of pediatric care for the AYA at 19 years of age.

From these analyses, the relationship between transfer to adult care within 60 days post-termination of pediatric care for the AYA 19 years of age and the factors was not significant for: timing in a transition program for encounters, X^2 (1, N = 10) = .1.600, p = .21, *phi* = .60 and years, X^2 (1, N = 10) = .625, p = .44, *phi* = .50, hemoglobinopathy, X^2 (1, N = 10) = .417, p = .52, *phi* = .41, disease severity, X^2 (1, N = 10) = .000, p = 1.00, *phi* = -.20), treatment plan, X^2 (1, N = 10) = .000, p = 1.00, *phi* = .20), and distance to clinic in miles for < 30 and ≥30, X^2 (1, n = 10) = .000, p = 1.00, *phi* = .00. Therefore, the null hypothesis was accepted. The result indicated that there was no relationship between the factors and transfer to adult care within 60 days post-termination of pediatric care for the AYA 19 years of age. However, the results indicated there was a large effect size difference between transition program participation in the length of timing and the likelihood of transfer to adult care within 60 days post-termination of pediatric care for the AYA 19 years of age for both the number of encounters (*phi* = .60) and years (*phi* = .50). Hemoglobinopathy status had a medium effect size difference (*phi* = .41) and likelihood of transfer to adult care within 60 days post-termination of pediatric care for the AYA 19 years of age. Treatment plan (*phi* = .20) and disease severity (*phi* = .20) had a small effect size difference and the likelihood of transfer to adult care within 60 days post-termination of pediatric care for the AYA 19 years of age. The results and cross tabulations are presented and summarized in Table 21.

Table 21

Between Factors Associations with Transfer to Adult Care (N = 10)

Groups	*N*	Yes *N* (%)	No *N* (%)	Yates' correction for continuity	*df*	*P*-Value	False *P*-value	*Phi* Value
Timing[a]								
Years								
< 3	2	2 (100)		.625	1	.44	1.26	.50
≥ 3	8	3 (38)	5 (62)					
Encounters								
< 3	5	4 (80)	1 (20)	1.60	1	.21	1.32	.60
≥ 3	5	1 (20)	4 (80)					
Hemoglobinopathy status				.417	1	.52	1.04	.41
HbSS and HbSβ^0Thal.	6	4 (67)	2 (33)					
HbSC and HbSβ^+Thal.	4	1 (25)	3 (75)					
Disease severity				.000	1	1.0	1.0	.20
MH positive for ACS, CVA, or both	5	2 (40)	3 (60)					
MH negative for ACS or CVA	5	3 (60)	2 (40)					
Treatment plan				.000	1	1.0	1.0	.20
TP positive for HU, CT, or both	5	2 (40)	3 (60)					
TP negative for HU or CT	5	3 (60)	2 (40)					
Distance to clinic				.000	1	1.0	1.0	.00
< 30 miles	5	4 (80)	1 (20)					
≥ 30 miles	5	1 (20)	4 (80)					

Note. Transfer to adult care within 60 days post-termination of pediatric care for the AYA at 19 years of age. [a]Timing in a transition in a transition program. 4 cells (100%) have expected count less than 5. The minimum expected count is 2.50.
ACS = acute chest syndrome; CT = chronic transfusion; CVA = cerebrovascular accident; HU = hydroxyurea therapy; MH = medical history; Thal. = Thalassemia; TP = treatment plan.

Standard Multiple Regression

Finally, a standard multiple regression analysis was performed to determine how much of the variance in the defined outcome measures of successful transition could be explained by the predictors: transition program participation, hemoglobinopathy status, disease severity, treatment plan, and distance to clinic entered into the model simultaneously. Transition program participation was examined for the number of years and encounters. Additionally, distance to clinic was examined for the total miles traveled one way from the recorded residency of the study participants. The first regression was computed for transfer to adult care within 60 days post-termination of pediatric care for the AYA 19 years of age. The results of this regression indicated that the predictors explained 6.2% of the variance (R^2 = .126, an adjusted R = -.062, F (6, 28) = .670, p = .67) seen in the transfer to adult care within 60 days post-termination of pediatric care for the AYA 19 years of age. Although not statistically significant, it was found that participation in a transition program for three or more years and treatment plan made the strongest contribution to explaining the degree of variance when all other variables in the model are controlled (β = .315, p = .11 and β = .216, p = .30, respectively). Next, the second regression model was computed for total *TRXANSITION Scale* score. The results of this regression indicated that the model was statistically significant, and the predictors explained 25.8% of the variance (R^2 = .389, an adjusted R = .258, F (6, 28) = 2.967, p = .02) seen in the total *TRXANSITION Scale* score. It was found that the predictor timing in a transition program of three or more years was found to be statistically significantly and made the strongest contribution to explaining the degree of variance when all other variables in the model are controlled (β = .373, p = .03). Although not statistically

significant, the second strongest predictor was treatment plan (β = .335, p = .06) followed by distance to clinic (β = .290, p = .11). The final regression was computed for the total $STAR_X$ score. The results of this regression indicated that 5% of the variance (R^2 = .136, an adjusted R = .050, F (6, 28) = .732, p = .63) seen in the total $STAR_X$ score. Although not statistically significant, it was found the predictor, treatment plan made the strongest contribution to explaining the degree of variance (β = -.793, p = .088). Additionally, hemoglobinopathy status (β = .222, p = .32), followed by distance to clinic (β = .150, p = .48) made the next strongest contributions to explaining the degree of variance. The results are presented and the models (1-3) are summarized in Tables 22-23.

Table 22

Standard Multiple Regression of the Predictors on the Dependent Variables: Models 1- 3

	R^2	Adj. R	*df*	*F-value*	*p*-value	False *p*-value	Partial eta
Model 1	*.126*	*.062*	*6*	*.670*	*.67*	*.67*	
Time in a transition program							
• Years							.30
• Encounters							.08
Hemoglobinopathy status							.02
Disease severity							.10
Treatment plan							.19
Distance to clinic							.11
Model 2	*.389*	*.258*	*6*	*2.967*	*.02**	*.06*	
Time in a transition program							
• Years							.41
• Encounters							.17
Hemoglobinopathy status							.06
Disease severity							.26
Treatment plan							.35
Distance to clinic							.30

Model 3	*.136*	*.050*	*6*	*.732*	*.63*	*0.95*	
Time in a transition program							
• Years							.09
• Encounters							.02
Hemoglobinopathy status							.19
Disease severity							.06
Treatment plan							.29
Distance to clinic							.14

Note. * Significant at the traditional alpha ($p < .05$).

Table 23

Standard Multiple Regression: Beta, SE, t-value, p-value, and False p-value: Models 1-3

	β	*SE*	*t*-value	*p*-value	False *p*-value
Model 1					
Intercept			1.159	.27	.94
Time in a transition program					
Years	.315	24.473	-1.671	.11	.77
Encounters	.100	32.500	.424	.68	.79
Hemoglobinopathy status	.021	29.233	-.096	.92	.92
Disease severity	.101	24.583	.528	.60	.84
Treatment plan	.216	26.564	-1.048	.30	.70
Distance to clinic	.118	28.854	-.565	.56	.98
Model 2					
Intercept			1.696	.12	.21
Time in a transition program					
Years	.373	1.084	-2.366	.03*	.21
Encounters	.179	1.440	.910	.37	.43
Hemoglobinopathy status	.060	1.295	-.320	.75	.75
Disease severity	.227	1.089	1.419	.17	.23
Treatment plan	.335	1.177	1.944	.06	.21
Distance to clinic	.290	1.278	-1.662	.11	.26
Model 3					
Intercept			1.606	.12	.72
Time in a transition program					
Years	.092	3.190	-.490	.63	.95
Encounters	.025	4.236	-.105	.91	.91
Hemoglobinopathy status	.222	3.810	-1.003	.32	.96
Disease severity	.057	3.204	-.300	.77	.92
Treatment plan	.325	3.463	1.590	.12	.72
Distance to clinic	.150	3.761	-.723	.48	.96

Note. SE = Standard error. * Significant at the traditional alpha level ($p < .05$).

Specific Aim and Research Question 2

Specific Aim 2

- *Describe the AYA with SCD's thoughts, experiences, concerns, and expectations of their transition program participation on successful transition.*

Research Question 2

- *What are the AYA with SCD's thoughts, experiences, concerns, and expectations of transition program participation on successful transition?*

To address specific aim and research question 2, qualitative data were gathered from focus groups and telephone interviews of (n = 13) AYA with SCD participating in the Pediatric to Adult Care Transition program at the USA-CSCC. The participants of the focus groups and telephone interviews were comprised of males (n = 8) and females (n = 5) ages 13- 21 years. From the focus groups and telephone interviews, audio-recordings were transcribed verbatim and then subsequently analyzed using content and thematic analysis. From the results of this analysis, exemplary words, phrases, and quotes were revealed, categorized, and coded inductively to develop the compelling overarching theme describing the impact of participation in a transition program on successful transition. The results of the qualitative data analyses include a description of the compelling words, phrases, exemplary quotes, sub-themes, and overarching emergent themes used to address the qualitative specific aim.

Thoughts, Concerns, and Experiences

Overarching theme, sub-themes, and codes.

One overarching theme and four sub-themes were derived from the qualitative data obtained from the focus groups and telephone interviews exemplifying the thoughts,

experiences, and concerns of the AYA with SCD describing transition program participation on successful transition. The overarching theme was that "Transition Program Participation Facilitates Preparedness." The linking sub-themes were: 1) Clarifying the process and providing support; 2) Promoting knowledge of SCD, health maintenance, self-management, and financial obligations; 3) Encouraging independence and taking responsibility for managing one's own care; and 4) Lessening emotional concerns and anxieties about the transfer to adult care. The overarching theme and contributing sub-themes and codes used to describe the impact of participating in a transition program are presented in Table 24.

Table 24

Theme, Sub-Themes, and Codes Describing Impact of Transition Program Participation

Overarching Theme: Participating in a transition program facilitates transition preparedness.	
Sub-Themes	Codes
Clarifying the process and providing support	Current Participants
	helpful and informative
	provided clarity on how to transition
	provided guidance on what to expect on the adult side
	Recently Transitioned
	easier and smoother move to adult care
	informative and helpful with repetitive discussions about the transition process
	supportive process without the feeling of abandonment
	issued advance notification about and assistance with the move to adult care
	provided an introduction to adult care compared to pediatric care

	provided a tutorial program in preparation for the move to adult care
Promoting knowledge of sickle cell disease, health maintenance, self-management, and financial obligation	Current Participants
	learning about the disease process
	taught hemoglobinopathy status
	provided new information on disease/family planning
	directions on self-care
	Recently Transitioned
	learning about sickle cell disease
	awareness of health maintenance
	taught self-management strategies to treat a pain crisis at home
	learned a co-pay is required for medical services
Encouraging independence and taking responsibility for managing one's own care	Current Participants
	engagement and inclusion in the transition process
	pushed self-care and less dependency on caregiver and parent
	talk more easily and directly to providers with eye contact
	Recently Transitioned
	encouraged to assume responsibility for self-care and engagement with healthcare providers
	realization of the need to advocate for self and not depend on the caregiver or parent
	can plan and make own appointments
Lessening emotional concerns and anxieties about the transfer to adult care	Current Participants
	ease some concerns by answering questions on how to transition
	Recently Transitioned
	ready for and at ease with the transfer to adult care
	positive feeling associated with the recognition as an adult by transition staff
	confidence in the ability to attend the adult clinic independent of parent or caregiver

	familiarity with and trust of the transition staff
	relationship building
	ease concerns about having a new provider with disease management strategies different from pediatrics

From the completing words and statements of the AYA, the PI, dissertation chair, and two dissertation committee members developed four sub-themes used to support the overarching theme describing the impact of transition program participation on successful transition of the AYA with SCD.

The data from the focus groups and telephone interviews revealed that transition program participation provided clarity on and support throughout the transition process. Individuals articulated that participation in a transition program provided assistance in the transfer to adult care process and a feeling of not being abandoned or transferred to an unfamiliar adult care provider and health care system without advance notification. The quotations from the two program participants that illustrate the sub-theme, clarifying the process and providing support were:

- *"It helps you to know, like what you have to do when you get older and when you getting ready to, like to go to the doctor on your own and so, you know what to do and you're not confused." (female #1)*
- *"It made the transition to the adult side like better. I guess you can say better, instead of just going from adolescent straight over. They were explaining how it would be instead of them just switching us over to a doctor." (female #1)*

Next, the data revealed that transition program participation promoted the development of knowledge about SCD, health maintenance, self-management, and

insurance copay in the adult health care system. Individuals articulated learning basic principles and facts about SCD and hemoglobinopathy status as a result of transition program participation. Some individuals reported learning that SCD is an inherited hematological disorder that can affect every organ of the human body and requires medical management with prescription medication, routine clinic visits, and hospital admissions. Participants also reported that the transition nurse coordinator and staff reiterated to them the importance of effectively communicating to health care providers their hemoglobinopathy status for disease-specific medical management. Other participants reported that the program taught them the importance of being aware of their significant others' sickle cell trait or disease status when planning a family. Some participants reported learning about the financial requirements by health care insurer of the insured adult individual when presenting to an adult care provider. Lastly, participants expressed that transition program participation provided information about self-management and health maintenance responsibilities as an adult, home management of a vaso-occlusive pain episode, and consequences of non-adherence with prescribed medications. Some statements illustrating the sub-theme, promotion of knowledge on SCD, health maintenance, self-management, and financial obligation were:

- *"I learned, like SS, anybody can have it or be born with it. You won't die or nothing like that, it's not contagious. You get sick a lot and go to a lot of doctor appointments." (female #3)*
- *"I learned how to manage my disease better than what I normally would have as a child, and that it's a blood disorder that deals with the red blood cells.*

And as far as the insurance now I have to pay a co-pay when I go to my doctor appointments." (female #1)

- *"I learned there are a lot of stuff you can do to prevent you from getting sick, like taking a hot shower to prevent you from getting sick and all of that. The PACT program taught me a lot. Like how to control my pain. How to take my medication correctly and stuff like that. Like, don't forget to take your medication." (male #1)*

Additionally, participants stated that transition program participation encouraged independence and taking responsibility for managing one's own care. They described how program encouraged participants to become more independent, and less dependent on the parent or family caregiver related to scheduling medical appointments and obtaining refills for prescribed medications. Individuals verbalized preparedness for the transfer to adult care independent of the parent or caregiver and confidence in their ability to attend an office visit and outpatient diagnostic studies on their own. One transition program participant's statement that illustrates the sub-theme, encouraging independence and taking responsibility for managing one's own care was:

- *"It got me ready to be an adult when I transitioned. I think I was already, ready to go to the adult side, I was the one who was giving myself the medicines and keeping my pain under control and all that. I was the one doing it at home." (male #1)*

Finally, the data provided a rich description identifying the concerns and fears about the transition to adult care and how transition program participation addressed the expressed concerns and fears about the process. When asked about their concerns and

fears about the transition process, some individuals expressed concerns about the development of a personal relationship with the providers in the adult health care system in comparison to the prior relationship with the pediatric providers they had known all of their lives. Others discussed concerns about the difficulties involved with the transfer to adult care and how to function as an adult in the medical management of their own disease. There were specific concerns about the process for obtaining a prescription at the pharmacy and scheduling an appointment with the adult health care provider. Some individuals expounded on how transition program participation facilitates preparedness for the transition process by lessening some of their emotional concerns and anxieties about the transfer to adult care. It was clearly stated by some individuals that the transition nurse coordinator and provider played an integral role in addressing their concerns and questions about the transition process. The transition nurse coordinator was expressly described as a trusted and approachable resource person who was as helpful in alleviating expressed concerns and fears. An illustrative statement of an AYA on how transition program participation lessens emotional concerns and fears was:

- *"They made me get over some of my fears, by like they would ask me questions and tell me how it would be on the adult side and all of that. Like, what sort of questions we should ask, or how we should start doing things on our own, like going to, going to get your own prescriptions filled, or set up our own appointments, and more adult stuff than we're usually used to." (male #1)*

The quotes of both the current and recently transitioned AYA used to exemplify and illustrate the sub-themes with randomly assigned identifiers are detailed in Table 25.

Table 25

Sub-Themes with Supporting Quotes (Identifiers Randomly Assigned)

Sub-Themes	Quotes
Clarifying the process and providing support	Current Participants *"It helps you to know, like what you have to do when you get older and when you getting ready to, like to go to the doctor on your own and so, you know what to do and you're not confused." (female #1)* *"They did help pretty well telling me how, how I should transition." (male #1)*
	Recently Transitioned Participants *"It just made it easier to understand and get use to whatever they might do different." (female #2)* *"It made the transition to the adult side like better. I guess you can say better, instead of just going from adolescent straight over. They were explaining how it would be instead of them just switching us over to a doctor." (female #1)* *"It gave you more of a realistic uh, an approach to the adult world I guess, like a faded version of the adult world in turn of your medical needs. It just made it easier to understand and get use to whatever they might do different from ah uh how we use to. Well, how our parents used to deal with it." (female #3)* *"I just feel like they made it a whole lot smoother. And they made it better. Since they just kept coming in and they slowly pushed us out there. They didn't just abandon us out there." (female #3)*
Promoting knowledge of sickle cell disease, health maintenance, self-management, and financial obligation	Current Participants *"I didn't know that much, then they gave me handouts and showed me videos. And then I started to learn more about the process and the disease itself." (male #3)* *"It's letting me know more about my sickle cell so that when I get into the adult, I'll know what, what I'm supposed to do." (male #4)*

	"I learned, like SS, anybody can have it or be born with it. You won't die or nothing like that, it's not contagious. You get sick a lot and go to a lot of doctor appointments." (female #3) *"It helped me realize somethings I didn't know. Like, what percentage of my kids would get sickle cell dependent on what type of person I would marry? Like, if someone didn't have the trait at all, or if they had the trait, or they had the disease too, and that kind of got me thinking that, I really don't want to marry someone with sickle cell." (male #1)* *It's preparing you to get older by taking your medication, the right medications, telling you when to take your medication, and when not to." (male #4)*
	Recently Transitioned Participants
	"I learned how to manage my disease better than what I normally would have as a child, and that it's a blood disorder that deals with the red blood cells. And as far as the insurance now I have to pay a co-pay when I go to my doctor appointments." (female #1) *"I'm much more conscious about myself and my health and making sure I don't get sick. I can't do everything 100% percent like other people may. I mean, I could if I trained for it right. There are limitations to certain things, and you need to be careful when people are sick and stuff like that." (female #1)* *"I learned there are a lot of stuff you can do to prevent you from getting sick, like taking a hot shower to prevent you from getting sick and all of that. The PACT program taught me a lot. Like how to control my pain. How to take my medication correctly and stuff like that. Like, don't forget to take your medication." (male #1)*
Encouraging independence and taking responsibility for managing one's own care	Current Participants
	"It pushed me toward doing things on my own instead of, you know, instead of me just looking around the room with a blank stare, just waiting for something to happen. Ah, it made me start setting up my own appointments and getting my own prescriptions." (male #1)
	Recently Transitioned Participants
	"I think it helped because, it made us realize that we have to ask questions on our own and not to just look at our mom or dad, who likes talk to the doctor for us."(female #2)

	"I guess like you, I feel more at ease kind of knowing more about what to do necessarily ah if that time comes and I have to go the hospital, and ah easier to like make appointments, and do all the technical stuff that your parents did when ah I were at women and children." (female #2) *"It got me ready to be an adult when I transitioned. I think I was already, ready to go to the adult side, I was the one who was giving myself the medicines and keeping my pain under control and all that. I was the one doing it at home." (male #1)*
Lessening emotional concerns and anxieties about the transfer to adult care	Current Participants *"They made me get over some of my fears, by like they would ask me questions and tell me how it would be on the adult side and all of that. Like, what sort of questions we should ask, or how we should start doing things on our own, like going to, going to get your own prescriptions filled, or set up our own appointments, and more adult stuff than we're usually used to." (male #1)* Recently Transitioned Participants *"I wasn't really worried. I thought the doctors would understand me. They made me get over some of my fear. They would like, ask me questions and tell me how it would be on the adult side and all of that." (male #1)* *"Ms. XXXXX was open. And you could talk to her about anything and she would help you, you know." (female #1)* *"Like I'm just used to Dr. XXXX and how she does things but as the transition went on I got used to the other doctors and other people, so it wasn't that bad." (female #1)* *"They talked directly to you, heard your problems like first hand and I feel more at ease kind of knowing more about what to do." (female #3)* *"I was worried that I wouldn't be able to, like make a personal connection with my doctors. That I wouldn't be able to talk to them and be comfortable but then that changed." (female #3)*

Note. SS= homozygous sickle cell anemia-HbSS disease.

