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Health Care Transition and Patient-Perceived Quality of Life in Sickle Cell Disease

Karen Alicia Haynes
Walden University

Walden University

College of Social and Behavioral Sciences

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Karen A. Haynes

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Chief Academic Officer
Eric Riedel, Ph.D.

Walden University
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Abstract

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MA, Prairie View A & M University, 2002

BS, Lamar University, 1994

Dissertation Submitted in Partial Fulfillment
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Doctor of Philosophy
General Psychology

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Abstract

Because of the high mortality rate of sickle cell disease (SCD) patients who do not continue care into adulthood, researchers have paid increasing attention to the health care transition experiences of SCD patients. However, a gap exists regarding patients' perspectives of care transition related to their quality of life. The purpose of this phenomenological study, guided by the biosocial-ecological systems model, was to explore the lived health care transition experiences of SCD patients in relation to their health-related quality of life. Data collection included open-ended interviews with 12 patients in the Southwestern United States. Colaizzi's (1978) method of phenomenological data analysis was used to identify themes, including resistance to transition; inadequate transitional support; lack of autonomy and education; fear, anxiety, and stress; and managing other life changes. Results contribute to the existing research on SCD health care transition, broaden understanding of the transition process and provide guidance for improving transition programs.

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Dedication

My dissertation study is dedicated to my youngest sibling, Tynecia Nicole Daniel, who lives with the painful effects of Sickle Cell Disease (SCD) daily. Tynecia, your strength and never-ending belief in God is a testimony to our family. You truly live out Tiffany McCoy’s philosophy, “I Have Sickle Cell Disease, But Sickle Cell Disease Doesn’t Have Me.” To our Angel in Heaven, Aubree, Rest in God’s perfect peace with the knowledge that your mommy loves you dearly and she will keep “Aubree Strong” as we work to find a cure for SCD. #RIPAubree

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First and foremost, I would like to thank God for allowing me to complete this very difficult part of my educational journey. To my husband, Jimmy Haynes, thank you for always having my back. Your never-ending support has not gone unnoticed. To my mother, Manuela Kinsale, thank you for being “the wind beneath my wings.” You have sacrificed much for me to have this opportunity to earn my doctoral degree, and for that I will remain eternally grateful to you. To our children, Amir, Amani, and Sajdah, my prayer is that you use my struggle to complete my dissertation as a personal testimony that “you can do anything through Christ who strengthens you” (Phil. 4:13). To my siblings, Valerson, Allison, Kirk, Tynecia, and Robert, special thanks to each of you for believing in me even when I doubted my abilities. Special thanks to Dr. Alecia Nero, Ms. Tonya Mitchell, Mrs. Princess Iroh, Mrs. Vanessa Faz, and the IRB at the hospital under study for being an intricate part of my dissertation study. You were simply amazing. Your contribution to my dissertation will never be forgotten. To my lifelong friends, anyone who knows me knows that I have too many to name so I will begin by saying, “Thank you for being a friend.” Each of you has heard my cries, laughter, anxiety, and a range of emotions. I wanted to take a moment to personally thank each of you from the bottom of my heart for never giving up on me. James Bailey, thank you for being my personal sounding board and one of my biggest fans. Big thanks to Dr. Singleton, whose words still ring in my ears, “An ABD-all but dissertation is not a degree.” To my Galena

Park ISD (GPISD) family, thank you for supporting my dream of earning my PhD. Special thanks to Dr. Angi Williams (Superintendent of Schools in GPISD) and Mrs. Andy Sellers (Director of Psychological Services); you are appreciated. Ms. Araceli DelaCruz, Dr. Ronda Reyna, Dr. Mekel Harris, Dr. Melvin Robinson, Dr. Alecia Nero, Dr. Darryl McWhorter, and Dr. Singleton, thank you for assisting me by reviewing my work as I developed my research questions. Dr. Marie Alcazar, there are no words to express the appreciation that I feel for the countless hours that you spent opening your home and your heart to me throughout this challenging journey. Thank you, thank you, thank you, Dr. Heisser-Metoyer (chair), Dr. Andrea Goldstein (methodologist/ committee member), and Dr. Tracy Masiello (URR/committee member) for accepting my invitation to serve on my dissertation committee and for providing guidance and support when needed. Dr. HM, as I have grown to affectionately refer to my chair, you may never know the power in your sweet voice and calm spirit. I owe a magnitude of gratitude to you. Your contribution to my dissertation is invaluable. Last but certainly not least, to the study participants who live with sickle cell disease daily, none of this would be possible without your willingness to speak with me about your innermost feelings. Your contribution to my dissertation work and social change as it relates to SCD is undeniably a step in the right direction. May God continue to bless each of you with the gift of good health and prosperity in all that you do. You have enlightened me.