Specific Aim and Research Question 3

Specific Aim 3

- *Describe the quantitative with qualitative findings and clinical implications on the impact of transition program participation on successful transition of the AYA with SCD that can inform the: (a) refinement of an existing transition program; (b) development of new strategies to facilitate the successful transition; and (c) improvement of the transition experience for this population.*

Research Question 3

- *What findings and clinical implications will emerge after comparing the results from the quantitative with qualitative phase of data analysis in order to lend clarity on the impact of transition program participation on the successful transition of the AYA with SCD in order to inform the: (a) refinement of an existing transition program, (b) development of new strategies to facilitate a more effective transition, and (c) improvement the transition experience of this population?*

Data Integration

To address specific aim and research question 3, quantitative and qualitative data were merged and then assessed for similarities and differences in order to develop a more comprehensive and in-depth contextual description and understanding of the impact of participation in a transition program on successful transition. Quantitatively, there was a statistically significant moderate to strong positive relationship between the total *TRXANSITION Scale* score and length of time spent in a transition program (r = .53, n =

35, $p < .01$), transfer to adult care ($r = .75$, $n = 10$, $p < .05$), and transfer to adult care within 60 days post-termination of pediatric care for the AYA 19 years of age ($r = .44$, $n = 10$, $p < .01$). Moreover, the mean rank total $STAR_X$ score was higher in those whose timing in the program was three years or more ($M = 19.23$, $n = 20$) than < 3 years ($M = 16.37$, $n = 15$). Additionally, the *TR$_X$ANSITION Scale* scores were higher in those whose timing in the program was three or more years ($M = 21.55$, $n = 20$) as compared to less than three ($M = 13.27$ 8.5, $n = 15$). Furthermore, transfer to adult care occurred within 60 days post-termination of pediatric care in 50% ($n = 5$) of the young adults at age 19 who had recently transitioned to adult care ($n = 10$).

Of interest, the results demonstrated that every transition program participants who transferred to adult care post-termination of pediatric care did so within 289 days. Qualitative results revealed one overarching theme and four sub-themes describing the impact of participation in a transition program. The overarching theme was "*Transition Program Participation Facilitates Preparedness."* The contributing sub-themes were: 1) *Clarifying the process and support;* 2*) Promoting knowledge of sickle cell disease, health maintenance, self-management, and financial obligations;* 3) *Encouraging independence and taking responsibility for managing one's own care; and* 4) *Lessening emotional concerns and anxieties*.

Additionally, the AYAs provided five suggestions and preferences to prepare current and future participants to smoothly transfer to adult care. The suggestions and preferences included: 1) life lesson workshops; 2) support groups and peer mentors; 3) tours of the local adult hospitals; 4) information contrasting the adult and pediatric hospital policy and procedures for pain management; and 5) guidebook with step-by-step

instructions on how to successfully complete the transfer to adult care process. The life lessons workshops described by the study participants included topics that would address budget and money management, daily activities and responsibilities of living with a chronic illness as an adult, coping strategies, and building effective communication skills in order to actively engage with adult care providers in the outpatient and inpatient setting. Study participants suggested that the transition nurse coordinator and providers develop a support group composed of current and recently transitioned AYA in order to provide peer support and mentoring throughout the transition process and living with SCD. Several individuals expressed positive feelings about having the opportunity to participate in a focus group to discuss and share with others who are experiencing the same process. Individuals reported that having a support system would provide additional support and aid in alleviating some of the emotional concerns and anxieties associated with adapting to and coping with a new environment, relationships, responsibilities, and expected behaviors in the adult health care system. Likewise, study participants requested tours of the local adult hospitals in the community in order to prepare for the transfer to the adult hospital setting. Moreover, it was suggested that time be allocated for a hospital representative and adult care provider to address questions or concerns about the health system during hospital tours. Lastly, they suggested that a guidebook with step-by-step instructions on how to transfer to adult care would simplify the transition process and provide guidance. Exemplar quotes illustrating their preferences and suggestions are listed in Table 26.

Table 26

Quotes of Participants' Preferences and Suggestions (Identifiers Randomly Assigned)

Preferences and Suggestions	Quotes
	Current and Recently Transitioned Participants
Life lesson workshops	*"Like workshops, life lessons workshops, some more stuff like how to budget everything while having to deal with other things, like buying your medicine and everything like that." (female #2 Recently transitioned participant)* *"I think you should um teach them how to talk to adult doctors when we are in the hospital and when, we are, like sometimes we may not be ourselves and we don't have our parents or anyone there at all." (female #3 Recently transitioned participant)*
Focus groups	*"This is a big help. I think sitting in a group with other people and listening how they help themselves, and giving each other ideas on how we should react to our pain crisis or how we should tell doctors how we normally are, or what to do in certain situations." (male #1 Current participant)*
Peer mentors	*"Have them have someone who has already transitioned to tell them about how they do things and stuff like that. Like, have an older person speak to the kids that are trying to transition the adult side." (female #1 Recently transitioned participant)*
Hospital tours	*"Give them options that may kind of ease their possible anxiety or fear of walking into ah hospital, like, not knowing where to necessarily go." (female #3 Recently transitioned participant)*
Information contrasting pediatric and adult hospital policy and procedures	*"I think you should let the kids know what their options are after they get, well after they get out of or before they get out of pediatrics or whatever. But you should let them know their option of doctors,*

	hospitals, medications, and stuff like that." (female #3 Recently transitioned participant)
Guidebook	*"They could give us a little small guide to show us what we should do or shouldn't do, tell us how to do it, or where to go online or who to call. That would help a lot." (male #1 Current participant)*

The similarities after merging the quantitative and qualitative data are presented and listed in Table 27.

Table 27

A Joint Display of Quan and Qual Analyses Similarities

Quantitative		Qualitative			
Specific Aims 1 & 2					
Determine the impact of participation in a transition program on successful transition.		Describe the thoughts, experiences, and concerns of AYA with SCD regarding the impact of their participation in a transition program on successful transition.			
Indicators	Measures	Sub-Themes	Quotes	Additional Findings	Quotes (Randomly Assigned Identifiers)
Disease, medication, and insurance knowledge	The mean rank scores were higher on the *STAR$_X$* and *TR$_X$ANSITION* Scale for the participants in the transition program with three or more years in the program.	Knowledge of sickle cell disease, health maintenance, self-management, and financial obligation	*"I didn't know that much, then they gave me handouts and showed me videos. And then I started to learn more about the process and the disease itself."(male #3)* *"I learned, like SS, anybody can have it or be born with it. You won't die or nothing like, that its' not*	There were also five suggestions and preferences of the AYA thought would be helpful to participants in a transition program for the movement to adult care: 1. life lesson workshops	*"This is a big help. I think sitting in a group with other people and listening how they help themselves, and giving each other ideas on how we should react to our pain crisis or how we should tell doctors how we normally are, or what to do in certain situations". (male #1)* *"They could give us a little small guide to show*

	The mean rank scores were higher on the *STAR$_X$* and *TR$_X$ANSITION Scale* for the recently transitioned as compared to the current participants of the transition program.	*contagious. You get sick a lot and go to a lot of doctor appointments." (female #3)* *"I learned it's a blood disorder that deals with the red blood cells. And as far as the insurance now I have to pay a co-pay when I go to my doctor appointments." (female #1)* *"It helped me realize somethings I didn't know. Like, what percentage of my kids would get sickle cell dependent on what type of person I would married. Like, if someone didn't have the trait at all, or if they had the trait, or they had the disease too, and that kind of got me thinking that, I really don't want*	2. support group and peer mentors 3. tours of the local adult hospitals 4. information contrasting the adult and pediatric hospital policy and procedures for pain management 5. guidebook with step-by-step instructions on how to successfully complete the transfer to adult care process	*us what we should do or shouldn't do, tell us how to do it, or where to go on line or who to call. That would help a lot". (male #1)* *"I think you should um teach them how to talk to adult doctors when we are in the hospital and when, we are, like sometimes we may not be ourselves and we don't have our parents or anyone there at all". (female #3)* *"I think you should have like, ah a group discussion with like the kids that are trying to transition. Have them have someone who has already transitioned to tell them about how they do things and stuff like that. Like have an older person to speak to the kids that*

			to marry someone with sickle cell."(male #1) *"The PACT program taught me a lot. Like how to control my pain. How to take my medication correctly and stuff like that. Like, don't forget to take you medication." (male #1)*	*are trying to transition the adult side". (female #1)* *" I think you should let the kids know what they're options are after they get, well after they get out of or before they get out of pediatrics or whatever. But you should let them know they're option of doctors, hospitals, medications, and stuff like that". (female #3)* *"Give them options that may kind of easy there possible anxiety or fear of walking into ah hospital, like, not knowing where to necessarily go". (female #3)*
Self-care and self-advocacy skills	The mean rank scores on the *STAR$_X$* and *TR$_X$ANSITION* Scale were	Encouraging independence and taking responsibility	*"Like, I think it helped because, it, it made us realize that we have to asked questions on our own and not to just look*	*"It pushed me toward doing things on my own instead of, you know, instead of me just looking around the room with a*

	higher for participation in the transition program for three or more years. Timing has a medium effect on the total *STAR$_X$* and *TR$_X$ANSITION Scale* scores. The mean rank scores on the *STAR$_X$* and *TR$_X$ANSITION Scale* were higher for the recently transitioned as compared to the current participants of the transition program.	for managing one's own care	*at our mom or dad, who likes talk to the doctor for us."(female #2)* *"I guess like you, I feel more at ease kind of knowing more about what to do necessarily ah if that time comes and I have to go the hospital, and ah easier to, to like make appointments, and do all the technical stuff that your parents did when ah I, ah you were at women and children." (female #2)* *"I'm much more conscious about myself and my health and making sure I don't get sick. I can't do everything 100% percent like other people may. I mean, I could if I trained for it right.*	*blank stare, just waiting for something to happen. Ah, it made me start setting up my own appointments and getting my own prescriptions." (male #1)* *"I guess like you, I feel more at ease kind of knowing more about what to do necessarily ah if that time comes and I have to go the hospital, and ah easier to, to like make appointments, and do all the technical stuff that your parents did when ah I, ah you were at women and children." (female #2)* *"It got me ready to be an adult when I transitioned. I think I was already, ready to go to the adult side, I was the one who was giving myself the medicines and keeping my*

			There are limitations to certain things, and you need to be careful when people are sick and stuff like that."(female #1) *"It got me ready to be an adult when I transitioned. I was the one who was giving myself the medicines and keeping my pain under control and all that. I was the one doing it at home." (male #1)*	*pain under control and all that. I was the one doing it at home." (male #1)*
Transfer to adult care of the adolescent and young adult at age 19	Transfer to adult care within 60 days post-termination of pediatric care of the adolescent and young 19 years of age occurred in half to the sample and all	clarifying the process and providing support promoting	*"It helps you to know, like what you have to do when you get older and when you getting ready to, like, like to go to the doctor on your own and so, you know what to do and you're not confused." (female #1)* *"It helps you like knowing what you have*	*"It just made it easier to understand and get use to whatever they might do different." (female #2)* *"It made the transition to the adult side like better. I guess you can say better, instead of just going from adolescent straight over. They were explaining how it would be instead of*

	had transferred within 289 days. Transfer to adult care of the AYA 19 years of age ranged from 5 to 289 days post-termination of pediatric care. Timing in the transition program of more than three years had a large effect on the transfer to adult care.	*to do when you go to the doctor and all the information that you need to know so they know how to help you." (female #1)* *"They did help pretty well telling me how, how I should transition." (male #1)* *"It just made it easier to understand and get use to whatever they might do different." (female #2)* *"It made the transition to the adult side like better. I guess you can say better, instead of just going from adolescent straight over. They were explaining how it would be instead of them just switching us*	*them just switching us over to a doctor." (female #1)* *"It gave you more of a realistic uh an approach to the adult world I guess, like a faded version of the adult world in turn of your medical needs. It just made it easier to understand and get use to whatever they might do different from ah uh how we use to. Well, how our parents used to deal with it." (female #3)* *"I just feel like they made it a whole lot smoother. And they made it better. Since they just kept coming in and they slowly pushed us out there. They didn't just abandon us out there." (female #3)*

	over to a doctor." (female #1) *"It just made it easier to understand and get use to whatever they might do different from ah uh how we use to. Well, how our parents used to deal with it." (female #3)* *"I just feel like they made it a whole lot smoother. And they made it better. Since they just kept coming in and they slowly pushed us out there. They didn't [illegible] us out (female #3)*

Specific Aim 3
Describe the results, findings, and clinical implications when comparing current evidence-based quantitative with qualitative data on the impact of participation in a transition program on successful transition of AYA with SCD in the (a) refinement of a transition program; (b) development of new strategies to facilitate successful transition; and (c) improvement of the transition experience for this population.

Results/Findings

Participation in a transition program can be associated with successful transition and facilitates preparedness for the transfer to adult care.

Knowledge of disease, medication, insurance, self-care, and self-advocacy scores on the *STAR$_X$* and *TR$_X$ANSITION Scale* can be seen to be higher with timing in a transition program of three or more years.

The transfer to adult care within 60 days post-termination of pediatric care for the AYA 19 years of age is more likely with greater length of years and number of encounters while participating in transition program.

Clinical Implications

To improve the transition experience, the onset of participation in a transition program within the context of three or more years can be associated with the defined outcome measures of successful transition.

Early access to and utilization of the educational, planning, and preparation services of a transition program is critical to preparedness for the transfer to adult care and successful transition of the AYA with SCD at the USA-CSCC and possibly other centers with a similar program.

The transition nurse coordinator and health care providers involved in the transition process play an integral role in facilitating, clarifying, and providing a supportive process as a resource person and liaison between the AYA, pediatrics, and adult care providers.

Refinement to the existing transition program

- Annual Open House Event to include a recently transitioned AYA
- USA Health System Adult Hospital tour
- Transition nurse coordinator attendance at every pediatric clinic
- Adult clinic policy change in relation to the no adjustment to the current plan of treatment on the first visit.

- Transitioned AYA are seen by the transition provider at the first visit and followed every three months for the first year

New strategies from the perspective of the AYA with SCD

- Life lesson workshops
- Support groups
- Peer mentors
- Tours of the local adult hospitals with information contrasting the adult and pediatric hospital policy and procedures for pain management
- Guidebook with step-by-step instructions on how to successfully complete the transfer to adult care process

Improvement

- Revise current methods of communication and advertisement of scheduled events to increase awareness of the current life lesson workshops and new programs such as text messages and social media
- Broaden the scope of the PACT committee to include a transitioned AYA and family caregiver
- Consult case management in order to address transportation to clinic for medical and transition services

Chapter Summary

In summary, this chapter presented the results of the descriptive, observational, cross-sectional concurrent quan + qual study describing the impact of participation in a transition program on successful transition to adult care and factors that may influence adaptation to and coping with the process. The results included an overview of the screening and enrollment of study participants, a detailed description of the sample sociodemographic characteristics, descriptive statistics of the study variables test of normality, and reliability of the survey instruments. Next, the findings from each component of the concurrent yet separate quantitative and qualitative data analyses were presented in both narrative formats as well as in tables. Finally, a side-by-side table was presented describing similarities of the quantitative and qualitative data after results from both analyses were integrated to provide a complete description and understanding of the impact of participation in a transition program on successful transition of AYA with SCD at the USA-CSCC.

CHAPTER FIVE

DISCUSSION

This final chapter presents a discussion of the findings from the evaluation and interpretation of the major findings regarding transition program participation in relation to the specific aims, research questions, Schlossberg's Transition Framework, previous research, limitations, and strengths. The implications of the findings for the current transition program at the University of South Alabama Comprehensive Sickle Cell Center (USA-CSCC) and future research are addressed.

The aim of this observational descriptive mixed methods study was to provide an in-depth description and contextual understanding of the impact of transition program participation on successful transition in sickle cell disease (SCD) and other factors that may influence adaptation to and coping with the transition process. Successful transition was measured quantitatively using the total scores on the *STAR$_X$* and *TR$_X$ANSITION Scale* and transfer to adult care within 60 days post-termination of pediatric care for the adolescent and young adult (AYA) 19 years of age, and qualitatively from the perspectives of the AYA using focus groups and telephone interviews. In general, the major findings revealed very few surprises based on a review of the literature, consistent with prior research, and the principal investigator's clinical observations of the pediatric and adult patient population's progression through the USA-CSCC Pediatric to Adult Care Transition (PACT) Program. The overall results demonstrated that transition

program participation was associated with successful transition and facilitated preparedness for the transfer to adult care through: 1) clarifying the process and providing support; 2) promoting knowledge of SCD, health maintenance, self-management, and financial obligations; 3) encouraging independence and taking responsibility for managing one's own care; and 4) lessening emotional concerns and fears about the transfer to adult care. Hemoglobinopathy status, disease severity, treatment plan, and distance to clinic in miles were found to influence AYAs' adaptation to and coping with the PACT program.

Study Sample

The study was conducted with a purposeful convenience sample of 35 current and recently transitioned to adult care AYA with SCD ages 13-21 who are participants of the PACT program at the USA-CSCC. The sample was evenly distributed between males and females with an African American ethnicity. For some, the disease was complicated by acute chest syndrome (ACS), cerebrovascular accident (CVA), or a combination of both and required a treatment plan consisting of hydroxyurea (HU) therapy, chronic transfusion (CT), or a combination. Overall, the sample did not differ from the non-study participants at the USA-CSCC.

With few exceptions, the sample characteristics were similar to those in previous research studies examining AYA with SCD transition program participation (Andemariam et al., 2014; Hankins et al., 2012; Smith et al., 2011). Exceptions include that in this study's sample the reported incidence of ACS (43%; $n = 15$) was higher, treatment plan consisting of HU therapy (43%; $n = 15$) was also higher, and number of individuals receiving CT (3%; $n = 1$) was lower (Andemariam et al., 2014; Hankins et al.,

2012). The differences between the findings of this study and previous research conducted by Andemariam et al. (2014) and Hankins et al. (2012) may be explained in that ACS may be diagnosed by health care providers as one of a broad spectrum of pulmonary diseases including atelectasis, pneumonia, acute respiratory distress, fat embolus, or multiple organ failure (Haynes & Kirkpatrick, 1993; Howard et al., 2015; Melton & Haynes, 2006; Okumura et al., 2008). Additionally, differences in HU can be explained by varying prescribing rates, lack of training for health care providers on the prescribing, maintenance, and therapeutic monitoring, poor adherence by the AYA with SCD, and fears of potential toxicities and side effects of the medication by individuals and parents or caregivers, often leading to the lack of its utilization (Brandow & Panepinto, 2010; Okumura et al., 2008). Moreover, differences in the utilization of CT may be explained by the potential risk of infections, development of multiple antibodies and alloimmunization to red blood cells (RBCs), secondary hemochromatosis, lack of access to comprehensive sickle cell and RBC infusion centers, and required indefinite adherence with transfusions, which can interfere with employment, activities of daily living, and post-secondary education (Brandow & Panepinto, 2010; Chou, 2013; Kanter & Kruse-Jarres, 2013; Pack-Mabien & Haynes, 2009). Finally, differences in the sample characteristics may be explained by geographical differences, urban as compared to rural within the context of access to and utilization of sickle cell centers for services, and variability in the number of individuals with SCD seen nationwide (Brousseau et al., 2010b; Hassell, 2010; Logan, Radcliffe, & Smith-Whitley, 2002; Telfair et al., 2003).

Schlossberg's Transition Framework

In general, the findings of this study supported Schlossberg's Transition Framework's philosophical assumption that an individual's ability to cope with and adapt to the transition process can be influenced by taking stock of four potential coping resources or factors referred to as "*The 4 S*" system: *self*, *situation*, *support*, and *strategies* (Schlossberg, 1981, 2011; Schlossberg et al., 1995). *Self* encompasses the personal and demographic attributes of an individual affected by the transition (Schlossberg, 1981, 2011; Schlossberg et al., 1995). *Situation* refers to the timing and concurrent stressors of the transition (Schlossberg, 1981, 2011; Schlossberg et al., 1995). *Support* identifies availability of internal and external environmental factors of support (Schlossberg, 1981, 2011; Schlossberg et al., 1995). *Strategies* refer to measures that an individual utilizes to navigate through or cope with the transition (Schlossberg, 1981, 2011; Schlossberg et al., 1995).

Consistent with Schlossberg's Transition Framework, the study results reinforced the importance of and relationships among successful transition and the SCD-specific coping resources: transition program participation (*strategy*), hemoglobinopathy status (*self*), disease severity and treatment plan (*situation*), and distance to clinic (*support*). For example, the results of this study demonstrated that transition program participation can have a positive influence on the AYA's ability to adapt to and cope with transition and transfer to adult care. This relationship can primarily be seen with the relationship between successful transition as measured by the $STAR_X$ and $TR_XANSITION$ *Scale* scores and length of program participation of three or more years and transfer to adult care. Additionally, this relationship can be seen from the results of the current study in the

voices of the AYA with SCD through the focus groups and telephone interviews describing their transition program participation experience. From their perspectives, transition program participation facilitated preparedness for the transition process through: 1) clarifying the process and providing support; 2) promoting knowledge of SCD, health maintenance, self-management, and financial obligations; 3) encouraging independence and taking responsibility for managing one's own care; and 4) lessening emotional concerns and fears about the transfer to adult care.

The results also demonstrated that hemoglobinopathy status, disease severity, treatment plan, and distance to clinic in miles for medical services can have an influence on the outcome measures of successful transition. Prior research on risk factors for an unsuccessful transition and the findings of this study demonstrated that a less severe form of SCD and distance to clinic > 20 miles can negatively influence the transition process, as opposed to those whose disease has been complicated by a history of ACS and/or CVA or treatment plan of HU and/or CT. This could be explained in part by the individuals' and/or parent(s)' or caregiver(s)' perception that their form of SCD is not severe and therefore there is less need to adhere to outpatient clinic follow-up appointments for medical management and transition services (Burlew et al., 2000; Logan et al., 2002; Majumdar, 2013; Musumadi et al., 2012; Pinckney & Stuart, 2004). Additionally, disease severity defined by a medical history positive for ACS and/or CVA can be a concurrent stressor, given the stringent requirements for adherence with frequent outpatient appointments and a treatment plan consisting of HU therapy, CT, or combination of both in the management of disease complications; such a treatment regimen indefinitely adds to the complexity of the transition process (Chou, 2013).