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Chapter 1: Introduction to the Study

Health care transition from pediatric to young adulthood is a challenge in the medical field (de Montalembert, Guitton, & French Reference Centre for Sickle Cell Disease, 2014). The difficulties of care transition are multifactorial and include participants and systems. The current literature indicated substantial barriers involving every aspect of the process that affects patients, caregivers, providers, and systems (Treadwell, Telfair, Gibson, Johnson, & Osunkwo, 2011). Because of additional medical complexity, these barriers are likely to be more evident in patients with chronic diseases such as sickle cell disease (SCD). Patients unprepared for transition from pediatric to adult care are more likely to return to their pediatric providers, utilize emergency rooms, and fail to keep follow-up appointments with health care providers (Bryant & Walsh, 2009).

Sickle cell disease is an inherited red blood cell disorder that has historically shortened patients' lifespans and prevented many from living past childhood. However, recent medical advances have made it possible for many SCD patients to survive into adulthood, making it necessary for them to transition to adult health care. Researchers studying transition difficulties for SCD patients indicated an alarming increase in mortality during this period (Brousseau, Owens, Mosso, Panepinto, & Steiner, 2010; Cadario et al., 2009; Debaun & Telfair, 2012; Quinn, Rogers, McCavit, & Buchanan, 2010). The lack of transitional support and patient readiness are two major barriers to successful health care transition for SCD patients (Bryant & Walsh, 2009). Other barriers include limited time for transitional planning, a lack of resources, poorly developed or nonexistent transitional plans, and no available health care providers (Bryant & Walsh, 2009).

An interdisciplinary approach to health care transition may increase communication and collaboration between SCD patients and their care providers during health care transition. Researchers have explored ways to decrease barriers to care continuity during this period. For example, Jordan, Swerdlow, and Coates (2013) stated that transitional health care should include a patient-centered approach and education for providers involved in the transitional process.

Although it is known that mortality risks for SCD patients increase during the period of care transition (Brousseau et al., 2010; Cadario et al., 2009; Debaun & Telfair, 2012; Quinn et al., 2010), researchers have not explored the process from the perspectives of patients who have successfully completed transition. Further, little is known about the influence of completed care transition on patients' health-related quality of life (HRQoL). In this phenomenological study, I addressed this knowledge gap by exploring the perspectives and experiences related to the care transition process and HRQoL among adult SCD patients who underwent a formal care transition program. Better understanding of patient perceptions of this process and their HRQoL during care transition may help health care professionals improve SCD care transition programs. This chapter includes the problem, study method, and theoretical framework for the study.

Background of the Problem

Sickle cell disease is an inherited genetic disorder that causes abnormal hemoglobin molecules, which results in sickle-shaped red blood cells. These abnormal blood cells can cause a host of medical complications. In addition to coping with these complications, patients must also deal with the psychosocial components of living with a chronic illness (Thomas & Taylor, 2002). As persons living with SCD already have a shortened lifespan, continuity of care is essential to health maintenance (Jordan et al., 2013). According to Hamideh and Alvarez (2013), persons living with SCD have an increased mortality risk after care transition, which is a serious concern for this patient population.

Health care transition for adolescents with chronic and disabling conditions is a national priority that was officially presented by the U.S. Surgeon General in 1984 (Reiss & Gibson, 2002). The Society of Adolescent Medicine and the American Academy of Pediatrics (as cited in Cooley, 2013) also published statements on the importance of youth care transition. Despite these recommendations, debate remains on best practices for structuring SCD transition programs and measuring program effectiveness (Treadwell et al., 2011).

In an effort to understand barriers to the successful transition of SCD patients, researchers have pinpointed several patient-centered issues (Jordan et al., 2013). Many patients express anxiety over parting ways with their pediatric providers and fear that adult care providers will not understand the disease process as it relates to their particular needs. Additional patient concerns include worries related to illness exacerbation and potential changes to available medical coverage (Telfair, Ehiri, Loosier, & Baskin, 2004). Because previous researchers have relied heavily on the experiences of patients currently undergoing care transition, little is known about this process from the perspectives of successfully transitioned patients.

Although researchers have paid increasing attention to the health care transition experiences of SCD patients, a gap exists on the perspectives of patients who have successfully completed care transition. Little is also known about patients' HRQoL during the transition process. I aimed to explore the lived experiences of SCD patients who successfully completed health care transition, specifically related to their HRQoL. The results of this investigation contributed to the existing research regarding health care transition for SCD patients, broadened general understandings of the transition process, and provided guidance for making improvements to transition programs.

Statement of the Problem

Although an increasing number of patients now survive SCD into adulthood, providers and existing health care systems have not adapted to this change in patient population. However, researchers have found that without effective transition processes, patients will suffer. Quinn et al. (2010) found that six out of seven deaths occurred in a sizable cohort shortly after care transition. Much of the literature on SCD transition supports the need to establish transition programs and address barriers to minimize documented mortality increases (de Montalembert et al., 2014). Exploring patient perspectives and experiences is one way to approach this problem. In addition, investigation of SCD patients' perceptions of their quality of life during the transition process may provide valuable information to guide the creation of transition programs and to improve upon previously defined patient-centered barriers.

Research Questions

The following research questions (RQs) guided the study.

RQ1: How do individuals who have transitioned from pediatric to adult care describe their lived experiences in pediatric care?

RQ2: How do individuals who have transitioned from pediatric to adult care describe the transition process?

RQ3: How do individuals who have transitioned from pediatric to adult care describe their experiences in adult care?

Purpose of the Study

In this phenomenological study, I investigated the lived experiences of 12 patients with sickle cell disease who were within the first 3 years of completing transitional care at the University of Texas Southwestern (USTW) Medical Center. The aim of this study was to explore SCD patients' perceptions of their experiences in care transition programs and their quality of life during care transition. The results of this study provide increased insights regarding the care transition process and may lead to the creation of interventions to improve survival rates.

Nature of the Study

This qualitative research study included a phenomenological design and required patient consent and IRB approval. The patients were in a hospital or medical setting receiving adult care services, and the interviews were conducted in that setting. UTSW was the IRB of record and oversaw the data collection. IRB approval was granted upon completion of the IRB application, Consent to Participate in Research form, and Authorization for Use and Disclosure of Health Information for Research Purposes form. UTSW's training institute, The Collaborative Institutional Training Initiative (CITI) Program, required me to successfully complete the following trainings prior to IRB approval: Conflict of Interest Training, CITI Good Clinical Practice, Human Subject Protection Course, Research HIPAA, and University of Texas Southwestern Medical Center Policies.

A phenomenological design was appropriate for this study because I aimed to describe and understand the lived experiences related to the health care transition process for SCD patients. The study included a purposeful criterion sample of 12 patients living with sickle cell disease who received transitional care at UTSW and were within 3 years of their transition to adult care. Patients ages 18 and over with SCD were invited to participate. Patients who were unable to speak English, had poor neurologic functioning, could not independently answer questions, or were unable to provide informed consent were excluded from this study.

Face-to-face interviews provided the primary data source for this study. The semistructured interviews consisted of open-ended questions designed to explore participants' perceptions of their health care transition experiences and quality of life during the transition process. Colaizzi's (1978) method of phenomenological data analysis, as described by Moustakas (1994), served as the study's analysis approach. After collecting and transcribing interview data, I analyzed the transcripts to gain an understanding of the predominant messages shared in the interviews.