Finally, distance to clinic in miles for medical services in relation to the lack of internal and external environmental support services can impact access to and utilization of medical services, particularly in a state with a large rural population and geographical disparities (Andemariam et al., 2014; Mayer, 2008; Telfair et al., 2003; Williams et al., 2015).

Major Findings

The findings of this study were consistent with those of Hankins et al. (2012) and Smith et al. (2011), who examined pilot transition programs of varying content and level of development. The findings of the previous research studies showed that transition program participation was a feasible, beneficial, and acceptable strategy for health care providers to facilitate transfer to adult care, resulting in higher disease knowledge scores (Hankins et al., 2012; Smith et al., 2011).

The overall results of this study demonstrated a moderate to strong correlation between transition program participation and the outcome measures of successful transition: total *STAR$_X$* and *TR$_X$ANSITION Scale* scores and transfer to adult care within 60 days for the AYA 19 years of age. This study found that length of time spent in a transition program is associated with successful transition and likelihood of transfer to adult care. Timing in a transition program of three or more years had a medium effect on the *STAR$_X$* and *TR$_X$ANSITION Scale* scores, and a large effect on the transfer to adult care within 60 days post-termination of pediatric care of the AYA 19 years of age. There were higher mean scores on the *STAR$_X$* and *TR$_X$ANSITION Scale* of the transition program participants who recently transitioned to adult care as compared to current participants, with a small effect on the total *STAR$_X$* and large effect on *TR$_X$ANSITION Scale* scores.

Lastly, timing in a transition program in relation to the number of years spent in the program makes the strongest contribution to explaining the total variances seen in successful transition as measured by the AYAs' total *STAR$_X$* and *TR$_X$ANSITION Scale* scores and successful transfer to adult care within 60 days post-termination of pediatric care.

The findings are also congruent with previous research by Andemariam et al. (2014), who examined transition program participation on successful transition and factors that may influence the process. Andemariam et al. (2014) found that AYA with a milder form of SCD, HbSβ^+ Thalassemia and HbSC, a treatment plan not consisting of CT, and distance to clinic more than 20 miles did not successfully transition to adult care. The results of the study conducted by Andemariam et al. (2014) also demonstrated that the implementation of transition preparation and planning in the transition program for the older AYA was inversely related to successful transition.

Overall, the findings from this study demonstrated that medical history positive for ACS, CVA, or both, treatment plan consisting of HU therapy, and distance to clinic less than 30 miles had a positive influence on the mean total *STAR$_X$* and *TR$_X$ANSITION Scale* scores. Higher mean total scores on the *STAR$_X$* and *TR$_X$ANSITION Scale* can be seen for individuals whose treatment plan consists of HU therapy and who travel less than 30 miles to clinic, compared to those not receiving HU therapy or traveling more than 30 miles to clinic. These two factors demonstrated a small to moderate effect on the total scores of the *STAR$_X$* and *TR$_X$ANSITION Scale*. A medium effect on the transfer to adult care of the young adult at age 19 within 60 days post-termination of pediatric care can be seen with the more severe forms of SCD, HbSS and HbSβ^0 Thalassemia; there is a

small effect with disease severity defined as a medical history positive for ACS and a treatment plan consisting of HU therapy. Lastly, the results indicated that variances seen on the total *STAR$_X$*, total *TR$_X$ANSITION Scale*, and transfer to adult care within 60 days post-termination of pediatric care for the AYA 19 years of age can be explained by the predictors. Among the predictors, the strongest contributors explaining the degree of variance on the outcome measures include the length of time spent in a transition program and treatment plan.

However, in contrast to the results of this study, Andemariam et al. (2014) found no association between the treatment plan consisting of HU therapy or medical history positive for ACS and successful transition. The difference may be explained by the limited number of individuals on HU therapy at the newer program examined by Andemariam et al. (2014) compared to the utilization of this therapy in the more established program examined in the current study.

Additionally, the findings of the current study are congruent with, support, and extend findings from previous research conducted by Smith et al. (2011) on the emotions and concerns of the AYA with SCD about the transition process pre- and post-transition after initiating a pilot transition program. Smith et al. (2011) generally found both positive and negative emotions and concerns and concluded that transition program participation may alleviate some concerns about the transition process. However, the researchers did not explore or describe how transition program participation addressed the emotions and concerns about the transfer to adult care. This could be explained by the researchers' use of the subscales from the patient version of the Sickle Cell Transfer Questionnaire (Smith et al., 2011). The self-report survey is structured and can consist of

direct questions with a list of pre-determined choices for the study participants to select, with the possibility of missing valuable data from the perspective of the study participant, resulting in the lack of understanding "how or why" or bias by researcher (Polit & Beck, 2012).

The overall results of the current study addressed this gap by providing insight into how transition program participation lessens the AYAs' concerns and fears about the transfer to adult care. The findings of this study demonstrated that transition program participation lessens emotional concerns and anxieties about the transfer to adult care. Primarily, this can be seen through the words of the AYA with SCD that transition program participation: 1) answers questions on how to transition; 2) promotes confidence in the ability of the AYA to attend the adult care clinic independent of the caregiver or parent; 3) builds relationships and familiarity with the transition coordinator and adult providers; and 4) eases concerns about having a new provider with knowledge and training in the management of their SCD.

The findings of this study on the preferences and suggestions of the AYA with SCD are congruent with the previous research conducted by Williams et al. (2015), who examined the learning preferences for transition education of 37 AYA using the Transition Education Survey. In general, Williams et al. (2015) found that transition education coordinated by a health care provider during a clinic visit and self-taught at home through a web-based social media interactive software program was preferred over the use of pamphlets or handouts. The current study revealed that life lesson workshops, support groups, peer mentors, hospital tours, and a guidebook with step-by-step instructions regarding how to transfer to adult care can be used for transition education

and learning of the AYA with SCD in preparation for transfer to adult care. The findings of this study, in contrast to those of Williams et al. (2015), support more interactive activities as a component in a transition program to meet the transitional needs of the AYA in preparation for the transfer to adult care. Some participants of this study also endorsed the involvement of a transition nurse coordinator and health care providers as a valuable resource person on the transition process and SCD educator during routine outpatient pediatric and adult clinic visits.

Finally, the study findings are congruent with and contribute to current best-practice guidelines and assumptions of the leading health organizations and policy makers that espouse beginning transition early during adolescence, in general around the age of 12. The overall results of this study demonstrated that the length of timing in a transition program can influence successful transition, indicated by higher scores on the total *STAR$_X$* and *TR$_X$ANSITION Scale* in the recently transitioned as compared to the current participants of a transition program (American Academy of Pediatrics, 2002, 2011). Additionally, the findings provide additional evidence that supports a planned, purposeful, and comprehensive transition process for every AYA with a chronic hematological disorder (Bryant et al., 2015). Finally, the findings contribute to the current evidence on the use of transition programs to educate the AYA in preparation for the transfer to adult care (American Academy of Pediatrics, 2002; Blum, 1995).

Limitations and Strengths

The research design and methods of this study have both limitations and strengths. The limitations include use of the cross-sectional design for data collection, purposeful convenience sample, AYA as study participants, self-report survey and focus

groups as a method of data collection, and inexperienced research assistants. The strengths of this study include its mixed methods methodology, purposeful sampling strategy, triangulation through the use of multiple data sources, and multi-disciplinary and highly skilled research team.

Limitations

First, the findings are limited by the cross-sectional design for data collection. This design provides only a snapshot of the transition process of the AYA with SCD at the USA-CSCC between February and June 2017. Hence, this may not represent the entire transition process, which can extend over a period of years (Polit & Beck, 2012). Moreover, selection bias can cause concern that the study sample may not be representative of the general target population of interest nor the non-study participants at the USA-CSCC. However, the cross-sectional study design is an economical and practical approach for describing a phenomenon and data collection during a single period or point in time (Polit & Beck, 2012). Additionally, the use of this study design is congruent with the previous research on transition program participation in AYA with SCD (Andemariam et al., 2014; Hankins et al., 2012; Smith et al., 2011). Although a longitudinal study design would have provided an appraisal of the transition process at different stages or changes throughout the process, it could have been restricted by problems associated with attrition (Polit & Beck, 2012).

Second, the findings of this study are limited by the use of a small convenience sample that may not be typical of the critical variables of interest or representative of AYA with SCD. As a result, the statistical findings may not be valid or generalizable to a larger sample (Polit & Beck, 2012; Urdan, 2010). However, this sample is comparable

to those used in previous research and representative of the target population of interest, with firsthand knowledge about transition program participation to purposefully and richly inform the researchers and provide an understanding of the impact of such programs on the successful transition of this population (Andemariam et al., 2014; Hankins et al., 2012; Polit & Beck, 2012; Smith et al., 2011). Likewise, the selection of the purposeful sample strategy and study site reduces potential risks to the study's rigor and credibility. Lastly, this sample of AYA with SCD ranging in age from 13-21 provides a diverse description and perspective with a wide range of responses on the impact of participation in a transition program both pre- and post-transition.

Third, this evaluation of transition program participation in SCD involved a target population of the AYA and a period marked by significant physical and psychosocial developmental changes (Horner, 2000). Likewise, the period of transition is marked by adaptation and coping with expected changes in behavior, new roles, relationships, environment, and many other factors that may influence this process (Andemariam et al., 2014; Burlew et al., 2000; Fortuna et al., 2012; Lebensburger et al., 2012; Schlossberg, 2011). During this period of transition, AYA may feel pressure or reluctance to speak in the presence of an adult stranger or provider unknown to them (Horner, 2000). Additionally, the AYA may not have the necessary cognitive, language, or social skills to communicate a description of a phenomenon or health concern effectively (Horner, 2000). However, when asked to describe a specific current or previous experience, the AYA have the required cognitive, language, and social skills to give a complete and descriptive response and participate in a focus group discussion with peers (Beattie & VandenBosch, 2007; Horner, 2000; Knight et al., 2009). Furthermore, research involving

this population is essential to improve adolescent health and medical management of AYA living with a chronic medical condition and to inform health policy and practice (Santelli et al., 2003).

Fourth, the quantitative findings of the study are limited to the use of a self-report survey to quantitatively measure the defined outcome measures of successful transition, which can raise questions of trustworthiness and accuracy. However, the self-report survey used in this study, *STAR$_X$*, was followed by the *TR$_X$ANSITION Scale*, a semi-structured data collection tool administered to the participants by trained research assistants. Participants' responses were scored based on a standardized scoring guide modified for the AYA with SCD and the purpose of the current study. The content of this modified scoring guide was validated by an expert panel of pediatric and adult care providers with expertise in the care of individuals with SCD. This panel of experts consisted of a pediatric hematology/oncology nurse practitioner and researcher, director of the USA-CSCC and adult care provider, and senior researcher. Moreover, both tools are reliable instruments and the content of the modified scoring guide valid for the purposes of this study (Cohen et al., 2015; Ferris et al., 2015; Ferris et al., 2012). Finally, the use of the mixed-methods study design addresses this limitation with the use of multiple data sources, including focus groups, telephone interviews, and review of medical records (Creswell & Plano Clark, 2011; Ivankova, Creswell, & Stick, 2006; Polit & Beck, 2012).

Fifth, although the purpose of the focus group and interview is to provide an in-depth contextual understanding and insight into the research problem, it should be noted that limitations exist. Both focus groups and interviews require a well-defined purpose,

carefully planned and conducive environment, and well-trained, skillful, and experienced moderator and support personnel (Cote-Arsenault & Morrison-Beedy, 2005). Additionally, the AYA may feel pressured or reluctant to speak when talking with an adult stranger or provider unknown to them during a focus group or interview (Horner, 2000). However, focus groups and interviews can be effective in the AYA population in order to gather detailed information and rich understanding about the experiences, concerns, and thoughts of AYA about a phenomenon (Cote-Arsenault & Morrison-Beedy, 2005; Horner, 2000).

During a focus group, the AYA population may be more relaxed and eager to share their experiences, concerns, and opinions in a discussion with their peers in a comfortable environment facilitated by a familiar individual (Horner, 2000). The focus groups were conducted in the privacy of the conference room at the local Sickle Cell Disease Association. This location provides social support services and hosts an annual Christmas party, tutorial program, and summer enrichment camp for individuals with SCD; telephone interviews were conducted from the USA-CSCC research office. Both the focus groups and interviews were conducted by the same research assistants who collected and administered the surveys and questionnaires in the quantitative phase of this study in order to create an atmosphere in which the participants felt at ease and comfortable (Polit & Beck, 2012). With the lack of an experienced moderator and observer, the PI and members of this dissertation committee cannot be certain of the consistency with which the research assistants engaged participants of the focus groups and telephone interviews successfully. To address this limitation and improve the rigor of the qualitative findings, debriefing sessions took place, notes were reviewed, and

training was provided to both the moderator and note-taker. Prior to the focus groups and interviews, training sessions were conducted with the research assistants on the use of the written focus group and telephone interview guide, and supervision was provided during both methods of data collection. Additionally, the dissertation chair, two members of the dissertation committee with expertise and background in analyzing qualitative data, and the principal investigator (PI), read and reviewed the transcripts independently and then convened to discuss discrepancies and similarities among the codes and sub-themes in order to reach a consensus. A data auditing system and detailed record keeping were maintained throughout the data analysis. Finally, a narrative report was sent to the participants of the focus groups and interviews to confirm or refute the research team's analysis of the data and provide corrections or additional information. The findings from the narrative reports confirmed the researchers' findings from the content and thematic analysis of the qualitative data.

Strengths

It should also be noted that there are significant strengths of this observational, descriptive, cross-sectional, mixed methods study. The strengths include use of the: 1) mixed methods design; 2) reliable survey instruments; 3) purposeful sample at the USA-CSCC pediatric and adult outpatient clinics with a transition program to richly inform researchers; and 4) multi-disciplinary highly skilled dissertation committee.

The MMR study design allows researchers to capitalize on the strengths and non-overlapping weaknesses of the quantitative and qualitative methodologies (Creswell & Plano Clark, 2011; Plano Clark & Ivankova, 2016). Additionally, MMR minimizes the potential of an alternative explanation or inferences of the results and produces more

credible evidence and generalizable findings with the use of multiple data sources (Creswell & Plano Clark, 2011; Ivankova, 2015; Polit & Beck, 2012). Finally, the concurrent quantitative + qualitative and cross-sectional design are economical, time efficient, and effective methods for the collection of multiple data sources over a relatively short timeframe (Creswell & Plano Clark, 2011; Ivankova et al., 2006). Moreover, the *STAR$_X$* and *TR$_X$ANSITION Scale* survey instruments used in this MMR study correlate with successful transition; the *TR$_X$ANSITION Scale* scoring user guide was modified and content validated for AYA with SCD to require a minimal amount of time commitment from study participants and administrator of the tools (Cohen et al., 2015; Ferris et al., 2015; Ferris et al., 2012). Furthermore, the purposeful sampling strategy of the USA-CSCC outpatient pediatric and adult clinics as a study site with a formalized transition program provided a readily accessible and suitable sample to inform the researchers on the impact of transition program participation on successful transition (Polit & Beck, 2012).

Finally, the research team was comprised of a highly skilled and multi-disciplinary team of researchers with multiple contributions. This dissertation committee consisted of three nurse researchers with pediatric and adult health care clinical and research backgrounds in hematology/oncology, palliative care, and health care transition, a sickle cell disease physician of more than 30 years, and a statistician. This committee also consisted of a PI with more than 21 years of clinical experience and expertise in the medical management and transition of AYA with SCD. The research background and training of this committee includes quantitative, qualitative, and MMR methodologies at the University of Alabama at Birmingham and research in the basic health sciences at the

USA-CSCC and College of Medicine. The multiple contributions of this research team included the study design, statistical guidance, content and thematic analysis, and administrative, technical, and material support.

Summary

In summary, it should be noted the study has been limited by its use of the cross-sectional design for data collection, purposeful convenience sample, AYA as study participants, self-report survey and focus groups as a method of data collection, and inexperienced research assistants. However, it should also be noted that the primary purpose of the study was to evaluate the link between transition program participation of the AYA with SCD and successful transition to purposefully inform the researchers on this complex phenomenon in order to address gaps in the literature, and provide a rich description and understanding of the transition process and factors that may influence this process.

Implications for the Current Transition Program and Practice

This descriptive, observational, cross-sectional concurrent quan + qual study provides a comprehensive description and contextual understanding of the impact of transition program participation on successful transition, with implications for the refinement of the current PACT program at the USA-CSCC. Overall, the findings of this study align with and contribute evidence-based data to current best-practice guidelines and assumptions of the American Academy of Pediatrics, American Society of Adolescent Medicine, American Society of Pediatric Hematology Oncology, and Association of Pediatric Hematology Oncology Nurses on transition program participation. Current best-practice guidelines and assumptions support a planned,

purposeful, and comprehensive transition process and formalized program participation for every AYA with a chronic disorder early during adolescence and coordinated by adult and pediatric providers in order to facilitate successful transition and preparedness for the transfer to adult care (American Academy of Pediatrics, 2002, 2011; Bryant et al., 2015).

The results of this study demonstrated that transition program participation can have a positive association with successful transition and preparedness for the transfer to adult care of the AYA with SCD at the USA-CSCC. This association between transition program participation and successful transition can be seen in relation to length of time spent in the program of three or more years. The study findings have implications for the current transition program at the USA-CSCC in relation to the critical nature and significance of early participation of AYA with SCD in the PACT program in order to facilitate successful transition and preparedness for the transfer to adult care. The program currently introduces the concept of transition to parents or caregivers and the adolescent at age 12 and initiates the process at age 13, coordinated by both adult and pediatric providers. The implications for this program involve the consideration of this team of providers to initiate the transition process at an earlier age as a potential strategy that can influence the AYAs' ability to adapt to and cope with the transition process as described in the current study and Schlossberg's Transition Framework (Schlossberg, 2011; Schlossberg et al., 1995). The study found that half of the recently transitioned program participants transferred to adult care within 60 days post-termination of pediatric care at age 19. On average, transfer to adult care post-termination of pediatric care occurred within 96 days. However, there was one individual whose transfer to adult care occurred in 289 days. This could be explained by the results of this study and the

previous research studies demonstrating that distance to clinic can be a factor with either a positive or negative influence on the transition process (Andemariam et al., 2014; Williams et al., 2015). The results of the current study and prior research highlight the need for case management involvement in transition programs; social support services through the local community and sickle cell disease community-based organizations could assist the AYA whose distance to clinic may be a factor that negatively affects access to care and creates a barrier to transition (Andemariam et al., 2014; Betz & Redcay, 2005; Williams et al., 2015).

Additionally, the results confirmed the importance of the transition nurse coordinator's and nurse practitioner's roles in the transition program and process at USA-CSCC. As integral players among health care providers of this population, the transition nurse coordinator and nurse practitioner were each described as educators of and resources for the AYA during the transition process. The transition nurse coordinator currently attends the outpatient pediatric clinic one day a week and may miss an opportunity to provide transition education, planning, and preparation to every participant of the PACT program. The results of this study suggest the providers of the PACT program consider the transition nurse coordinator's attendance at every pediatric clinic in order for participants to have an opportunity to receive transition services at each clinic appointment based on the educational and learning needs of the individual AYA.

From the findings of the current study, learning preferences and strategies for transition education and learning were revealed and included: life lessons workshops, peer mentoring, support groups, hospital tours, and guidebook with step-by-step instructions on how to transfer to adult care. The study findings also suggest that the

health care providers and transition nurse coordinator of the existing transition program at USA-CSCC incorporate more interactive approaches in addition to the current methods to facilitate the preparedness of the current and future participants of this program for the transfer to adult care. This consideration can be seen as an important step in the refinement and development of new strategies that parallel and meet the learning needs and preferences of the transitioning AYA in order to facilitate a more effective process and improved transition experience.

The results of this study demonstrated that the *TR$_X$ANSITION* Scale used to quantitatively measure the development of disease, medication, and insurance knowledge and acquisition of self-care and self-advocacy skills correlated to the length of time spent in a transition program and transfer to adult care. The results have implications for the usefulness of the *TR$_X$ANSITION* Scale in the PACT program and possibly newly developing programs in order to assess and track progression of the AYA with SCD in preparation for the transfer to adult care in alignment with the six core elements of successful transition (The Center for Health Care Transition Improvement, 2014). From this instrument, the total scores and subscales could be used by health care providers to identify deficits in transition education and preparation in order to develop an individualized plan of action that is age and developmentally appropriate for the AYA (Cohen et al., 2015; Ferris et al., 2015).

Finally, it is speculated that the findings may also have implications for the refinement of other and possibly newly developing transition programs with new strategies for a more effective process and improved transition experience of the AYA within the SCD community.

Future Directions

The findings of this descriptive, observational, cross-sectional study and its innovative mixed methods study design evaluating transition program participation and successful transition in the AYA with SCD could be used to generate hypotheses for future research on transition programs in order to provide a more in-depth understanding of the factors that can influence the process. Specifically, a longitudinal study could evaluate transition program participation from the onset of this process to integration into the adult health care system at a larger sickle cell center or multi-center study for more generalizable findings and statistically powered results on transition programs. Further research could be used to contribute to the current literature and build on the findings of this study regarding transition program participation and factors that may influence adaptation to and coping with this process in order to develop new or model programs. Future studies could also provide additional evidence on the usefulness of Schlossberg's Transition Framework in nursing, adolescent care, and understanding the transition process of the AYA and factors that may influence this complex phenomenon in a growing and at-risk population.

Chapter Summary

In summary, transition from pediatric to adult care is a critical period in the lives and medical management of AYA with SCD. A review of the literature reveals a host of factors that may influence the transition process. This descriptive, observational, cross-sectional concurrent quantitative + qualitative study was deemed by the research team to be the best approach to evaluate the impact of transition program participation on successful transition and factors that may influence adaptation to and coping with the

process. The results indicate that transition program participation can have a positive influence on successful transition and facilitate preparedness for the successful transition through: 1) clarifying the process and providing support; 2) promoting knowledge of SCD, health maintenance, self-management, and financial obligations; 3) encouraging independence and taking responsibility for managing one's own care; and 4) lessening emotional concerns and fears about the transfer to adult care. Primarily, this can be seen within the context of transition program participation of three or more years for transition services, education, planning, and preparation.

These findings support the Schlossberg's Transition Framework's philosophical assumption that transition is a process that occurs over time and can be influenced by taking stock of four potential coping resources: self, situation, support, and strategy. Additionally, findings support previous research and current best-practice guidelines and assumptions regarding transition program participation as a strategy to facilitate successful transition. While the findings demonstrate an association between transition program participation and successful transition, it should be noted that the study evaluated transition program participation of AYA with SCD at one of a limited number of comprehensive sickle cell centers in the United States. The USA-CSCC is a well-established and unique sickle cell center with both adult and pediatric outpatient clinics and a formalized pediatric to adult care transition program coordinated by a highly skilled and experienced multi-disciplinary team of health care providers. However, the findings of this study could be used to refine the current transition program, develop new strategies for a more effective process, and improve the transition experience of this population at the USA-CSCC and possibly other sickle cell centers with similar

formalized programs. Finally, the findings could be used to generate hypotheses for future research at larger sickle cell centers with formalized transition programs.

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APPENDIX A

LETTER OF SUPPORT AND ADMINISTRATIVE APPROVAL

UNIVERSITY OF SOUTH ALABAMA

COMPREHENSIVE SICKLE CELL CENTER

TELEPHONE: (251) 470-5893
2451 FILLINGIM STREET • MCSD 1530
MOBILE, ALABAMA 36617-2293
FAX: (251) 470-5895

June 20, 2016

Marie Bakitas DNSc, NP-C, FAAN
Professor, Marie O'Koren Endowed Chair
University of Alabama Birmingham School of Nursing
1720 2nd Avenue South
Birmingham, Alabama 35294-1210

Dear Dr. Bakitas:

It is my pleasure to support the research activities of the proposed dissertation titled "Successful Transition to Adult Care: Impact of Participation in a Transition Program" being submitted to the University of Alabama Birmingham School of Nursing by Ms. Ardie Pack-Mabien.

Effective transitioning is a challenge for healthy populations. Transitioning clients with a chronic, lifelong illness is often met with additional challenges such as inadequate insurance or no insurance, a lack of health care providers, a weak family structure and poor self-esteem. It is during this anticipated period of transition that the adolescent and young adult with sickle cell disease is at greatest risk for: (a) an increased rate of morbidity and mortality; (b) higher health care cost; (c) higher emergency room utilizations; and (d) recurrent hospital admissions in addition to the many challenges and risk factors which lend to an unsuccessful transition and transfer to the adult health care delivery system.

As director of the University of South Alabama Comprehensive Sickle Cell Center, I fully support the research activities of the proposed dissertation by Ms. Pack-Mabien. Furthermore, findings from such a research study will likely provide insight that facilitates transition readiness and successful transfer of sickle cell clients into the adult health care delivery system here at the University of South Alabama.

Respectfully submitted,

Johnson Hayes, Jr.

July 26, 2016

Marie Bakitas DNSc. NP-C, FAAN
Professor, Marie O'Koren Endowed Chair
University of Alabama Birmingham School of Nursing
1720 2nd Avenue South
Birmingham, Alabama 35294-1210

Dear Dr. Bakitas:

It is my genuine pleasure to write this letter in support of the research activities in the proposed dissertation entitled "Successful Transition to Adult Care: Impact of Participation in a Transition Program" being submitted to the University of Alabama Birmingham School of Nursing by Ms. Ardie Pack-Mabien. I have worked with Ardie for 20 years. As Director of the Pediatric Hematology/Oncology Division at the University of South Alabama (USA), I feel well positioned to understand the challenges of transition in sickle cell patients.

At USA, we have participated in several key trials leading to significant developments correlating with greatly improved patient survival. However, the incidence of some sickle related complications increases as our patients reach adolescence and adulthood. These patients also face many challenges including ineffective management of their condition, uncertainty about their future as independent adults, lack of insight into their disease, and poor communication with health care providers. These challenges underscore the significance of this project in the lifelong medical management of the adolescent and young adult with sickle cell disease. Effective strategies are of paramount importance to address the increased rate of morbidity and mortality, higher health care costs, higher emergency room utilization, and recurrent hospital admissions seen with unsuccessful transition.

As Division Director, I fully support the research activities of the proposed dissertation by Ms. Pack-Mabien. Furthermore, the findings from such a research study of this caliber would provide insight into the development of a successful transition program. This could greatly benefit our patients here at the USA and serve as a model for the community of adolescents and young adults with sickle cell disease at large.

Respectfully submitted,

Felicia L. Wilson, MD
Professor of Pediatrics
Director, Division of Hematology/Oncology
University of South Alabama

UNIVERSITY OF SOUTH ALABAMA

COLLEGE OF MEDICINE
DEPARTMENT OF PEDIATRICS AND
ADOLESCENT MEDICINE
PEDIATRIC HEMATOLOGY/ONCOLOGY

1504 SPRINGHILL AVENUE, ROOM 5230
MOBILE, ALABAMA 36604-3273
APPOINTMENTS: (251) 405-5147 (option 3)
OFFICE: (251) 405-5115
FAX: (251) 405-5120

June 15, 2016

Marie Bakitas DNSc, NP-C, FAAN
Professor, Marie O'Koren Endowed Chair
University of Alabama Birmingham School of Nursing
1720 2nd Avenue South
Birmingham, Alabama 35294-1210

Dr. Bakitas,

It is my pleasure to support the research activities of the proposed dissertation titled "Successful Transition to Adult Care: Impact of Participation in a Transition Program" being submitted to the University of Alabama Birmingham School of Nursing by Ms. Ardie Pack-Mabien.

Transitioning adolescent population to the adult world is challenging in any chronic disease process. It's particularly perplexing in sickle cell population due to myriad issues especially the psychosocial aspect of the disease. As you are well aware, it is during this anticipated period of transition that the adolescent and young adult with sickle cell disease is at risk for: (a) increased rate of morbidity and mortality; (b) higher health care cost; (c) higher emergency room utilizations; and (d) recurrent hospital admissions in addition to the many challenges and risk factors for an unsuccessful transition. Throughout the country there is a need for a reliable and successful transition program for patients with sickle cell disease. Several models have been proposed but none has met the expected success criteria.

As the Medical Director of the division of Pediatric Hematology/Oncology at the University of South Alabama, I fully support the research activities of the proposed dissertation by Ms. Pack-Mabien. The findings from such a research study of this caliber would provide insight into the facilitation of the successful transition in this population and greatly benefit our patients here at the University of South Alabama and the community of adolescents and young adults with sickle cell disease at large.

Sincerely,

Hamayun Iman, MD, MSc
Professor of Pediatrics
Medical Director

UNIVERSITY OF SOUTH ALABAMA

COLLEGE OF MEDICINE
DEPARTMENT OF PEDIATRICS AND
ADOLESCENT MEDICINE
DIVISION OF
PEDIATRIC HEMATOLOGY/ONCOLOGY

1504 SPRINGHILL AVENUE, ROOM 5230
MOBILE, ALABAMA 36604-3273
APPOINTMENTS (251) 434-3685
TELEPHONE: (251) 405-5113
FAX: (251) 405-5120

Marie Bakitas DNSc, NP-C, FAAN
Professor, Marie O'Koren Endowed Chair
University of Alabama Birmingham School of Nursing
1720 2nd Avenue South
Birmingham, Alabama 35294-1210

Dr. Bakitas,

It is my pleasure to support the research activities of the proposed dissertation titled "Successful Transition to Adult Care: Impact of Participation in a Transition Program" being submitted to the University of Alabama Birmingham School of Nursing by Ms. Ardie Pack-Mabien.

The management of patients with sickle cell disease is very complex and tedious. It involves multidisciplinary approach, numerous screening investigations and pain therapy regimens tailored to meet individual patient needs. Successful transition to adult care is pivotal in the lifelong medical management of the adolescent and young adult with sickle cell disease. It is during this anticipated period of transition that the adolescent and young adult with sickle cell disease is at risk for: (a) increased rate of morbidity and mortality; (b) higher health care cost; (c) higher emergency room utilizations; and (d) recurrent hospital admissions in addition to the many challenges and social factors for an unsuccessful transition. The above mentioned project is a unique program designed to facilitate smooth transition and sharing responsibility with the patients without intimidating them. This program is highly appreciated by families and healthcare providers of our community.

As an associate professor of pediatrics at the University of South Alabama-Division of Hematology/Oncology, I fully support the research activities of the proposed dissertation by Ms. Pack-Mabien. Furthermore, the findings from research study of such a caliber would provide insight into the facilitation of the successful transition in this population and greatly benefit our patients here at the University of South Alabama and the community of adolescents and young adults with sickle cell disease at large.

Respectfully submitted, July 20th, 2016

Abdul Hafeez Siddiqui, MD
Associate Professor of Pediatrics

Sickle Cell Disease Association of America—Mobile Chapter, Inc.

July 1, 2016

Marie Bakitas DNSc, NP-C, FAAN
Professor, Marie O'Koren Endowed Chair
University of Alabama Birmingham School of Nursing
1720 2nd Avenue South
Birmingham, Alabama 35294-1210

Dr. Bakitas,

It is my pleasure to support the research activities of the proposed dissertation titled "Successful Transition to Adult Care: Impact of Participation in a Transition Program," being submitted to the University of Alabama at Birmingham School of Nursing by Ms. Ardie Pack-Mabien.

The Sickle Cell Disease Association of America– Mobile Chapter (SCDAA-MC) understands the importance of this research, as we work diligently to prepare our clients for adulthood, by engaging them through afterschool tutorial programs, summer enrichment, and vocational rehabilitation programs. As you are well aware, it is during this anticipated period of transition that the adolescent and young adult with sickle cell disease is at risk for: (a) increased rate of morbidity and mortality; (b) higher health care cost; (c) higher emergency room utilizations; and (d) recurrent hospital admissions in addition to the many challenges and risk factors for an unsuccessful transition.

As the Executive Director of SCDAA-MC, I fully support the research activities of the proposed dissertation by Ms. Pack-Mabien. Furthermore, the findings from such a research study of this caliber would provide insight into the transition experience and transfer of care to the adult health care delivery system in this vulnerable population as well as greatly benefit our the local sickle cell community.

Respectfully submitted,

Keava Boswell Jones

Keava Boswell Jones, Esq.
Executive Director

APPENDIX B

INSTITUTIONAL REVIEW BOARD APPROVAL

THE UNIVERSITY OF ALABAMA AT BIRMINGHAM

Institutional Review Board for Human Use

Form 4: IRB Approval Form
Identification and Certification of Research
Projects Involving Human Subjects

UAB's Institutional Review Boards for Human Use (IRBs) have an approved Federalwide Assurance with the Office for Human Research Protections (OHRP). The Assurance number is FWA00005960 and it expires on November 8, 2021. The UAB IRBs are also in compliance with 21 CFR Parts 50 and 56.

Principal Investigator:	Pack-Mabien, Ardie V
Co-Investigator(s):	LADORES, SIGRID L LANDIER, WENDY RAJU, DHEERAJ A
Protocol Number:	**X161128003**
Protocol Title:	*Successful Transition to Adult Care: Impact of Participation in a Transition Program*

The IRB reviewed and approved the above named project on 12/29/16. The review was conducted in accordance with UAB's Assurance of Compliance approved by the Department of Health and Human Services. This Project will be subject to Annual continuing review as provided in that Assurance.

This project received EXPEDITED review.

IRB Approval Date: 12/29/16

Date IRB Approval Issued: 12/29/16

IRB Approval No Longer Valid On: 12/29/17

F Urthaler MD

Ferdinand Urthaler, M.D.
Chairman of the Institutional Review
Board for Human Use (IRB)

Investigators please note:

The IRB approved consent form used in the study must contain the IRB approval date and expiration date.

IRB approval is given for one year unless otherwise noted. For projects subject to annual review research activities may not continue past the one year anniversary of the IRB approval date.

Any modifications in the study methodology, protocol and/or consent form must be submitted for review and approval to the IRB prior to implementation.

Adverse Events and/or unanticipated risks to subjects or others at UAB or other participating institutions must be reported promptly to the IRB.

THE UNIVERSITY OF ALABAMA AT BIRMINGHAM
Office of the Institutional Review Board for Human Use

470 Administration Building
701 20th Street South
Birmingham, AL 35294-0104
205.934.3789 | Fax 205.934.1301 | irb@uab.edu

APPROVAL LETTER

TO: Pack-Mabien, Ardie V

FROM: University of Alabama at Birmingham Institutional Review Board
Federalwide Assurance # FWA00005960
IORG Registration # IRB00000196 (IRB 01)
IORG Registration # IRB00000726 (IRB 02)

DATE: 27-Dec-2017

RE: IRB-161128003
Successful Transition to Adult Care: Impact of Participation in a Transition Program

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The IRB reviewed and approved the Continuing Review submitted on 09-Nov-2017 for the above referenced project. The review was conducted in accordance with UAB's Assurance of Compliance approved by the Department of Health and Human Services.

Type of Review: Expedited (Category 7)
Determination: Approved
Approval Date: 27-Dec-2017
Approval Period: One Year
Expiration Date: 26-Dec-2018

Item 10b checked yes however the two amendments approved by the UAB IRB wasn't submitted with your renewal packet.

In the future please be mindful to submit all required documentation, thank you.

Documents Included in Review:

- ipr.171109
- protocol.USA.171109

irb@southalabama.edu

UNIVERSITY OF SOUTH ALABAMA

TELEPHONE: (251) 460-6308
CSAB 138 · MOBILE, AL. 36688-0002

INSTITUTIONAL REVIEW BOARD
February 2, 2017

Principal Investigator:	Ardie Pack-Mabien, MSN, FNP-BC, PhD student		
IRB # and Title:	IRB PROTOCOL: 17-015 [996238-1] Successful Transition to Adult Care:Impact of Participation in a Transition Program		
Status:	APPROVED	Review Type:	Expedited Review
Approval Date:	February 1, 2017	Submission Type:	New Project
Initial Approval:	February 1, 2017	Expiration Date:	January 31, 2018
Review Category:	Category: 45 CFR 46.110 (7): Research on individual or group characteristics or behavior		
DHHS/FDA Subpart D:	45 CFR 46.404: FDA 50.51 - Research not involving greater than MINIMAL RISK to children		

This panel, operating under the authority of the DHHS Office for Human Research and Protection, assurance number FWA 00001602, and IRB Database #00000286, has reviewed the submitted materials for the following:

1. *Protection of the rights and the welfare of human subjects involved.*
2. *The methods used to secure and the appropriateness of informed consent.*
3. *The risk and potential benefits to the subject.*

The regulations require that the investigator not initiate any changes in the research without prior IRB approval, except where necessary to eliminate immediate hazards to the human subjects, and that **all problems involving risks and adverse events be reported to the IRB immediately!**

Subsequent supporting documents that have been approved will be stamped with an IRB approval and expiration date (if applicable) on every page. Copies of the supporting documents must be utilized with the current IRB approval stamp unless consent has been waived.

Notes:

irb@southalabama.edu

UNIVERSITY OF SOUTH ALABAMA

TELEPHONE: (251) 460-6308
CSAB 138 · MOBILE, AL. 36688-0002

INSTITUTIONAL REVIEW BOARD
April 6, 2017

Principal Investigator:	Ardie Pack-Mabien, MSN, FNP-BC, PhD student
IRB Number and Title:	IRB PROTOCOL: 17-015 [996238-2] Successful Transition to Adult Care:Impact of Participation in a Transition Program
Event:	Amendment/Modification
Date of Review:	April 6, 2017

The Institutional Review Board has received your report concerning the following event:

Acknowledment has been made for the addition of Natalie Williams as key personnel and she has completed NIH Protecting Human Research Participants and HIPAA for research trainnig.

irb@southalabama.edu

UNIVERSITY OF SOUTH ALABAMA

TELEPHONE: (251) 460-6308
CSAB 138 · MOBILE, AL. 36688-0002

INSTITUTIONAL REVIEW BOARD
June 30, 2017

Principal Investigator:	Ardie Pack-Mabien, MSN, FNP-BC, PhD student
IRB Number and Title:	IRB PROTOCOL: 17-015 [996238-3] Successful Transition to Adult Care:Impact of Participation in a Transition Program
Date of Review:	June 30, 2017

Acknowledgment is made for the additional method of data collection to include face to face interviews

irb@southalabama.edu

UNIVERSITY OF
SOUTH ALABAMA

TELEPHONE: (251) 460-6308
CSAB 138 · MOBILE, AL. 36688-0002

INSTITUTIONAL REVIEW BOARD
January 24, 2018

Principal Investigator:	Ardie Pack-Mabien, MSN, FNP-BC, PhD student		
IRB # and Title:	IRB PROTOCOL: 17-015 [996238-4] Successful Transition to Adult Care:Impact of Participation in a Transition Program		
Status:	APPROVED	Review Type:	Expedited Review
Approval Date:	January 4, 2018	Submission Type:	Continuing Review
Initial Approval:	February 1, 2017	Expiration Date:	January 31, 2019
Review Category:	Category: 45 CFR 46.110 (7): Research on individual or group characteristics or behavior		
DHHS/FDA Subpart D:	45 CFR 46.404: FDA 50.51 - Research not involving greater than MINIMAL RISK to children		

This panel, operating under the authority of the DHHS Office for Human Research and Protection, assurance number FWA 00001602, and IRB Database #00000286, has reviewed the submitted materials for the following:

1. *Protection of the rights and the welfare of human subjects involved.*
2. *The methods used to secure and the appropriateness of informed consent.*
3. *The risk and potential benefits to the subject.*

The regulations require that the investigator not initiate any changes in the research without prior IRB approval, except where necessary to eliminate immediate hazards to the human subjects, and that **all problems involving risks and adverse events be reported to the IRB immediately!**

Subsequent supporting documents that have been approved will be stamped with an IRB approval and expiration date (if applicable) on every page. Copies of the supporting documents must be utilized with the current IRB approval stamp unless consent has been waived.

Notes:

Expedited review and approval for the continuation of research granted for one additional year to retain the anniversary of the expiration date of the initial IRB approval; remaining activities are limited to data analysis only

APPENDIX C

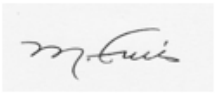
LETTER OF PERMISSION FOR SURVEY INSTRUMENTS

November 8, 2016

To Whom It May Concern:

PhD Student at University of Alabama at Birmingham, School of Nursing, Ms. Ardie Pack-Mabien, RNC, MSN, FNP-BC has permission to use the Scoring Guide for the TRxANSITION Scale for her dissertation. Please contact me if you have any questions or concerns.

Sincerely,



Maria E. Ferris, MD, MPH, PhD
Associate Professor and Director, Pediatric Renal Transplant and Healthcare Transition Programs
University of North Carolina at Chapel Hill

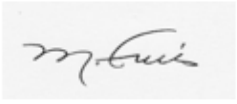
UNC KIDNEY CENTER

June 17, 2016

To Whom It May Concern:

Ms. Ardie Pack-Mabien has permission to use the STARx Transition Readiness Questionnaire, The TRxANSITION Scale™, and the Nephrology Medical Passport™ for her dissertation. Please contact me if you have any questions or concerns.

Sincerely



Maria E. Ferris, MD, MPH, PhD
Associate Professor and Director, Pediatric Renal Transplant and Healthcare Transition Programs
University of North Carolina at Chapel Hill

THE UNIVERSITY of TENNESSEE HEALTH SCIENCE CENTER

COLLEGE of NURSING

920 Madison Avenue
Memphis, TN 38163
Phone: (901) 448-6128
Fax: (901) 448-4121

November 1, 2016

Ardie Pack-Mabien, RNC, MSN, FNP-BC
5720 Fifth Street
Satsuma, Alabama 36572

Dear Ardie:

I am writing in response to your request to use and modify Interview Guides, Demographic forms, and Participant Views questionnaires which were administered to participants in the "Exploring Family Communication about Sickle Cell Disease" study. As principal investigator of this study, I worked with Dr. Jerlym Porter and Dr. Jane Hankins to develop these measures to collect data from adolescents with sickle cell disease, their parents, and siblings. You may also use the protocol we followed to prepare for and facilitate the data collection process. You have my permission to use and modify the questions in the Interview Guide, Demographic forms, Parent Views questionnaires, and protocol as appropriate for your study. I understand that you will be mentored and supervised by Dr. Marie Bakitas, faculty member at the University of Alabama Birmingham School of Nursing, during your dissertation research.

Best wishes to you as you pursue your current study and your future research in this area.