After examining participant responses, I determined thematic commonalities among the interviewees using Colaizzi's (1978) six procedural steps for thematic analysis. Key statements were identified to develop formulated meanings. Those meanings were then clustered into themes. The steps of the Colaizzi method included (a) reading the written responses, (b) extracting significant statements or phrases that directly pertained to the transition to adult health care, (c) formulating meaning from these significant phrases, (d) organizing meanings into clusters, which were then referred to as *themes*, (e) describing the results of the thematic analysis and integrating the phenomenon of interest, and (f) validating core themes through member checking.

I used the qualitative analysis software program, NVivo 11, to assist with data organization and analysis. The use of NVivo also facilitated the categorization of supportive excerpts for identified themes. I coded the data according to the themes that emerged. Through this process, I endeavored to report an interpretation of the deeper meaning of the data.

Theoretical Framework

The biosocial-ecological systems model (Treadwell et al., 2011) provided the theoretical framework for the study. According to Bronfenbrenner and Ceci (1994), the biosocial-ecological systems model of health is useful for evaluating the effectiveness of SCD transitional programs. Griffin et al. (2013) adapted the model to investigate SCD transition and emphasize the influences of five primary environmental systems on individuals. These five systems include the individual, the microsystem, the mesosystem, the exosystem, and the macrosystem (Griffin et al., 2013). The individual system signifies an individual's unique features as characterized by diagnosis, age, gender, and ethnicity. The microsystem includes family, school, church, peers, and health care providers who play important roles in individual development. The mesosystem consists of individuals' life experiences and the connections between various microsystems. The exosystem comprises relationships between various indirect external environmental influences such as neighbors, mass media, local politics, industry, and social studies. Finally, the macrosystem consists of cultural influences and attitudes regarding individuals' roles within society. It is the interplay of these systems in patients' lives that can influence the success or failure of the health care transition process (Treadwell et al., 2011). Figure 1 presents a model of the developmental-biosocial ecological model of SCD transition, adapted by Griffin et al. (2013).

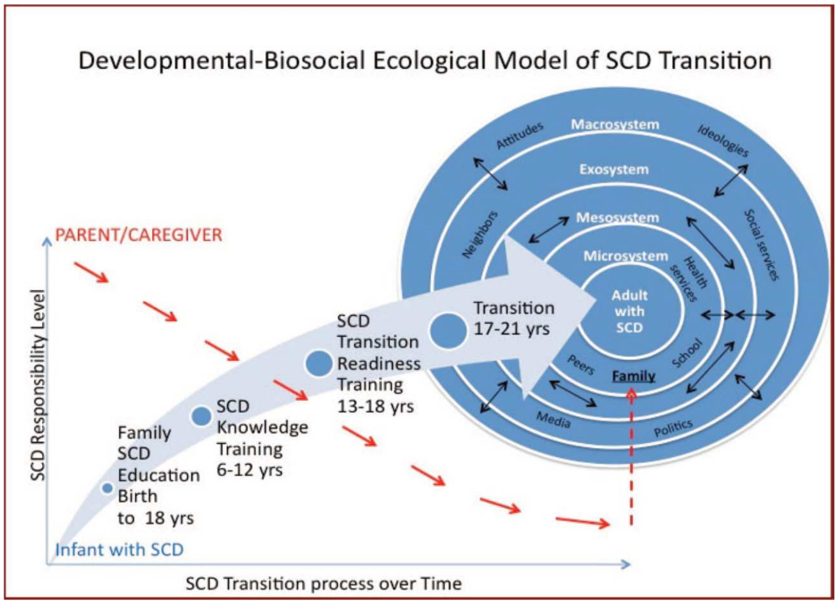

Figure 1. Developmental-biosocial ecological model of SCD transition.

Griffin et al. (2013) used a developmental-ecological framework to design a transition program for SCD patients, which demonstrated increased transition success. The program, called SCD-ABC Transition, “was developed to specifically address the developmental needs of the maturing adolescent and the social-ecological challenges associated with living with SCD” (Griffin et al., 2013, pp. 259–260). Use of the developmental-ecological framework emphasized the importance of beginning the process of transition early in life and continuing to prepare children and adolescents for transition to adult care throughout pediatric treatment. Researchers concluded that use of the model to create transition programs for SCD patients could improve independent self-care, disease knowledge, and long-term health outcomes for SCD patients (Bryant & Walsh, 2009).