Sincerely,

J. Carolyn Graff

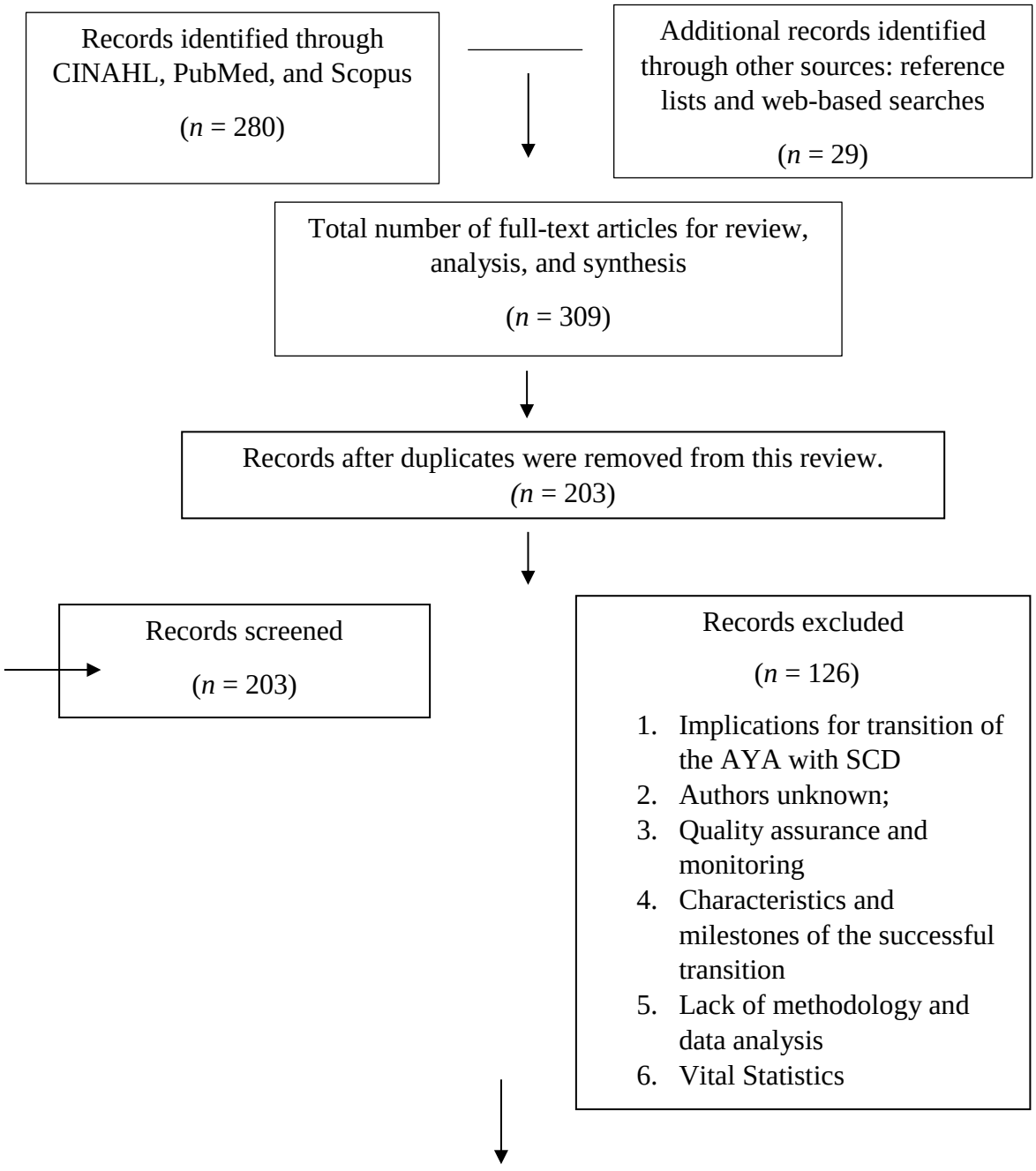
J. Carolyn Graff, Ph.D., RN
Professor, College of Nursing
Chief of Nursing, Boling Center for Developmental Disabilities
Director, Ph.D. Program in Nursing Science
jgraff@uthsc.edu
901.448.6544 (office)

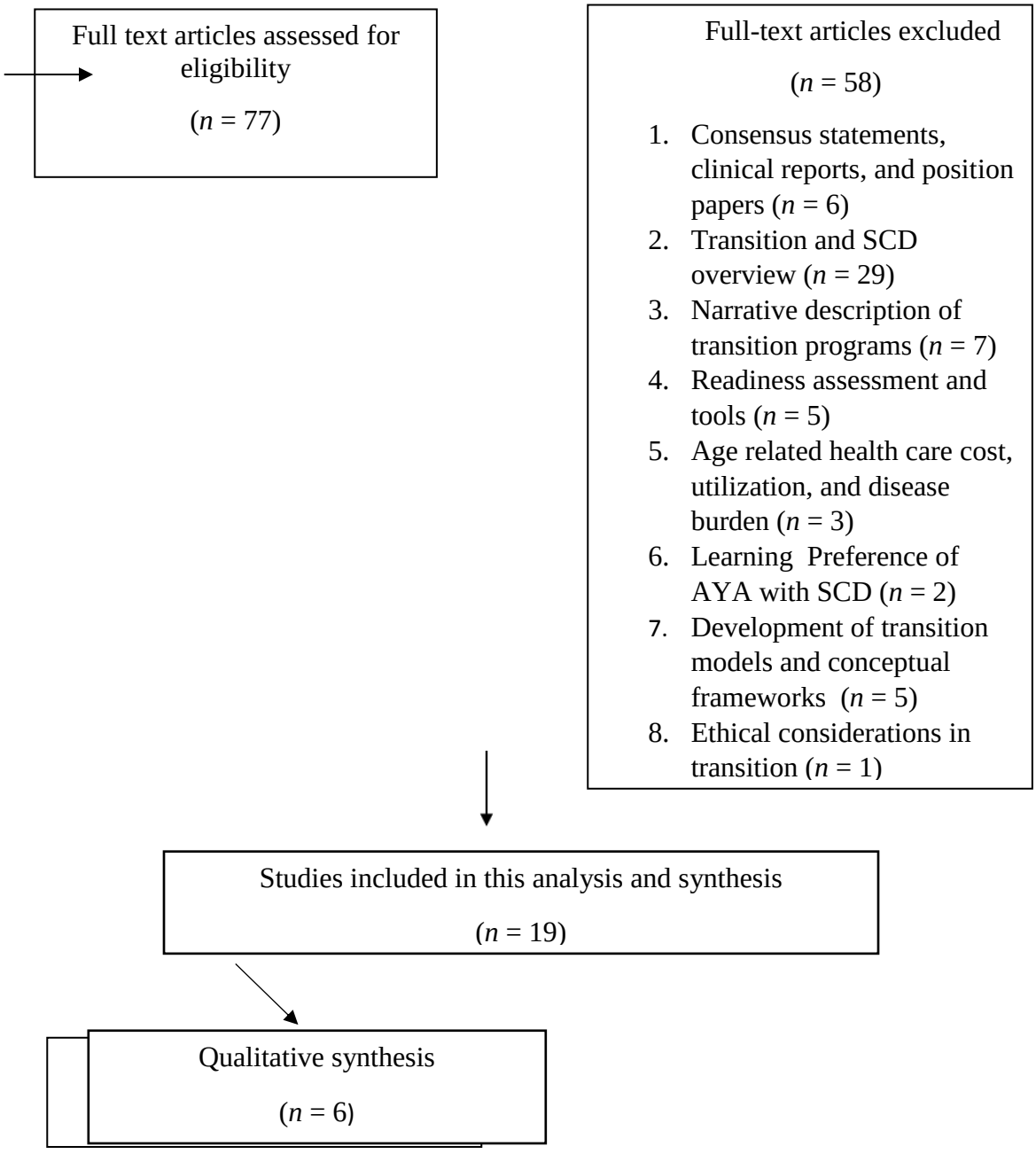
APPENDIX D

LITERATURE REVIEW FLOW DIAGRAM OF THE COMPLETE SEARCH AND SELECTION PROCESS (PRISMA)

Figure 6

Literature Review Flow Diagram of the Complete Search and Selection Process (PRISMA)





Note. Screening process of the full-text articles selection for eligibility, analysis, and synthesis of the literature on the transition of adolescent and young adults with sickle cell disease. Adapted from Zhou, Roberts, Dhaliwal, and Della (2016). Transitioning adolescents and young adults with chronic disease and/or disabilities from pediatric to adult care services-an integrative review.
n = number of full-text articles.

APPENDIX E

RECRUITMENT ANNOUNCEMENT AND FLYER

Teenagers and Young Adults with Sickle Cell Disease!!!!
Your help is needed to learn more about the transition from pediatrics to adult care

What is the purpose of this research study?
The purpose of this study is to learn more about the participation in a transition program on the successful transition from pediatric doctors to adult care doctors. The study is being conducted by Ardie Pack-Mabien, a doctoral student at the University of Alabama at Birmingham, School of Nursing.

Who can voluntarily participate?
You can voluntarily participate in this research study if:

- You are or your child is a teenager or young adult between the ages of 13 to 21 years with sickle cell disease
- You are or your child is a current or recently transitioned to adult care participant of the PACT program.
- You or your child can read and understand the English language.

Where Will the Study Take Place?
The study will take place in Mobile Alabama at:

- The University of South Alabama Comprehensive Sickle Cell Pediatric and Adult Sickle Cell Outpatient Clinics.
- The Sickle Cell Disease Association of America-Mobile Chapter.

What Will Happen If You Decide to Participate?
You will be asked to:

1. Answer questions about yourself and the participation in a PACT program.
2. Participate in a group discussion on the movement from your current doctor to an adult care doctor.
3. Give your thoughts on the results of this study to the researcher.

What are the benefits of taking part in this study?

- There may be no direct benefits for taking part in this study.
- Study participants will receive a $20 Visa gift card and parent(s) or caregiver will receive a Visa $15 gift card in appreciation for distance travel and time. Only parents of non-driving teens who provide transportation to and from the focus group discussion will be compensated.

For more information or to take part in this research study, please contact Ardie Pack-Mabien at (251) 470-5889 or (251) 582-4248 (numerical beeper).

Attention: Focus Group Discussion Time Has Arrived

It's time to tell your story and give your opinion on the transition from pediatrics to adult care and participation in the Pediatric to Adult Care Transition Program

You will receive a **$20.00** pre-paid Visa gift card and your parent will receive a **$15.00** pre-paid Visa gift card for your time and travel.

Where: Sickle Cell Disease Association of America-Mobile Chapter at 1453 Springhill Ave across the street from the old pediatric sickle cell clinic and Subway.

Time: 3:00pm -**You must be on time!!**

Day: Wednesday, April 12th, 2017

See you there,

Ardie Pack-Mabien, CRNP, PhD candidate

University of Alabama at Birmingham

Attention: Focus Group Discussion Time Has Arrived

It's time to tell your story and give your opinion on the transition from pediatrics to adult care and participation in the Pediatric to Adult Care Transition Program

You will receive a **$20.00** pre-paid Visa gift card and your parent will receive a **$15.00** pre-paid Visa gift card for your time and travel.

Where: Sickle Cell Disease Association of America-Mobile Chapter at 1453 Springhill Ave across the street from the old pediatric sickle cell clinic and Subway.

Time: 3:00pm -**You must be on time!!**

Day: Thursday, April 13th, 2017

See you there,

Ardie Pack-Mabien, CRNP, PhD candidate

University of Alabama at Birmingham

Sickle Cell Today

USA Comprehensive Sickle Cell Center

Volume 14 Issue 1 April 2017

TABLE OF CONTENTS

USA Comprehensive Sickle Cell Center
Main Office (251) 470-5893
Fax (251) 470-5895
Clinical Research (251) 471-7703
Pediatric Clinic (251) 405-5147
Adult Clinic (251) 470-5890
Community-based

Sickle Cell Disease: Sleep Quality and Pain

William A. Broughton, MD, Professor of Medicine
Division of Pulmonary/Critical Care and Sleep Medicine, University of South Alabama

Disturbance of sleep is common in sickle cell disease (SCD). One study suggests that 33% of those afflicted with SCD experience recurrent or chronic pain. Most SCD patients (87%) also report not sleeping well. There is a well studied relationship between poor sleep and the degree to which pain is experienced in many conditions. What is clear is that pain always disrupts sleep. What is unclear in SCD is whether disrupted sleep makes the pain experience worse.

If we think that poor quality sleep might be associated with a worse pain experience and we know that sleep disruption worsens SCD sufferer's self efficiency (a person's belief that they can cope with life's challenges), it seems reasonable to do all one can to optimize sleep quality. What can you do? First, you should consider specific medical disorders.

- *Sleep apnea syndrome* is common and is easily diagnosed. If you snore loudly, wake up gasping and choking, or others report that you stop breathing during sleep you should see a sleep specialist to see if special testing is needed.
- *Restless legs syndrome (RLS)* is a feeling of discomfort in the legs that legs. The discomfort usually resolves after sleep onset and is always gone in the morning. There is no test for RLS. There are specific medicines that will relieve it. Ask your doctor.

Second, there are several things you can do on your own to improve your sleep quality. The following interventions require only some thoughtfulness and minor life style modifications.

- Use caffeine intelligently. Caffeine lasts about 6 hours in your system. Studies show that caffeine use before bed makes it harder to fall asleep and will make you get up to urinate more frequently at night. You should avoid caffeine-containing drinks for at least 6 hours before sleep and perhaps consider avoiding it altogether.
- If you take "fluid pills" diuretics, do your best not to take them right before bed. Usually the effects of these drugs last for about 6 hours. Try to take your last dose in the mid-afternoon at the latest.
- Keep a regular sleep wake schedule - plan your sleep onset and wake time near the same times every day. Your

not have sickle cell disease. She has sickle cell trait and will likely never have any problems. Most importantly is to let her know that she has sickle cell trait and if her future spouse does not have the trait, there is a 50% chance with each of her pregnancies, her children will also have sickle cell trait. Of even greater concern is that if she marries someone with the trait there is a 50% chance that with each pregnancy, the child will have sickle cell disease. The question that plagued Isabella the most was the most difficult to ask, "How long will I live?" Dr. Hernandez explained that sickle beta plus thalassemia tends to be the mildest form of sickle cell disease and that survival, as best we know, closely parallels that of the general population. This provided some relief to Isabella. Dr. Hernandez thought for one visit, they were off to a good start regarding the young couples understanding of what sickle cell trait and disease entails. He further assured them he would be there for them and to approach their bright futures with an open mind. He went on to tell Isabella there are some routine tests he likes to monitor annually in all of his sickle cell patients and that if there is anything ever of concern he would notify her and bring her back in. Other than this, he would like to see her in follow up every six months for now. As the young couple left they felt somewhat better but still less certain about their futures, whether or not they would have more children, and would they stay in Castle Rock. For now they took peace in what they had, family, and decided they would do whatever was required to make sure their family was healthy and happy.

Fact: In Alabama mandatory newborn screening for sickle cell, independent of racial designation, was implemented in 1988. Since 1988, 5.8% of all babies born in Alabama, racial designated as white, test positive for sickle cell trait.

Teenagers and Young Adults with Sickle Cell Disease

Your help is needed to learn more about the transition from pediatrics to adult care!!

Ardie Pack-Mabien, CRNP
University of South Alabama Comprehensive Sickle Cell Center

What is the purpose of this research study?
The purpose of this study is to learn more about the impact of participation in a transition program on the successful transition from pediatric doctors to adult care doctors. The study is being conducted by Ardie Pack-Mabien, a doctoral student at the University of Alabama at Birmingham, School of Nursing.

Note: Participation in this study is voluntary.

Who can voluntarily participate?

You can participate in this research study if:
- You are or your child is a teenager or young adult between the ages of 13 to 21 years with sickle cell disease;
- You are or your child is a current participant in the PACT program or has recently transitioned to adult care;
- You or your child can read and understand the English language.

Where will the study take place?

The study will take place in Mobile Alabama at:
- The Pediatric and Adult Sickle Cell Outpatient Clinics;

What will happen if you decide to participate?

You will be asked to:
- Answer questions about yourself and the participation in the transition program;
- Participate in a group discussion on the movement from your current doctor to an adult care doctor;
- Give your thoughts on the results of this study to the researcher.

What are the benefits of taking part in this study?

- There may be no direct benefits for taking part in this study;
- Study participants will receive a $20 Visa gift card and parent(s) or caregiver will receive a Visa $15 gift card in appreciation for distance travel and time. Only parents of non-driving teens who provide transportation to and from the focus group discussion will be compensated.

For more information or to take part in this research study, please contact Ardie Pack-Mabien at (251) 470-5889 or (251) 582-4248 (numerical beeper).

APPENDIX F

INFORMED CONSENTS AND SCRIPTS

ASSENT FORM

TITLE OF RESEARCH: Successful transition to adult care: Impact of participation in a transition program

INVESTIGATOR: Ardie Pack-Mabien, MSN, CRNP, PhD Student, University of Alabama at Birmingham
Marie Bakitas, DNSc, NP-C, FAAN, Professor, Marie O'Koren Endowed Chair, University of Alabama at Birmingham

SPONSOR: University of Alabama at Birmingham, School of Nursing
University of South Alabama Comprehensive Sickle Cell Center

The investigators named above are doing a research study.

These are some things we want you to know about research studies:
We are asking you to be in a research study. Research is a way to test new ideas. Research helps us learn new things.

Whether or not to be in this research is your choice. You can say Yes or No. Whatever you decide is OK. You will still receive good care from your doctors.

Why am I being asked to be in this research study?
You are being asked to be in the study because you have sickle cell disease and currently participate in the Pediatric to Adult Care Transition (PACT) program.

What is the study about?
The researchers need to learn more about the move from the childhood doctors and nurses to the adult doctors, nurses, and hospitals. For example, the researchers will look at what you know about sickle cell disease and the skills needed to make an appointment with your doctors and take care of yourself.

What will happen during this study?
If you agree to be in this study, you will

- Have to answer questions during your regular clinic visit at the pediatric sickle cell clinic about what you know about sickle cell disease and movement from your current childhood sickle cell doctors and nurses to adult doctors and nurses at the pediatric sickle cell clinic.
- Take part in a focus group (discussion) at the Sickle Cell Disease Association.
- Get a $20.00 Visa pre-paid gift card at the end of the group discussion.
- Give your ideas, thoughts, or suggestions on the results of the study.

You will receive a reminder in the mail and by telephone about the group discussion two weeks before and 24 hours before the focus group. In addition, you will receive the results of the study in the mail to make comments on and return by mail in a self-addressed and stamped envelope.

Will the study hurt?
No. There will be no need to test your blood or perform any procedures.

What else should I know about the study?
If you feel sick or afraid that something is wrong with you, tell an adult at once. You do not have to answer any questions that are asked of you.

What are the good things that might happen?
People may have good things happen to them because they are in a research study. These are called "benefits." The researchers hope to learn about the best way to help children with sickle cell disease know about their disease and prepare for the move to an adult doctor for medical care. The researchers might find out something that will help other children like you to make the move to adult care better.

What if I don't want to be in this study?
You do not have to be in the study if you do not want to. Your doctors and nurses will still take care of your sickle cell disease. If you don't want to be in this study, you can continue to get your medical care at the University of South Alabama Comprehensive Sickle Cell Center Pediatric Sickle Cell Clinic.

Who should I ask if I have any questions?
If you have any questions about this study, you or your parents can call the principal researcher, Ardie Pack-Mabien, Nurse Practitioner at (251) 470-5889 or (251) 470-5893.

Do I have to be in the study?
No, you do not have to be in the study. Even if you say yes now, you can change your mind later. It is up to you. No one will be mad at you if you don't want to do this.

Signatures
Before deciding if you want to be in the study, ask any questions you have. You can also ask questions during the time you are in the study.

If you sign your name below, it means that you agree to take part in this research study.

Your Name (Printed)	Age
Your Signature	Date
Signature of Person Obtaining Consent	Date

CONSENT FORM
Age 14 and 17 years

TITLE OF RESEARCH:	Successful transition to adult care: Impact of participation in a transition program
INVESTIGATOR:	Ardie Pack-Mabien, MSN, CRNP, PhD Student, University of Alabama at Birmingham Marie Bakitas, DNSc, NP-C, FAAN, Professor, Marie O'Koren Endowed Chair, University of Alabama at Birmingham
SPONSOR:	University of Alabama at Birmingham, School of Nursing University of South Alabama, Comprehensive Sickle Cell Center

Purpose of the Research

We are asking you and your child to take part in a research study. We are asking your child to take part in this study because your child is an adolescent or a young adult diagnosed with sickle cell disease and is currently a participant of the Pediatric to Adult Care Transition (PACT) program. This study is for adolescents age 13 to 17 and young adults 18 to 21 years who have sickle cell disease and are current participants of the PACT Program. This research study will help us to learn more about the impact of participation in the PACT program on the successful transition from the childhood doctor to an adult care doctor. We are also trying to learn more about the factors that may affect the movement from the childhood doctors to adult care. This study will involves approximately 62 adolescents and young adults with sickle cell disease at the University of South Alabama Comprehensive Sickle Cell Center located in Mobile, Alabama.

Explanation of Procedures

You will be asked to complete a study demographic form. Your child will be asked to complete a study demographic form, two brief questionnaires during your routine scheduled appointment at the pediatric sickle cell clinic, and participate in a focus group (discussion) about the participation in the Pediatric to Adult Care Transition Program. The focus group will take place at the Sickle Cell Disease Association of America-Mobile Chapter. The focus group will last for approximately 60-90 minutes and will be audiotaped. If your child cannot attend the focus group, you and your child will be contacted by telephone and by mail to participate in an one-on-one telephone interview that will be audiotaped. Your child will also receive a brief written description of the results from the focus group to read, agree or disagree with, and provide extra information. A self-addressed stamp envelope will be sent in the mail with an enclosed short written description of the results of the focus group.