The five systems of the biosocial-ecological systems model provided a useful lens for analyzing data collected during interviews. Interview questions were based on the five systems of the biosocial-ecological systems model, in relation to health care transition and quality of life in SCD patients. This framework also helped me organize themes that emerged from participants' responses to the semistructured open-ended questions related to the effectiveness of care transition and patient health-related quality of life (HRQOL). This measure of life quality includes the physical, psychological, and social domains of health that are influenced by individuals' experiences, beliefs, and perceptions (Dale, Cochran, Roy, Jernigan, & Buchanan, 2011). I used the definition of HRQoL provided by Dale et al. (2011) for this study.

Definitions

Health care: Support provided by a medical professional for the well-being of an individual with medical needs (Centers for Disease Control and Prevention, 2013).

Health care transition: A process that requires the attention of pediatric and adult care providers as a patient moves from receiving care in a pediatric setting to receiving care in an adult setting (Sawicki et al., 2011).

Health care transfer: The process of moving patient medical records from one provider to another provider or facility (Cooley & Sagerman, 2011).

Health-related quality of life (HRQoL): The physical, psychological, and social domains of health that are influenced by individuals' experiences, beliefs, and perceptions (Dale et al., 2011).

Patient: A person who receives medical care from a medical provider.

Physician: A person who receives specialized training in the medical field to provide care to persons in need of medical attention.

*Sickle cell diseas*e: A genetic blood disorder that is transferred from the parent to the child from birth (Edwards et al., 2005).

Assumptions

A few assumptions were inherent in the study. First, I assumed participants would respond truthfully to the interview questions. The protection of participants' identities encouraged honest, forthcoming responses. I also assumed that each participant would have a unique perspective to offer, given the variance of life and health care ordeals that sickle cell patients experience. Finally, I assumed that the questions included in the interview protocol would effectively address the research questions. A panel of experts reviewed the questions, which I revised accordingly, to ensure the interview protocol aligned with the study's purpose.

Scope and Delimitations

The scope of this study included patients living with sickle cell disease who received transitional care and who were ages 18 and over. Many conditions may influence the transition from pediatric to adult care during a patient's life; however, recent advances in SCD treatment have necessitated the transition of more SCD patients to adult care. This development represented a gap in the existing research. Therefore, I chose to limit the focus of this investigation to patients with SCD, rather than investigating care transition among patients with other conditions.

Although patients who received transitional care for more than 3 years may have valuable insight, the focus of this study included SCD patients who recently transitioned into adult care. Therefore, only those who were within their first 3 years of transitional care were included. In addition, the scope included patients receiving care from UTSW. Those who are unable to speak English, had poor neurologic functioning, could not independently answer questions, or were unable to provide informed consent were excluded from this study. These criteria were established to ensure that all participants were able to clearly communicate their experiences and perceptions during the phenomenological interviews. To ensure transferability of this research to other contexts, the procedures were thoroughly described and a rich audit trail was maintained through audio-recordings of interviews, transcripts, and research notes.

Limitations

A research study may contain restrictions that are not necessarily within the control of the researcher, known as limitations (Rudestam & Newton, 1992). Data may have been influenced by recall bias in older participants, which I attempted to mitigate by narrowing the age range of participants. In addition, this potential bias was reasonably addressed by limiting the pool of participants to those who were within their first 3 years of transition, thereby reducing the history that participants were required to recall to answer interview questions. Another possible limitation was the disclosure provided by participants. Despite ensured confidentiality, it is possible that participants may have been reticent to share information that would cast a negative light on individuals who assisted them during the care transition process.

Significance of the Study

Results from the study improve understanding related to the health care transitions of patients with SCD. Information gleaned from this study may be used to improve and restructure existing health care transition programs for this patient population. By understanding patient perspectives and experiences of health care transition related to HRQoL, the study contributed to social change by providing information needed to improve the transition process. Although health care transition is an experience that many people with chronic health conditions undergo, successful transition for SCD patients is crucial for reducing mortality rates and helping patients live longer, healthier lives. Findings from the study may be used by stakeholders including doctors, health care administrators, and health insurance companies to inform policy and improve patient quality of life.

Summary

Transition from pediatric to adult care is a national problem for patients living with SCD. Researchers have found that successful transition is not only the responsibility of pediatric providers, but also requires engaged adult providers (Bryant & Walsh, 2009). Participation in structured programs may improve certain aspects or goals of transition. Researchers have discovered that patients living with SCD often experience medical and psychosocial problems because of their illness. Unfortunately, the best way to successfully transition patients with SCD is still unknown. Accordingly, this phenomenological study addressed the transition experiences of patients living with SCD. The following chapter provides a review of relevant literature.

Chapter 2: Literature Review

According to Rees, Williams, and Gladwin (2010), sickle cell disease (SCD) is a common and severe disorder “associated with episodes of acute illness and progressive organ damage, and is one of the most common severe monogenic disorders worldwide” (p. 2018). Clinical treatment for the disease is basic and includes the use of blood transfusions and hydroxycarbamide; however, no drugs have been developed specifically to target its cause. *Sickle cell disease* is a term used to classify all of the disease genotypes including sickle cell anemia, hemoglobin SC disease, and HbS/ß-thalassaemia (Rees et al., 2010). The disorder affects the hemoglobin of red blood cells, causing them to develop into crescent shapes. According to the National Institutes of Health (NIH, 2012), this sickling process results in the breakdown of red blood cells that can lead to anemia, oxygen deprivation, hypertension, and heart failure. The disease affects an estimated 70,000 to 80,000 people in the United States and millions more worldwide (NIH, 2012). Sickle cell disease is an inherited condition that is most common among people of African descent (NIH, 2012).

Children diagnosed with SCD rarely survived past adolescence decades ago; however, medical advances now make it possible for many children with SCD to survive well into adulthood (Smith, Lewis, Whitworth, Gold, & Thornburg, 2011). Because individuals with this disease require ongoing, comprehensive care, improved longevity is often dependent on continued access to medical care after the patient leaves pediatric care (Griffin et al., 2013). The failure to take responsibility for disease management results in increased mortality risks for SCD patients shortly after they transition out of pediatric care (Quinn et al., 2010). Researchers indicated that as SCD patients transition from structured pediatric care to fragmented adult health care that requires significant patient autonomy, they often experience decreased care options and support (Debaun & Telfair, 2012). Although some SCD patients are able to navigate this transition successfully, many more experience barriers (American Academy of Pediatrics, 2002; Scal & Ireland, 2005).

To maximize care provided to transitioning SCD patients and improve survival rates, it is necessary to explore factors that could contribute to better care experiences. Of particular importance is the health-related quality of life (HRQoL) among SCD patients, its effect on treatment, and transition success. In the study, I explored the lived experiences of 12 patients living with sickle cell disease to better understand their experiences of care transition and HRQOL.

The purpose of this chapter is to orient the reader to the existing research related to SCD, health care transition, and HRQoL. A review of current studies provides valuable context, highlight the lack of current research and illustrating the implications of the study.

Search Strategy

I performed an extensive review of available literature for this analysis. I accessed several online databases through Walden University's online library, including Academic OneFile, Academic Search Complete, InfoTrac, Sage Journals, PubMed, ScienceDirect, and Springer. Seminal literature was also identified using the Google Scholar search engine. A variety of search terms were utilized, including *sickle cell disease*, *health care transition*, *pediatric care*, *adult care*, *developmental-biosocial ecological model of SCD transition*, *health care transfers*, *health-related quality of life*, *adolescent*, *chronically ill youth*, *chronic disease*, *transition of care*, *transition*, *chronic care*, *adolescent care transition*, *sickle cell transition*, and *youth with special health care needs*.