Risks and Discomforts

There are no physical risks or discomforts for participating in this study. Although not likely, some children and teenagers may not feel at ease answering questions about their feelings, concerns, and experience. The questions asked during the focus group discussion will be directed at the group as a whole and no child will be single-out to answer a question.

Benefits

You and your child may not benefit directly from taking part in this study. However, the results of this study may help us to better understand the transition process and factors that may affect the successful transition to an adult care doctor to make changes to the current PACT program, develop new ideas to make the transition process easier, and improve the transition experience of adolescences and young adults with sickle cell disease.

Alternatives

The alternative is for your child to not participate in this study.

Confidentiality

Information obtained about you and your child for this study will be kept confidential to the fullest extend allowed by law. However, research information that identifies you and your child may be shared with the Institutional Review Boards at the University of Alabama at Birmingham and University of South Alabama who are responsible for ensuring compliance with laws and regulations related to research. The information obtained from this research study may be published for scientific purposes; however, your child's identity will not be given out.

AUTHORIZATION TO USE AND DISCLOSE INDIVIDUALLY IDENTIFIABLE HEALTH INFORMATION FOR RESEARCH PURPOSES

Purpose
Federal privacy laws protect the use and release of your identifiable health information, which is called protected health information (PHI). Under these laws, your protected health information cannot be used or disclosed to the research team for this research study unless you give your permission. Study records that identify you will be kept confidential as required by law.

What protected health information will be used or disclosed?
The information that will be used and/or disclosed for this research study includes:

- Name
- Diagnosis
- Date of birth
- Age
- Gender
- Telephone number
- Mailing Address
- Zip Code
- Medical records to confirm medical history, timing in the PACT program

The results of this research study might be published in medical papers but no information that identifies you as an individual will be published.

Who will use my protected health information and to whom will it be disclosed?
In addition to the study principal investigator and the research staff, the following individuals may have access to identifiable information related to your participation in this research study:

- The University of South Alabama Health System to include the University of South Alabama Comprehensive Sickle Cell Center Adult and Pediatric Sickle Cell Outpatient Clinic.
- The University of South Alabama Research Compliance and Assurance Office may review your protected health information for the purpose of monitoring the appropriate conduct of this research study

- The University of South Alabama Institutional Review Board may review your protected health information as part of its responsibility to protect the rights and welfare of research subjects.
- The University of Alabama at Birmingham (UAB), School of Nursing and Institutional Review Board.

Right to refuse authorization for collection of protected health information
If you decline to provide this authorization, you will not be able to participate in the research study. However, your decision to deny authorization will not affect your future medical care.

Does my authorization expire?
This authorization does not have an expiration date.

Right to withdraw permission to use protected health information
At any time, you may cancel this authorization in writing by contacting the principal investigator listed on the first page of the consent form. If you withdraw permission, you will be removed from the study. However, information gathered before the cancellation date may be used if necessary in completing the research study or any follow-up for this study.

Potential for re-disclosure
Your protected health information will not be used or disclosed to any other person or entity, except as required by law. Your PHI may also be disclosed for authorized oversight of this research study by other regulatory agencies or for other research for which use of your PHI has been approved by the Institutional Review Board. Please be aware that once protected health information is disclosed, it may no longer be protected and may be shared without your permission. However, the research team and the University's Institutional Review Board (a panel of doctors, scientists and community advocates who have the job of making sure the rights and welfare of study participants are protected) are careful to protect your privacy and limit the disclosure of identifying information about you.

Data Security
- Information about your participation in this study is stored in a computer; we will take the following precautions to protect it from unauthorized disclosure, tampering or damage: All questionnaires will be labeled with a code number. Identifiers such as name will be kept in a locked cabinet separate from study data, accessible only to principal investigator and key members of this study.
- The study data will kept on a password protected, encrypted computer drive and locked in a cabinet that will be accessible only to the principal investigator of this study.
- There is a limit to the confidentiality that can be guaranteed due to the technology itself.

Voluntary Participation and Withdrawal

Whether or not you and your child take part in this study is your choice. There will be no penalty if you decide not to allow your child to be in the study. If you decide not to allow your child to be in the study, your child will not lose any benefits you and your child are otherwise owed. You are free to withdraw your child from this research study at any time. Your choice to leave the study will not affect you and your child's relationship with this institution or the University of South Alabama Comprehensive Sickle Cell Center. If you would like to stop your child's participation in this study, please contact the principal investigator, Ardie Pack-Mabien at 251 470-5889 or 470-5893.

Cost of Participation

There will be no cost to you for taking part in this study. You are still responsible for costs associated with your normal clinic appointments, such as medical co-pays.

Payment for Participation in Research

You will receive a $15 Visa pre-paid gift card if you provide a ride for your child to and from the focus group. Your child will receive a $20 Visa pre-paid gift card. You and your child will receive the Visa pre-paid gift card at the completion of the focus group to compensate you and your child for time and travel to the Sickle Cell Disease Association of America-Mobile Chapter for the participation in the focus group. The Visa pre-paid gift card will be provided one-time only. No additional compensation will be provided to you and your child. Only one parent will be compensated for providing transportation to the focus group.

Question

If you have any questions, concerns, or complaints about the research, you may contact Ardie Pack-Mabien. She will be glad to answer any of your questions. Ms. Pack-Mabien may be contacted at (251) 470-5889, 470-5893, or amabien@health.southalabama.edu.

If you have questions about your rights as a participant in this study, please contact the University of South Alabama Institutional Review Board (IRB) at (251) 460-6308 during regular business hours. The regular business hours are 8:00 a.m. to 5:00 p.m. CT, Monday through Friday. The IRB is a group of physicians and community advocates who make sure a research study is ethical and that the rights of the subjects are protected.

Legal Rights

You are not waiving any of your legal rights by signing this informed consent document.

Signatures

You are making a decision whether or not to have your child participate in this study. Your signature indicates that you have read or have been read to you and understand the purpose, procedures of this research, and the information provided above and decided to allow your child to participate.

You have had an opportunity to ask questions which have been answered to your satisfaction.

You voluntary agree to allow your child to participate in this research as described.

You acknowledge receiving and reading the Medical Subject's Bill of Rights.

You will receive a copy of this signed consent form.

Signature of Participant 14-17 Years of Age Date

Signature of Parent or Guardian Date

Signature of Person Obtaining Consent Date

CONSENT FORM
18 years old and older

TITLE OF RESEARCH:	Successful transition to adult care: Impact of participation in a transition program
INVESTIGATOR:	Ardie Pack-Mabien, MSN, CRNP, PhD Student, University of Alabama at Birmingham Marie Bakitas, DNSc, NP-C, FAAN, Professor, Marie O'Koren Endowed Chair, University of Alabama at Birmingham
SPONSOR:	University of Alabama at Birmingham, School of Nursing University of South Alabama Comprehensive Sickle Cell Center

Purpose of the Research

We are asking you to take part in a research study. We are asking you to take part in this study because you are a young adult diagnosed with sickle cell disease and are currently or recently transitioned participant of the Pediatric to Adult Care Transition (PACT) program. This study is for adolescents age 14 to 17 and young adults 18 to 21 years who have sickle cell disease and are current or recently transitioned to adult care participants of the PACT Program. This research study will help us to learn more about the impact of participation in the PACT program on the successful transition from the childhood doctor to adult care doctor. We are also trying to learn more about the factors that may affect the movement from the childhood doctor to adult care. This study will involves approximately 62 adolescents and young adults with sickle cell disease at the University of South Alabama Comprehensive Sickle Cell Center located in Mobile, Alabama.

Explanation of Procedures

You will be asked to complete a study demographic form and two brief questionnaires during your routine scheduled clinic appointment at the pediatric or adult clinic and participate in a focus group (discussion) about the impact of participation in the PACT program. The focus group will take place at the Sickle Cell Disease Association of America-Mobile Chapter. The focus group discussions will last for approximately 60-90 minutes and will be audiotaped. If you cannot attend the focus group discussion, you will be contacted by telephone and or mail for a one-on-one telephone interview that will be audiotaped. You will also receive a brief written description of the results from the focus group to read, agree or disagree with, and provide extra information. A self-addressed stamp envelope will be sent in the mail with an enclosed short written description of the results of the focus group.

Risks and Discomforts

There are no physical risks or discomforts for participating in this study. Although not likely, some young adults may not feel at ease answering questions about their feelings, concerns, and experience. The questions asked during the focus group will be directed toward the group as a whole and you will not be single-out to answer a question.

Benefits

You may not benefit directly from taking part in this study. However, the results of this study may help us to better understand the transition process and factors that may affect the successful transition to adult care doctor to make changes to the current PACT program, develop new strategies to make the transition process easier, and improve the transition experience of adolescents and young adults with sickle cell disease.

Alternatives

The alternative is for you to not participate in this study.

Confidentiality

Information obtained about you for this study will be kept confidential to the fullest extend allowed by law. However, research information that identifies you may be shared with the Institutional Review Boards at the University of Alabama at Birmingham and University of South Alabama who are responsible for ensuring compliance with laws and regulations related to research. The information obtained from this research study may be published for scientific purposes; however, your identity will not be given out.

AUTHORIZATION TO USE AND DISCLOSE INDIVIDUALLY IDENTIFIABLE HEALTH INFORMATION FOR RESEARCH PURPOSES

Purpose
Federal privacy laws protect the use and release of your identifiable health information, which is called protected health information (PHI). Under these laws, your protected health information cannot be used or disclosed to the research team for this research study unless you give your permission. Study records that identify you will be kept confidential as required by law.

What protected health information will be used or disclosed?
The information that will be used and/or disclosed for this research study includes:

- Name
- Diagnosis
- Date of birth
- Age
- Gender
- Telephone number
- Mailing Address
- Zip Code
- Medical records to confirm medical history, timing in the PACT program

The results of this research study might be published in medical papers but no information that identifies you as an individual will be published.

Who will use my protected health information and to whom will it be disclosed?
In addition to the study principal investigator and the research staff, the following individuals may have access to identifiable information related to your participation in this research study:

- The University of South Alabama Health System to include the University of South Alabama Comprehensive Sickle Cell Center Adult and Pediatric Sickle Cell Outpatient Clinic.
- The University of South Alabama Research Compliance and Assurance Office may review your protected health information for the purpose of monitoring the appropriate conduct of this research study

- The University of South Alabama Institutional Review Board may review your protected health information as part of its responsibility to protect the rights and welfare of research subjects.
- The University of Alabama at Birmingham (UAB), School of Nursing and Institutional Review Board.

Right to refuse authorization for collection of protected health information
If you decline to provide this authorization, you will not be able to participate in the research study. However, your decision to deny authorization will not affect your future medical care.

Does my authorization expire?
This authorization does not have an expiration date.

Right to withdraw permission to use protected health information
At any time, you may cancel this authorization in writing by contacting the principal investigator listed on the first page of the consent form. If you withdraw permission, you will be removed from the study. However, information gathered before the cancellation date may be used if necessary in completing the research study or any follow-up for this study.

Potential for re-disclosure
Your protected health information will not be used or disclosed to any other person or entity, except as required by law. Your PHI may also be disclosed for authorized oversight of this research study by other regulatory agencies or for other research for which use of your PHI has been approved by the Institutional Review Board. Please be aware that once protected health information is disclosed, it may no longer be protected and may be shared without your permission. However, the research team and the University's Institutional Review Board (a panel of doctors, scientists and community advocates who have the job of making sure the rights and welfare of study participants are protected) are careful to protect your privacy and limit the disclosure of identifying information about you.

Data Security
- Information about your participation in this study is stored in a computer; we will take the following precautions to protect it from unauthorized disclosure, tampering or damage: All questionnaires will be labeled with a code number. Identifiers such as name will be kept in a locked cabinet separate from study data, accessible only to principal investigator and key members of this study.
- The study data will kept on a password protected, encrypted computer drive and locked in a cabinet that will be accessible only to the principal investigator of this study.
- There is a limit to the confidentiality that can be guaranteed due to the technology itself.

Voluntary Participation and Withdrawal

Whether or not you take part in this study is your choice. There will be no penalty if you decide not to be in the study. If you decide not to be in the study, you will not lose any benefits otherwise owed. You are free to withdraw from this research study at any time. Your choice to leave the study will not affect your relationship with this institution or the University of South Alabama Comprehensive Sickle Cell Center. If you would like to stop your participation in this study, please contact the principal investigator, Ardie Pack-Mabien at 251 470-5889 or 470-5893.

Cost of Participation

There will be no cost to you for taking part in this study. You are still responsible for costs associated with your normal clinic appointments, such as medical co-pays.

Payment for Participation in Research

You will receive a $20 Visa pre-paid gift card at the completion of the focus group to compensate you for your time and travel to the Sickle Cell Disease Association of America-Mobile Chapter for the participation in the focus group. The Visa pre-paid gift card will be provided one-time only. No additional compensation will be provided to you.

Question

If you have any questions, concerns, or complaints about the research, you may contact Ardie Pack-Mabien. She will be glad to answer any of your questions. Ms. Pack-Mabien may be contacted at (251) 470-5889, 470-5893, or amabien@health.southalabama.edu.

If you have questions about your rights as a participant in this study, please contact the University of South Alabama Institutional Review Board (IRB) at (251) 460-6308 during regular business hours. The regular business hours are 8:00 a.m. to 5:00 p.m. CT, Monday through Friday. The IRB is a group of physicians and community advocates who make sure a research study is ethical and that the rights of the subjects are protected.

Legal Rights

You are not waiving any of your legal rights by signing this informed consent document.

Signatures

You are making a decision whether or not to have your child participate in this study. Your signature indicates that you have read or have been read to you and understand the purpose, procedures of this research, and the information provided above and decided to allow your child to participate.

You have had an opportunity to ask questions which have been answered to your satisfaction.

You voluntary agree to allow your child to participate in this research as described.

You acknowledge receiving and reading the Medical Subject's Bill of Rights.

You will receive a copy of this signed consent form.

Signature of Participant or Legally Authorized Representative Date

Signature of Person Obtaining Consent Date

Transition to Adult Care: Impact of Participation in a Transition Program

Informed Consent Script: Pediatric Sickle Cell Clinic

Age 14-17

Please introduce yourself to the adolescent, parent(s) or caregiver(s), and young adults upon entering the exam room. Give your name and title.

Hello, my name is ……..and I am …… working with Ardie Pack-Mabien, Nurse Practitioner here at the University of South Alabama Sickle Cell Center and doctoral student at the University of Alabama at Birmingham School of Nursing. Ms. Pack-Mabien is conducting a study to look at the transition of children and young adults. I am here today because you or your child has sickle cell disease and is a current participants of the Pediatric to Adult Care Transition Program here at the University of South Alabama Sickle Cell Center.

I would like to talk to you about her study.

If they agree begin with the discussion with the purpose of the study, location, research activities, voluntary nature and compensation, confidentiality, and statement of potential benefits.

Purpose

The purpose of the study being conducted by Ms. Pack-Mabien is to learn about the transition from the childhood doctors and nurses to adult care for the treatment of sickle cell disease and the impact of participation in the Pediatric to Adult Care Transition program on the successful transition to adult care.

Location

The study will be take place here at the sickle cell clinic and across the street at the sickle cell disease association.

Research Activities

You and your child will be asked to complete a study demographic form. Your child will also be asked to complete two questionnaires today and take a part in a one-time focus group lasting 60 - 90 minutes scheduled for a later date and time. If your child cannot come to the focus group, you child will be asked to participate in a one-on-one telephone interview lasting 60 - 90 minutes. You and your child will be notified by telephone and mail of the date and time for the focus group and if applicable telephone interview. Your child will be asked to read a brief written description of the results of focus group for the entire study. After reading the

description of the results, your child will be asked to agree or disagree with the focus group results and provide additional information.

Voluntary Nature of Participation

You and your child's participation in the study by Ms. Pack-Mabien is voluntary and completely separate from your child's medical care. You and your child's participation or refusal will have no effect on your child's medical care.

Compensation

Your child will be compensated for his or her time and travel to the focus group. If your child cannot drive, one parent or caregiver will be compensated for driving the child to and from the focus group held at the sickle cell disease association. If your child cannot attend the focus group then your child will be contacted for a one-on-one telephone interview but will not be compensated.

Confidentiality

You and your child's privacy is important to Ms. Pack-Mabien. She will do everything possible to protect you and your child's privacy. You and your child's name will not be disclosed in any publication or lecture. A randomly assigned number will be recorded on the demographic form and questionnaires. The results of this study will be reported as a group. Information from the study will be kept in a secure location. The focus group and telephone interview will be audio-recorded but your child's name will not be disclosed.

Statement of Potential Benefits

The information learned from this study may be used to improve the current Pediatric to Adult Care Transition program and transition experience of current and future participants of this program.

Ask if there are any questions at this point,

Do you or your child have any questions at this time?

Then ask if they are interested in hearing more about the study:

Would you like to hear more about the study?

If the child and/or parent(s) or caregiver(s) declines, thank them for their time and end the conversation.

If the child and/or parent(s) or caregiver(s) say yes, then proceed by giving them a copy of the informed consent to look at while you read, review, and go over every page of the informed consent. Children under 14 should receive the assent of minor consent. You should then state to

potential study participant and parent(s) or caregiver(s) that they can ask questions at any time during the informed consent process.

Here is a copy of the informed consent.

I am going to read the informed consent to you and your child at this time. You can stop me at any time to ask me a question.

Begin by going over the informed consent page by page and paragraph by paragraph and pausing to allow for questions. You should have a copy of the informed consent and the potential study participant. If a minor age 13, you should also provide a copy of assent of minor form and informed consent to the parent(s) or caregiver(s). You should include both minor age 13, adolescent, young adult, and parent(s) or caregiver(s) in the informed consent discussion and process.

At this point you, child, adolescent, or young adult and parent(s) or caregiver(s) should have a copy of the informed consent.

After you have read and reviewed every page, again ask if there are any questions. Allow parent(s) or caregiver(s) and child 15-30 minutes to discuss in privacy the decision about participation in the study. Inform them that you will leave the room and come back in 15-30 minutes for a decision.

If you do not have any questions, I am going to step out of the room for 15-30 minutes to allow you to discuss your decision in private. Thank you for your time and listening to me.

After 15-30 minutes, knock on the door of the exam room. Upon entering the room, greet the potential study participant and parent(s) or caregiver(s) and restate your name.

Hello again, My name is ……..and I am the…… with Ms. Pack-Mabien.

Ask the parent(s) or caregiver(s) and child if they have made a decision about participation in the study.

Have you and your child made a decision about participation in the study?

If they refuse, thank them for their time and listening to you about the study and provide a flyer with contact information should they have additional questions or change their mind about participation in the study.

Thank you for your time and offer a flyer with information about the study and contact information for the principal investigator.

If they agree to participate then proceed with obtaining the parent's initial on every page and signature on the signature page. Have both the parent and adolescent sign the signature pages.

For the adolescent age 13, have he or she sign the assent of minor form. You should also obtain signature from a witness (this can be a member of the sickle cell center nursing or medical staff).

Thank you for agreeing to participate, let me get you, Ms. or Mr. ……. ...to initial every page and signature on the signature page of the informed consent and your child (say child's name here) signature on the signature page.

Have the signatures witnessed by a member of the nursing staff and copy the signed informed consent and assent of minor forms.

Give a copy of the signed consent to the child and one copy to the parent. The original informed consent is to be given to the principal investigator.

Proceed with the two survey instruments and demographic sheet. You should read the instructions on the *STARx* and utilize the *TRxANSITION Scale* scoring guide for response to the questions on this tool.

Here is your copy of the consent. If there are no questions, let's begin.

First give the study demographic form and a pen to the parent and child (Study demographic forms are designated for the parent and child).

First we will complete the demographic form for you and your child.

After the study demographic form is completed by the parent or caregiver then proceed with giving the adolescent the *STARx* self-report questionnaire to be completed by the study participant. If child need assistant reading, offer to read to child or allow parent to assist.

Now we I will give you the first questionnaire to complete. Would you like for me or your parent or caregiver read it to you or help you read the questionnaire?

If no, let the child complete independently without assistance.

If yes, you may read or allow the parent or caregiver to read.

After completion of the *STARx*, begin with reading the *TRxANSITION Scale* question and use the *TRxANSITION Scale* scoring guide to choose the appropriate based on the study participant response.

Now we will begin the last questionnaire. I will ask the questions and you will tell me your answer.

Once complete obtain a current and alternate mailing address, home telephone and cellphone number, and if applicable email address. Please remind parent or caregiver that this information will be used to contact them with the date and time of the focus group and if applicable one-on-

one telephone. Again thank parent(s) or caregiver and study participant for their time and participation.

Thank you for your time and participation. If you have any questions please feel free to contact Ms. Pack-Mabien.

Transition to Adult Care: Impact of Participation in a Transition Program

Informed Consent Script: Adult and Pediatric Sickle Cell Clinic

Age 18-21

Please introduce yourself to the adolescent, parent(s) or caregiver(s), and young adults upon entering the exam room. Give your name and title.

Hello, my name is ……and I am …… working with Ardie Pack-Mabien, Nurse Practitioner here at the University of South Alabama Sickle Cell Center and doctoral student at the University of Alabama at Birmingham School of Nursing. Ms. Pack-Mabien is conducting a study to look at the transition of children and young adults. I am here today because you or your child has sickle cell disease and is a current or recently transitioned participants of the Pediatric to Adult Care Transition Program here at the University of South Alabama Sickle Cell Center.

I would like to talk to you about her study.

If they agree begin with the discussion with the purpose of the study, location, research activities, voluntary nature and compensation, confidentiality, and statement of potential benefits.

Purpose

The purpose of the study Ms. Pack-Mabien will be conducting is to learn about the transition from the childhood doctors and nurses to adult doctors and nurses for the treatment of your sickle cell disease and the impact of participation in the Pediatric to Adult Care Transition program on the successful transition to adult care.

Location

The study will be take place here at the sickle cell clinic and the sickle cell disease association located across the street.

Research Activities

You will be asked to complete a study demographic form and two questionnaires today. You will also be asked to take a part in a group lasting 60-90 minutes at a later date and time. If you cannot come to the focus group, you will be asked to participate in a one-on-one telephone interview lasting 60-90 minutes. You will be notified by telephone and mail of the date and time for the focus group and if applicable telephone interview. You will be asked to read a written description of the results of the focus group for the entire study. After reading the description of the results, you will be asked to agree or disagree with the results and provide additional information.

Voluntary Nature of Participation

Your participation in the study by Ms. Pack-Mabien is voluntary and completely separate from your medical care. Your participation or refusal will have no effect on your medical care.

Compensation

You will be compensated for your time and travel to the focus group discussion. If you cannot drive, one parent will be compensated for driving you to and from the focus group discussion held at the sickle cell disease association. If you cannot attend the group discussion then you will be contacted for a telephone interview but will not be compensated.

Confidentiality

Your privacy is important to Ms. Pack-Mabien. She will do everything possible to protect your privacy. Your name will not be disclosed in any publication or lecture. A randomly assigned will be recorded on the demographic and questionnaires. The results of this study will be reported as a group. Information from the study will be kept in a secure location. The focus group and telephone interview will be audio-recorded but your name will not be disclosed.

Statement of Potential Benefits

The information learned from this study may be used to improve the current Pediatric to Adult Care Transition program and transition experience of current and future participants of this program.

Ask if there are any questions at this point,

Do you have any questions at this time?

Then ask if they are interested in hearing more about the study:

Would you like to hear more about the study?

If the potential study participant declines, thank he or she for their time and end the conversation.

If the potential study participant answers, yes, then proceed by giving them a copy of the informed consent to look at while you read, review, and go over every page of the informed consent. You should then tell the potential study participant that he or she can ask questions at any time during the informed consent process.

Here is a copy of the informed consent.

I am going to read the informed consent to you at this time. You can stop me at any time to ask me a question.

Begin by going over the informed consent page by page and paragraph by paragraph and pausing to allow for questions. You should have given a copy of the informed consent and the potential study participant and you should have a copy of the informed consent.

At this point, you and the potential study participant should have a copy of the informed consent.

After you have read and reviewed every page, again ask if there are any questions. Allow the potential study participant 15-30 minutes to review the inform consent in private and to make a decision about the participation in the study. Inform the potential study participant that you will leave the room and come back in 15-30 minutes for a decision.

If you do not have any questions, I am going to step out of the room for 15-30 minutes and allow to have some privacy to think about your decision. Thank you for your time and listening to me.

After 15-30 minutes, knock on the door of the exam room. Upon entering the room, greet the potential study participant and parent(s) or caregiver(s) and restate your name.

Hello again, My name is ……. and I am the…… with Ms. Pack-Mabien.

Ask the potential study participant if he or she has made a decision about his or her participation in the study.

Have you made a decision about participation in the study?

If they refuse, thank them for their time and listening to you about the study and provide a flyer with contact information should they have additional questions or change their mind about participation in the study.

Thank you for your time and offer a flyer with information about the study and contact information for the principal investigator.

If they agree to participate then proceed with obtaining signatures on the signature page. You should obtain signature from a witness (this can be a member of the sickle cell center nursing or medical staff).

Thank you for agreeing to participate, let me get you to initial every page and your signature on the signature page of the informed consent.

Give a copy of the signed consent to the study participant. The original informed consent is to be given to the principal investigator.

Proceed with the two survey instruments and study demographic form. You should read the instructions on the STARx and utilize the TRxANSITION Scale scoring guide for response to the questions on this tool.

Here is your copy of the consent. If there are no questions, let's begin.

First give the study demographic form and a pen to the study participant.

First we will complete the demographic form.

After the study demographic form is completed by the parent or caregiver then proceed with giving the adolescent the *STARx* self-report questionnaire to be completed by the study participant. If child need assistant reading, offer to read to child or allow parent to assist.

Now we I will give you the first questionnaire to complete. Would you like for me to read it or you read the questionnaire?

If no, let the study participant complete independently without assistance

If yes, you may read or allow the parent or caregiver to read.

After completion of the *STARx*, begin with reading the *TRxANSITION Scale* question and use the *TRxANSITION Scale* scoring guide to choose the appropriate based on the study participant response.

Now we will begin the last questionnaire. I will ask the questions and you will tell me your answer.

Once complete obtain a current and alternate mailing address, home telephone and cellphone number, and if applicable email address. Please remind parent or caregiver that this information will be used to contact them with the date and time of the focus group and if applicable one-on-one telephone. Again thank parent(s) or caregiver and study participant for their time and participation.

Thank you for your time and participation. If you have any questions please feel free to contact Ms. Pack-Mabien.

APPENDIX G

INSTRUMENTS

Adolescent and Young Adult Demographic Form: 13-17

Successful Transition to Adult Care: Impact of Participation in a Transition Program

ID number of child_____

Write in the answer and check or circle

1. How old are you? _____
2. Are you a boy or girl?
   a. Boy
   b. Girl
3. What is your race/ethnicity (circle all that apply)?
   a. African American or Black
   b. Asian
   c. Hispanic or Latino
   d. Native American
   e. White
   f. Other
4. What is the highest grade in school that you completed?

Less than 7th grade	1
Junior high school (7th to 9th grade)	2
Partial high school (10th to 11th grade)	3
High school graduate	4
At least one year of college or specialized training	5
College or university graduate	6
Graduate professional training (graduate degree)	7

ID Number _____

5. Do you have a job?
    a. Yes
    b. No
6. If you have a job, what is your job? _____
7. How many brothers and sisters do you have? _____
8. How old are your brothers and sisters?
    a. Brothers_____
    b. Sisters_____
9. Where are you in the order of children in your family?
    a. Oldest
    b. Middle
    c. Youngest

10. What type of Sickle Cell Disease do you have?
    a. HbSS
    b. HbSC
    c. HbS Beta null Thalassemia
    d. HbS Beta plus Thalassemia
11. Are you taking medicines for your sickle cell?
    a. Yes
    b. No
    c. If yes, name your medicines?
        1.
        2.
        3.

ID Number _____

4.
5.
6.

12. Do you have any health problems other than sickle cell disease?
    a. Yes
    b. No
    c. If yes, name your other health problems
        1.
        2.
        3.
        4.
        5.
        6.

13. In the past month, how many times have you experienced a sickle cell disease related problems in the last year? _____

14. Do you think your health is?
    a. Poor
    b. Fair
    c. Good
    d. Very Good

15. Please provide your main mailing address, home telephone and cell phone number, and an alternate telephone number for notification of the focus group or telephone interview if you cannot attend the focus group.

Home mailing address: _____

_____

Home telephone number_____

Cell phone number_____

Alternative telephone number_____

Parent and Child Demographic Form adapted from Porter et al., (2014).

Parent Demographic Form

Successful Transition to Adult Care: Impact of Participation in a Transition Program

ID number of child_____

Write in the answer and check or circle the answer that best describes you.

1. Relationship to your child with sickle cell disease.

   _____ Mother

   _____Father

   _____Other (Write relationship here_____)

2. What is your job or occupation? _____

3. What is the highest grade in school that you completed?

Less than 7th grade	1
Junior high school (7th to 9th grade)	2
Partial high school (10th to 11th grade)	3
High school graduate	4
At least one year of college or specialized training	5
College or university graduate	6
Graduate professional training (graduate degree)	7

4. What year were you born? _____
5. What is your race/ethnicity (circle all that apply)?

   a. African American or Black

   b. Asian

c. Hispanic or Latino

d. Native American

e. White

f. Other

6. What community do you live in?

a. The City of Mobile

b. The City of Prichard

c. Another city outside of Mobile, name of the city where you live_____

d. Mobile County

e. Baldwin County

f. Another County, name of county where you live_____

7. What is the annual income of all the person in the household together?

a. Less than $10,000 1

b. $10,000-$19,999 2

c. $20,000-$29,999 3

d. $30,000-$39,999 4

e. $40,000-$49,999 5

f. $50,000-$59,999 6

g. $60,000-$69,999 7

h. Over $75,000 8

8. How many children do you have? _____

9. What are the ages of your children? _____

10. How old is your child with sickle cell disease? _____

11. Is your child with sickle cell disease a boy or girl?

a. Boy b. Girl

12. What type of sickle cell disease does your child have?

a. HbSS b. HbSC

c. HbSβeta null Thalassemia d. HbSβeta plus Thalassemia

13. Does your child take Hydroxyurea for his or her sickle cell disease take at home?

a. Yes b. No

14. Does your child take Jadenu for his or her sickle cell disease?

a. Yes b. No

b.

ID Number of child_____

15. What medicines does your child take for his or her sickle cell disease?

1.

2.

3.

4.

16. Is your child on a chronic transfusion regimen?

a. Yes b. No

17. What complications has your child with sickle cell disease experienced as a result of this disease?

1. 2.

3. 4.

5. 6.

7. 8.

17. What is the health of your child with sickle cell disease?

a. Poor

b. Fair

c. Good

d. Very Good

18. How many sickle cell disease related problems has your child has in the last year? _____

19. What is the birth order of your child with sickle cell disease?

First born	1
Second born	2
Third born	3
Fourth born	4
Fifth born	5
Sixth born	6
Other	7

Write in the birth order of your child with sickle cell disease if it is not listed above_____

20. What kind of insurance does your child have? _____

21. Please provide your main mailing address, home telephone and cell phone number, and an alternative telephone number for notification of the focus group or telephone interview if necessary.

Home mailing address: _____

_____

Home telephone number_____
Cell phone number_____
Alternative telephone number_____

Parent Demographic Form adapted from Porter et al., (2014).

Young Adult Demographic Form: 18 and older

Successful Transition to Adult Care: Impact of Participation in a Transition Program

ID number_____

Write in the answer and check or circle the answer that best describes you.

1. What type of sickle cell disease do you have?

    a. HbSS

    b. HbSC

    c. HbS *Beta* null Thalassemia

    d. HbS *Beta* plus Thalassemia

2. Are you a male or female?

    a. Male

    b. Female

3. How old are you? _____

4. What year were you born? _____

5. What is your race/ethnicity (circle all that apply)?

    a. African American or Black

    b. Asian

    c. Hispanic or Latino

    d. Native American

ID Number_____

e. White

f. Other

6. What is your job or occupation? _____

7. What is the highest grade in school that you completed?

Less than 7th grade	1
Junior high school (7th to 9th grade)	2
Partial high school (10th to 11th grade)	3
High school graduate	4
At least one year of college or specialized training	5
College or university graduate	6
Graduate professional training (graduate degree)	7

8. What community do you live in?

a. The City of Mobile

b. The City of Prichard

c. Another city outside of Mobile, name of the city where you live_____

d. Mobile County

e. Baldwin County

f. Another County, name of county where you live_____

ID Number _____

9. What is the annual income of all the persons in the household together?

   a. Less than $10,000 1

   b. $10,000-$19,999 2

   c. $20,000-$29,999 3

   d. $30,000-$39,999 4

   e. $40,000-$49,999 5

   f. $50,000-$59,999 6

   g. $60,000-$69,999 7

   h. Over $75,000 8

10. How many children do you have? _____

11. What are the ages of your children? _____

12. Do you take Hydroxyurea for your sickle cell disease?

   a. Yes b. No

13. Do you take Jadenu for your sickle cell disease?

   a. Yes b. No

ID Number_____

14. What medicines does you take for your sickle cell disease?

1.

2.

3.

4.

15. Are you on a chronic red blood cell transfusion regimen?

a. Yes b. No

16. What complications have you experienced related to your sickle cell disease?

1. 2.

3. 4.

5. 6.

7. 8.

17. What is the health?

a. Poor

b. Fair

c. Good

d. Very Good

ID Number_____

18. How many sickle cell disease related problems have you had in the last year? _____

19. What is your birth order?

First born	1
Second born	2
Third born	3
Fourth born	4
Fifth born	5
Sixth born	6
Other	7

Write in the birth order if it is not listed above_____

20. What kind of insurance do you have? _____

21. When was your last seen in the pediatric sickle clinic visit? _____

22. When were you seen in the adult sickle cell clinic? _____

ID Number_____

23. Please provide your main mailing address, home telephone and cell phone number, and an alternative telephone number for notification of the focus group or telephone interview if necessary.

Home mailing address: _____

_____

Home telephone number_____

Cell phone number_____

Alternative telephone number_____

Do Not Write Below This Section

This section is to be completed by a member of the research team.

Date of last pediatric visit_____

Date of first adult clinic visit_____

Length of time (months) in the PACT program_____

Young adult 18 and Older Demographic Form adapted from Porter et al., (2014).

Site ID: _____
Patient ID: _____
Date: _____

STARx Transition Readiness Questionnaire (Adolescent Version)

DIRECTIONS

Patients with chronic health conditions need to have special skills and do special tasks to stay healthy.

On the following pages, please check the box underneath the answers that describe you most.

If you do not understand a question, just ask for help. We're here to help you ☺

Site ID: _____
Patient ID: _____
Date: _____

Section 1 :

- **How often have you done the following things?**
- **Please check the box that tells how often you have done each thing in the *PAST 3 MONTHS*.**

In the past 3 months …	Never	Almost Never	Sometimes	Almost Always	Always	I do not take medicines right now
1. How often did you make an effort to understand what your doctor told you?	☐	☐	☐	☐	☐	
2. How often did you take your medicines on your own?	☐	☐	☐	☐	☐	☐
3. How often did you ask your doctor or nurse questions about your illness, medicines or medical care?	☐	☐	☐	☐	☐	
4. How often did you make your own appointments?	☐	☐	☐	☐	☐	
5. How often did you need someone to remind you to take your medicines?	☐	☐	☐	☐	☐	☐
6. How often did you use things like pillboxes, schedules, or alarm clocks to help you take your medicines when you were supposed to?	☐	☐	☐	☐	☐	☐
7. How often did you use the internet, books or other guides to find out more about your illness?	☐	☐	☐	☐	☐	
8. How often did you forget to take your medicines?	☐	☐	☐	☐	☐	☐
9. How often did you work with your doctor to take care of new health problems that came up?	☐	☐	☐	☐	☐	

Site ID: _____
Patient ID: _____
Date: _____

Section 2:

- **Some patients know a lot about their health and some patients don't.**
- **How much do you know?**
- **Please check the answer that best describes how much you feel you know *TODAY*.**

	Nothing	Not Much	A little	Some	A Lot	I do not take medicines right now
10. How much do you know about your illness?	☐	☐	☐	☐	☐	
11. How much do you know about taking care of your illness?	☐	☐	☐	☐	☐	
12. How much do you know about what will happen if you don't take your medicines?	☐	☐	☐	☐	☐	☐

Site ID: _____
Patient ID: _____
Date: _____

Section 3:

- **Some patients may find it hard to do certain things.**
- **How easy or hard is it for you to do the following things?**
- **Please check the answer that best describes how you feel *TODAY*.**

	Very Hard	Somewhat Hard	Neither Hard nor Easy	Somewhat Easy	Very Easy	I do not take medicines right now
13. How easy or hard is it to talk to your doctor?	☐	☐	☐	☐	☐	
14. How easy or hard is it to make a plan with your doctor to care for your health?	☐	☐	☐	☐	☐	
15. How easy or hard is it to see your doctor by yourself?	☐	☐	☐	☐	☐	
16. How easy or hard is it to take your medicines like you are supposed to?	☐	☐	☐	☐	☐	☐
17. How easy or hard is it to take care of yourself?	☐	☐	☐	☐	☐	
18. How easy or hard do you think it will be to move from pediatric to adult care?	☐	☐	☐	☐	☐	

Patient Name			Date	
Medical Record #		Transition ID	Institution	

UNC TR$_x$ANSITION Scale™ for Adolescents and Young Adults:

Instructions: *Read the question to the patient, and circle the choice on the right that best describes the patient's response. Sum the scores for each section in the "Subtotal" row. Not all questions may be applicable to each patient. Divide the subtotal by the number of applicable questions in each section to obtain the "Proportion".*

Type of chronic health condition		Yes	Somewhat	No
1	Can you tell me the name of your health condition?	1.0	0.5	0.0
2	Can you describe symptoms of your health condition?	1.0	0.5	0.0
3	Can you tell me how this condition may affect your health in the future?	1.0	0.5	0.0
	Sum the scores for this section Subtotal T	____ out of 3		
	Divide the subtotal by the number of applicable questions Proportion T			

R$_x$: Medications		>90% Correct	51-90 % correct	<50% correct
4	Can you tell me the names of the medicines, vitamins, and/or supplements you are supposed to be taking?	1.0	0.5	0.0
	[If possible, write meds in advance and circle them as the patient names them]			
5	Can you tell me when you are supposed to take [name each medication, vitamin, and supplement patient should be taking]?	1.0	0.5	0.0
6	Can you tell me why you are taking [name each medication, vitamin, and supplement patient should be taking]?	1.0	0.5	0.0
7	Can you tell me what could happen to you if you stopped taking [name each medication, vitamin, and supplement patient should be taking]?	1.0	0.5	0.0
	Sum the scores for this section Subtotal R$_x$	____ out of 4		
	Divide the subtotal by the number of applicable questions Proportion R$_x$			

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Funding: The UNC Kidney Center, Center for Education Research and Therapeutics, and K.B. Reynolds Charitable Trust. Version 12_18_09

Adherence

		Yes	Sometimes	No
8	In a typical week, do you usually miss a full day of medicine, either because you forgot to take it or didn't want to take it?	0.0	0.5	1.0
9	Do you usually have trouble remembering to take your medicines every day?	0.0	0.5	1.0
10	Do you usually come to your doctor appointments when they are scheduled?	1.0	0.5	0.0

Sum the scores for this section — Subtotal A: ____ out of 3

Divide the subtotal by the number of applicable questions — Proportion A:

Nutrition

		Yes	Somewhat	No	
11	Do you know how to read nutrition labels on food or drinks to see if they are healthy choices?	1.0	0.5	0.0	
12	Do you know if there is any special diet you are supposed to follow because of your health condition?	1.0	0.5	0.0	
13	*[If the patient is on a special diet]* Can you name specific examples of the foods or drinks that you should not have?	1.0	0.5	0.0	N/A

Sum the scores for this section — Subtotal N: ____ out of (2 or 3)

Divide the subtotal by the number of applicable questions — Proportion N:

Self-management skills

		Yes	Sometimes	No
14	Do you usually remember to take your medicines on your own?	1.0	0.5	0.0
15	Does someone usually have to remind you to take your medicines?	0.0	0.5	1.0
16	Do you usually call in your prescription refills yourself?	1.0	0.5	0.0

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17	Do you usually pick-up refills from the pharmacy yourself?	1.0	0.5	0.0	
18	Do you yourself usually call or email your doctor when you have a question or need to speak with him/her?	1.0	0.5	0.0	
19	Do you usually make your own doctor appointments?	1.0	0.5	0.0	
20	*[If the patient has medical procedures to perform]* Do you usually perform your medical procedures yourself (catheterization, insulin shots, etc?)	1.0	0.5	0.0	N/A
	Sum the scores for this section — Subtotal S	__out of (6 or 7)			
	Divide the subtotal by the number of applicable questions — Proportion S				

Note: *Some patients may be too young for the following questions to be appropriate. Score these patients as 0's, as these are important skills not yet obtained.*

Issues of reproduction		Knows full answer	Knows answer	Doesn't know answer	
21	Would your health condition likely affect your ability to: *[If female]* become pregnant? *[If male]* get someone pregnant?	1.0	0.5	0.0	
22	*[Females only]* Do you know if your health condition would get worse if you got pregnant?	1.0	0.5	0.0	N/A
23	*[Females only]* Would any of your medicines be harmful to an unborn baby if you become pregnant?	1.0	0.5	0.0	N/A
24	Can you tell me ways sexually active people protect themselves from unwanted pregnancy or sexually transmitted diseases?	1.0	0.5	0.0	
	Sum the scores for this section — Subtotal I Male Female	_____ out of 2 _____ out of 4			
	Divide the subtotal by the number of applicable questions — Proportion I				

Trade / School

		Yes	Has some idea	No
25	Can you tell me about your future plans in regards to school and/or a job?	1.0	0.5	0.0
26	Can you tell me how your current health insurance status will change after you graduate from high school?	1.0	0.5	0.0
	Sum the scores for this section — Subtotal T	____ out of 2		
	Divide the subtotal by the number of applicable questions — Proportion T			

Insurance

		Yes	Somewhat	No	
27	Can you tell me why it is important to have health insurance?	1.0	0.5	0.0	
28	Can you tell me the name of your current health insurance provider?	1.0	0.5	0.0	
29	[*If he/she is currently insured*] Can you tell me at what age your current health insurance coverage will end?	1.0	0.5	0.0	N/A
30	Can you tell me how you can get health insurance for yourself when you are an adult?	1.0	0.5	0.0	
	Sum the scores for this section — Subtotal I	____ out of (3 or 4)			
	Divide the subtotal by the number of applicable questions — Proportion I				

Ongoing support

		Yes	Has some idea	No
31	When you are an adult, who will manage your health condition, for example help you remember to take your medicines, call in prescription refills, pick up meds from pharmacy, and make doctor appointments?	1.0	0.5	0.0
	Sum the scores for this section — Subtotal 0	____ out of 1		

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New health care providers		Yes	Has some idea	No
32	Can you tell me how you would find a new doctor if you needed one?	1.0	0.5	0.0
33	Can you tell me how you could transfer your medical records from one doctor to another?	1.0	0.5	0.0
	Sum the scores for this section	Subtotal N	_____ out of 2	
	Divide the subtotal by the number of applicable questions	Proportion N		

Raw total score	*Sum all section subtotals here (max 33)*	
T.R.A.N.S.I.T.I.O.N Score™	*Sum all section proportions, or divide the raw total score by the total number of eligible questions (max 10)*	

http://unckidneycenter.org/hcprofessionals/transition.html

TRXANSITION SCALE ANSWER AND SCORING GUIDE FOR SICKLE CELL DISEASE

Question	Knows a lot = 1	Knows a little =0.5	Doesn't know=0	N/A
1.	They say they have Sickle Cell Anemia, Sickle cell disease, or name the genotype: HbSS, HbSC, HbS β null thalassemia or HbS β plus thalassemia.	They give a general answer like "something is wrong with my blood", I have sickle cell disease.	They have no idea.	
2.	They can name physical symptoms that they have experience directly related to or caused by the health condition. For example: pain crisis of any joint in the body, low blood count, stroke, difficulty with vision, breathing problem, asthma, low blood count, big spleen, elevated iron level, hip problem, or kidney problem. They may also be able to name symptoms that others may experience but they do not For example, lost their spleen or had some type of surgery.	They name generic symptoms such as feeling tired but are not specific.	They do not have any symptoms or they name symptoms that are unrelated to their health condition such as menstrual cramps, toothache, or muscle spasm.	
3.	They are able to name more than one way their health condition may affect their future health and they are specific. They may say I can't or won't be able to do PE at school, play a football or basketball, take dance or cheerleading or work because I have sickle cell disease.	They can name only one way how their health condition may affect their future health OR they give a general response such as "I can more/less of what I want to do or like to do".	They are unable to report or do not know how their future health may be affected.	
4.	They are able to name all of the medicines they take for their health condition such as Folic Acid, Pen VK, Norco, Tylenol, Ibuprofen, Hydroxyurea, or Adcnu.	They are able to name some of the medicines they take for their health condition.	They do not know any of the medicines they take for their health condition.	They do not have any prescribed medicines for their health condition.
5.	They know when they take	They know when	They do not know	They do not

TRXANSITION SCALE ANSWER AND SCORING GUIDE FOR SICKLE CELL DISEASE

	each of their medicines. For example, "I take my Penicillin twice a day (in the morning and at night) and Hydroxyurea once a day at bedtime".	they are supposed to take some of their medicines but not all of them.	when they are supposed to take any of their medicines.	have any prescribed medicines for their health condition.
6.	They know why they take each of their medicines. For example, "I take Folic Acid to help my blood count". "I take Noreo for pain". I take ladeau for my iron level being high".	They know why they take some of their medicines, but not all of them.	They do not know why they take any of their medicines.	They do not have any prescribed medicines for their health condition.
7.	They are able to list consequences for each medicine (what happens if they do not take their medicines) such as "I will have pain or my blood count will be low".	They are able to identify general consequences for not taking their medicines, but cannot give specific consequences for each medicine.	They do not know what could happen if they do not take their medicines.	They do not have any prescribed medicines for their health condition.
8.	They do not ever miss a full day of medicine.	They miss a full day every now and then but not regularly.	They miss a full day at least once a month.	They do not take any prescribed medicines for their health condition.
9.	They do not have difficulty remembering to take their medicines every day.	They sometimes have difficulty remembering to take their medicines every day.	They always have difficulty remembering to take their medicines every day.	They do not take any prescribed medicines for their health condition.
10.	They come to their appointments as scheduled or they cancel/reschedule ahead of time.	They sometimes forget when their appointments are scheduled and show up late or do not show up at all.	They usually do not attend their appointment when scheduled.	
11.	Yes, they read nutrition labels on foods/drink.	They sometimes read nutrition labels.	They never read nutrition labels.	
12.	They can name the diet their doctor has asked them to	They know they aren't supposed	They do not know If they are	

	follow such as no Vitamin C if they are taking Jadenu, no caffeine, or carbonated drinks.	to eat/drink certain things but they do not know why (cannot name specific diet).	supposed to follow a diet or not.	
13.	They are able to name at least 3 specific foods/drink they are supposed to have more or less such as 8 bottles of water a day, high fiber diet such as fruits and vegetables or no spite, coke, or tea, food or vitamin rich in iron.	They can name less than 3 examples of foods/drinks they are supposed to have more or less of.	They do not know examples of any food/drinks they are supposed to have more or less of.	They do not have a diet.
14.	They usually remember to take their medicine on their own without requiring a reminder.	They sometimes remember to take their medicines on their own, but they also sometimes, need a reminder.	They do not remember to take their medicines on their own and rely on someone to remind them.	They do not take prescribed medicines for their health condition.
15.	They do not need someone to remind them to take their medicines.	They sometimes need someone to remind them to take their medicines.	They always need someone to remind them to take their medicines.	They do not have any prescribed medicines for their health condition.
16.	They always call in prescription refills themselves or manage their own refill via the internet.	They sometimes call in refills themselves or manage them via the internet.	They never call in refills themselves or manage them via the internet.	They do not have any prescribed medicines for their health condition.
17.	They always pick their refills up from the pharmacy. If they do not have a driver's license, they at least ride with someone and are responsible for going inside with an adult to pick up their medicines.	They may go with someone to pick up their refills but they do not do it on their own.	They never pick up their refills on their own.	They do not have any prescribed medicines for their health condition.
18.	They contact their health providers on their own via email or telephone without help from their parent(s) or	They sometimes contact their health providers on their own but	They never contact their health providers on their own.	They have never had to contact a provider.

	caregiver (s).	mostly tell their parent(s) or caregiver(s) and let them make contact.		
19.	They are usually responsible for checking out after an appointment and scheduling a follow-up appointment as necessary or they make their medical appointments on their own via phone and coordinate it with their school or work schedule.	They sometimes schedule appointments for themselves, but mostly their parent(s), caregiver(s), or providers do it for them.	They never schedule doctor appointments on their own.	
20.	They always perform their own medical procedures.	They sometimes perform their own medical procedures, but someone else does it for them most of times.	They rely on someone else to perform their medical procedures.	They do not have any medical procedures to perform on their own.
21.	They know their health conditions will or will not affect their ability to have children, the chance of having a child with or without sickle cell trait or disease.	They don't think they will have a problem getting pregnant or having a child with sickle cell trait or sickle cell disease.	They do not know.	
22.	They know specific risk associated with pregnancy in sickle cell disease. They know there is a risk of having more severe or frequent pain episodes with pregnancy. A pregnant woman with sickle cell disease is more likely to have a miscarriage, preterm labor, or low-birth-weight baby.	They are aware that risks may exist but they are unable to name them. They say there may be some problems but they are not specific.	They do not know if their health condition will cause risks associated with pregnancy.	
23.	They are able to name medicines they are currently taking that would be harmful to an unborn baby. For example, Hydroxyurea	They are aware that they are on medicines that would be harmful to an unborn	They do not know if any of their medicines would be harmful to an unborn baby.	Males except for Hydroxyurea.

	(males and females) and Jadenu are contraindicated during pregnancy and breastfeeding.	baby but they cannot specify which medicines they are.		
24.	To prevent pregnancy: they report use of both condoms and other form of birth control such as the pill, diaphragm, implantable device, or abstinence.	To prevent pregnancy: they report either condoms or other form of birth control.	They cannot name any method use to prevent pregnancy.	
25.	They have a specific plan post-high school or college. They know they will be attending college, or entering the workforce. They have an idea of what they would like to be or do.	They do not have a specific plan or idea. If they are in high school, they "think" they might go to college, but they haven't decided. If they are in college, they have not declared a major or identified a field of study or post-college employment.	They have no post-high school/college plans or they don't know.	
26.	They are able to report that health insurance helps pay for (or reduce the cost of) medicines, doctor visits, hospital stays, lab works and etc., things that are medically necessary.	They know their health insurance helps pay for "stuff" but they are not specific.	They don't know the importance of health insurance.	
27.	They are able to name their primary insurance provider.	They know they have insurance but they don't know the name.	They do not know if they have insurance and do not know the name of the insurance.	They do not have insurance coverage. They are self-pay.
28.	For patients covered by their parent's insurance, they know that they are eligible to be covered until age 26, no matter if they are married, not living in their parent's home, or in school.	They have an idea that their parent's insurance may end at a certain age, but they are unsure what age	They do not know when their health insurance will end.	They do not have insurance coverage. They are self-pay.

	For patients with Medicaid, they know that they can receive coverage under MIC (Medicaid for Infants and children) until they turned 19 years old. Once they turn 19, they will have to apply as an adult. ** The most important knowledge is that they know: (a) their health insurance status and coverage changes; (b) how and when to apply for ongoing health insurance such as Medicaid and MIC; and (c) who to seek information from regarding their health insurance status.	specifically. For patients with Medicaid, they have an idea they can receive coverage but they are unsure of the specific requirements or who to contact.		
29.	They know they can get health insurance coverage through their job. If their job does not offer coverage, they can buy it on their own, or they may qualify for government assistance depending on their financial status.	They say they can get coverage by looking on the internet or going to the local sickle cell disease association or social services department. They do NOT identify employment as a way to get health insurance.	They do not know how to get coverage.	
30.	They report that they will be primarily responsible for taking care of their health needs. They may recognize that others can help and provide support.	They will depend on someone else to primarily take care of their own health needs.	They do not know who will take care of their health needs.	
31.	They report asking their medical provider for a recommendation/referral to an adult primary care provider and sickle cell provider.	They say they will look on the internet or ask a family member/friend for recommendations and the current	They do not know.	

Successful Transition to Adult Care: Impact of Participation in a Transition Program

Focus Group Guide

Figure 2. Dissertation Focus Group Guide for 13-18

Directions: Sections written in *italics* are to be read to participants:
Supplies:
2 digital recorders
2 pencils
2 pens

Time of the Focus Group:

Date:

Place: Sickle Cell Disease Association of America, Mobile Chapter community-based program conference room.

Designated Focus Group by Age:

Facilitator:

Position of the Facilitator:

Research Study Title: Successful Transition to Adult Care: Impact of Participation in a Transition Program

Description of the Purpose:

This proposed dissertation will investigate the impact of participation in a PACT transition program on the successful transition with defined disease specific key indicators and outcome measures. The data generated by this proposed dissertation could be utilized to: (a) provide evaluative evidence-based data on the effectiveness of transition programs; (b) inform, modify, and/or expand current transition programs, practices, and services; and (c) improve the transition experience of AYA with SCD.

Introduction:
Welcome the participant upon arrival.

Once all participants have arrived (wait at least 5-10 minutes after scheduled arrival time).

Start Focus Group; describe the purpose of the focus group.

Welcome and thank you so very much for taking time out of your schedule to participate in this focus group. You have been invited to participate in this focus group to gain valuable information, description, and understanding of the personal experiences of participation in a Pediatric to Adult Care Transition (PACT) Program from the perspective of the adolescent and young adult with sickle cell disease. We want to learn more about what you think, how you feel about participation in the PACT program, and how you are getting ready for the move to adult care when you turn 19. Any information you share will be used for the purpose of the research study only. The focus group will take approximately 60-90 minutes. It will be audio-recorded for the purposes of making sure I don't miss any of your comments or take any of your comments out of context. Your name will not be used in any transcript of the recording.

At this point, ask the participant if he or she have any questions. Once all questions have been answered to the participant satisfaction please begin.

Do you have any questions about the purpose of this focus group?

Again, thank you for agreeing to participant in this focus group. Before I get into our discussion, let me make a few requests of you. First, speak up so that your comments are captured by the audio-recorder. Please say exactly what you think. Don't worry about what I think. There is no right or wrong answers. You are not required to answer any question you do not want to answer. Your answer to the questions are completely voluntary.

Introduction of the Interview Questions/Topics

The interviewer will introduce each question and explore it thoroughly before moving on to another question/topic. The facilitator will elicit the study participant's thoughts, personal experiences, and opinion, and use probes as needed to assist the study participant in providing a detailed description, elaboration, or clarity on the study participants' thoughts, personal experiences, opinions, and giving examples whenever possible.

Question will be addressed in the following order:

Begin with 2 icebreakers to open up the discussion and start both audio-recorders.

1. *So, what does it feel like being a teenager?*

2. *Well tell me this, what has it been like being a member of the PACT program?*

Begin with the focus group discussion questions:

1. *Now tell me, what are some concerns, fears, or worries that you have about changing from current doctors and nurses to adult care with new doctors and nurses to receive treatment for your sickle cell disease when you turn 19?*
    a. *Do you feel the PACT program has been helpful in addressing your concerns, fears, and worries about being ready and changing to new adult doctors and nurses? If so, how? If not, why not?*
2. *What factors do you think may affect your transition from your current doctors and nurses to adult care with adult doctors and nurses?*
    a. *Can you tell me how these factors help or block your transition?*
3. *How prepared do you feel you are for the transition to adult care? Can you give me some examples of when you did or did not feel prepared for the transition?*
        a. *What are you learning about your disease, medications, and insurance coverage and/or requirements as a grown up or young adult with SCD?*
        b. *What does it means when you say you have sickle cell disease?*
        c. *How has what you know about your sickle cell disease changed since participating in the PACT program?*
        d. *What other issues or topics would you like to learn about the transition to adult care?*

e. *Describe how you would tell your medical history and current illness to health care providers?*

4. *How is the PACT program helping you to get ready for the transition to adult care?*
   a. *In what ways has the program been helpful in getting you ready for the transition to adult care?*
5. *What changes do you feel need to be made to the PACT program to help you to successfully prepare and plan for the move to adult care? And how do you think the changes could or should be made? In order words,*
   a. *What do you think a PACT program should offer to help you successfully move from pediatrics to an adult care doctor?*
   b. *What do you need to make the move from pediatrics to adult care easier?*
6. *How has the PACT program helped you to function as a young adult or grown-up in the office of the new adult doctors and nurses?*
   a. *In what ways do you think you are on the right track to begin taking charge of your health?*
   b. *Are there other types of educational materials, resources, or information that you think would be helpful to participants of a PACT program for the movement to adult care doctors and nurses?*
   c. *What else could the PACT program do to help you get ready for the transition to adult care?*
7. *Have you thought about identifying an adult doctor?*

Follow-up/ Probing Questions:

1. *Is there anything else you would like to tell me about the impact of participation in the PACT program?*
2. *Is there anything else that may affect your successful transition to adult care?*
3. *Are there other types of education, resources, or information you think would be helpful in preparing young people like yourself for the transition to adult care and knowledge of sickle cell disease?*
4. *Do you have any question for me at this time regarding this focus group?*

Thank the focus group participant again for their time commitment and travel to the focus group. Give instructions to study participants to see the research assistant or principal investigator individually to complete the paperwork to be compensated for their time commitment and travel to participate in the focus group interviews.

Thank you for your time commitment, travel, and agreeing to participate in this focus group. At this time please proceed across the hall to the counseling room to receive your compensation.

Focus Group Guide derived from Figure 7.4 Creswell (2013, p. 165) and (Porter, Graff, Lopez, & Hankins, 2014).

References

Creswell, J. W. (2013). *Qualitative inquiry and research design: Choosing among five approaches* (3rd ed.). Thousand Oaks, CA: Sage.

Porter, J. S., Graff, J. C., Lopez, A. D., & Hankins, J. S. (2014). Transition from pediatric to adult care in sickle cell disease: Perspectives on the family role. *Journal of Pediatric Nursing, 29*(2), 158-167. doi: 10.1016/j.pedn.2013.10.002

Successful Transition to Adult Care: Impact of Participation in a Transition Program

Focus Group Guide

Figure 2. Dissertation Focus Group Guide for 19-21

Directions: Sections written in *italics* are to be read to participants:
Supplies:
2 digital recorders
2 pencils
2 pens

Time of the Focus Group:

Date:

Place: Sickle Cell Disease Association of America, Mobile Chapter community-based program conference room.

Designated Focus Group by Age:

Facilitator:

Position of the Facilitator:

Research Study Title: Successful Transition to Adult Care: Impact of Participation in a Transition Program

Description of the Purpose:

This proposed dissertation will investigate the impact of participation in a PACT transition program on the successful transition with defined disease specific key indicators and outcome measures. The data generated by this proposed dissertation could be utilized to: (a) provide evaluative evidence-based data on the effectiveness of transition programs; (b) inform, modify, and/or expand current transition programs, practices, and services; and (c) improve the transition experience of AYA with SCD.

Introduction:
Welcome the participant upon arrival.

Once all participants have arrived (wait at least 5-10 minutes after scheduled arrival time).

Start Focus Group; describe the purpose of the focus group.

Welcome and thank you so very much for taking time out of your schedule to participate in this focus group interviews. You have been invited to participate in this focus group to gain valuable information, description, and understanding of the personal experiences of participation in a Pediatric to Adult Care Transition (PACT) Program from the perspective of the adolescent and young adult with sickle cell disease. We want to learn more about what you think, how you feel about participation in the PACT program, and how you are getting ready for the move to adult care when you turn 19. Any information you share will be used for the purpose of the research study only. The focus group will take approximately 60-90 minutes. It will be audio-recorded for the purposes of making sure I don't miss any of your comments or take any of your comments out of context. Your name will not be used in any transcript of the recording.

At this point, ask the participant if he or she have any questions. Once all questions have been answered to the participant satisfaction please begin.

Do you have any questions about the purpose of this focus group?

Thank you for agreeing to participant in this focus group. Before I get into our discussion, let me make a few requests of you. First, speak up so that your comments are captured by the audio-recorder. Please say exactly what you think. Don't worry about what I think. There is no right or wrong answers. You are not required to answer any question you do not want to answer. Your answer to the questions are completely voluntary.

Introduction of the Interview Questions/Topics

The facilitator will introduce each question and explore it thoroughly before moving on to another question/topic. The facilitator will elicit the study participant's thoughts, personal experiences, and opinion, and use probes as needed to assist the study participant in providing a detailed description, elaboration, or clarity on the study participants' thoughts, personal experiences, opinions, and giving examples whenever possible.

Question will be addressed in the following order:

Begin with 2 icebreakers to open up the discussion and start both audio-recorder.

1. *So, what does it feel like being a young adult and all grown-up?*

2. *Well tell me this, what was it like being a member of the PACT program?*

Begin with the focus group discussion questions:

1. *Now tell me, what are some concerns, fears, or worries that you had about changing from your past childhood doctors and nurses to adult care with new doctors and nurses to receive treatment for your sickle cell disease when you turn 19?*
    a. *Do you feel the PACT program was helpful in addressing your concerns, fears, and worries about being ready and changing to new adult doctors and nurses? If so, how? If not, why not?*
2. *What factors do you think may have affected your transition from your current doctors and nurses to adult care with adult doctors and nurses?*
    a. *Can you tell me how these factors help or block your transition?*
3. *How prepared do you feel you are for the transition to adult care? Can you give me some examples of when you did or did not feel prepared for the transition?*
        a. *What have you learned about your disease, medications, and insurance coverage and/or requirements as a grown up or young adult with SCD?*
        b. *What does it means when you say you have sickle cell disease?*
        c. *How has what you learned about your sickle cell disease changed since participating in the PACT program?*
        d. *What other issues or topics would you have liked to learn about the transition to adult care?*

e. *Describe how you would tell or have told your medical history and current illness to health care providers?*

4. *How is the PACT program helping you to get ready for the transition to adult care?*
   a. *In what ways has the program been helpful in getting you ready for the transition to adult care?*
5. *What changes do you feel need to be made to the PACT program to help you to successfully prepare and plan for the move to adult care? And how do you think the changes could or should be made? In order words,*
   a. *What do you think a PACT program should offer to help you successfully move from pediatrics to an adult care doctor?*
   b. *What do you need to make the move from pediatrics to adult care easier?*
6. *How has the PACT program helped you to function as a young adult or grown-up in the office of the new adult doctors and nurses?*
   a. *In what ways do you think you have taken charge of your health?*
   b. *Are there other types of educational materials, resources, or information that you think would be helpful to participants of a PACT program for the movement to adult care doctors and nurses?*
   c. *What else could the PACT program have done to help you get ready for the transition to adult care?*
7. *Have you thought about identifying an adult doctor?*

Follow-up/ Probing Questions:

1. *Is there anything else you would like to tell me about the impact of participation in the PACT program?*
2. *Is there anything else that may affect your successful transition to adult care?*
3. *Are there other types of education, resources, or information you think would be helpful in preparing young people like yourself for the transition to adult care and knowledge of sickle cell disease?*
4. *Do you have any question for me at this time regarding this interview?*

Thank the focus group participant again for their time commitment and travel to the focus group. Give instructions to study participants to see the research assistant or principal investigator individually to complete the paperwork to be compensated for their time commitment and travel to participate in the focus group interviews.

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