Theoretical Foundation

The biosocial-ecological systems model (Treadwell et al., 2011) provided the theoretical framework for the study. This model can be used to evaluate transition programs for SCD patients by emphasizing five systems of influence, including individual, microsystem, mesosystem, exosystem, and macrosystem (Griffin et al., 2013). I designed the interview questions to explore participants' lived experiences within each of these systems. The interplay of these systems can influence the success of transition programs. According to Treadwell et al. (2011), the microsystem involves the immediate environment including family, peer groups, school, and neighborhood. The mesosystem refers to connections between microsystems, while the exosystem includes external factors that affect the development indirectly. Finally, the culture of an individual is encompassed by the macrosystem (Treadwell et al., 2011).

Griffin et al. (2013) used a developmental-ecological framework to design a transition program for SCD patients that demonstrated increased transition success. The program, called SCD-ABC Transition, was created to specifically address the developmental needs and social-ecological challenges of the maturing adolescent living with SCD. Use of the developmental-ecological framework emphasized the importance of beginning the process of transition early in life and continuing to prepare children and adolescents for the transition to adult care throughout pediatric treatment. Researchers concluded that use of the model to create transition programs for SCD patients could improve independent self-care, disease knowledge, and long-term health outcomes for SCD patients (Dale et al., 2011).

Health-Related Quality of Life (HRQoL)

According to the World Health Organization (1946), health includes the absence of disease and the presence of physical, social, and mental well-being. Health-related quality of life (HRQoL) includes the physical, psychological, and social domains of health that are influenced by individuals' experiences, beliefs, and perceptions (Dale et al., 2011). Quality of life (QoL) factors include health status, cognitive function, sexual satisfaction, daily activities, emotional health, and social well-being (dos Santos & Neto, 2013). Researchers indicated that children with SCD often experience psychological and social problems that impede their QoL (Anie, 2005; Barakat, Lash, Lutz, & Nicolaou, 2006; Palermo, Schwartz, Drotar, & McGowan, 2002). Quality of life domains commonly affected by SCD include pain, disease knowledge, school issues, treatment procedures, physical function, self-esteem, and sociodemographic factors (Palermo et al., 2002; Panepinto, Pajewski, Foerster, Sabris, & Hoffman, 2009).

Some researchers suggested that the low QoL among children with SCD may be related to socioeconomic status (Palermo, Riley, & Mitchell, 2008; Panepinto et al., 2009). Hijmans et al. (2010) conducted a quantitative investigation to assess whether reduced QoL was related to the disease or low SES in children with SCD. Study participants included 40 children with SCD and 36 healthy siblings, all between the ages of 6 and 18 years (Hijmans et al., 2010). Hijmans et al. administered the KIDSCREEN-52, which is a self-report questionnaire used to assess HRQoL, to all participants.

Data analysis revealed that the HRQoL of children with SCD was similar to the HRQoL of healthy siblings (Hijmans et al., 2010). The main differences between the SCD patients and their healthy siblings existed within the domains of physical ability and autonomy, of which SCD patients scored much lower. Hijmans et al. concluded that the lower HRQoL commonly observed in children with SCD may be more strongly related to low SES status than other factors, with the exception of physical and autonomy domains:

> As children with SCD are not only affected by their disease but also by their low SES, children with SCD seem to be especially vulnerable compared to other patient populations, and need specific care in the hospital. Therefore, we argue for routine monitoring of HRQoL in children with SCD. (p. 7)

Similarly, dos Santos and Neto (2013) performed a cross-sectional descriptive study to explore the relationship between HRQoL and a variety of sociodemographic characteristics in patients with SCD. Dos Santos and Neto administered the Medical Outcomes 36-Item Short-Form Health Survey (Martinez et al., 2000) to assess the following QoL domains: functional ability, physical aspects, pain, perception of health, social and emotional health, mental health, and vitality. The researchers included 32 patients with SCD in the study.

Dos Santos and Neto found that those patients who had the greatest loss of functional ability or limitations demonstrated the lowest QoL scores. Unemployment was exhibited by 68.8% of patients, and 87.5% had a per capita income equal to 1.5 minimum wages. According to the researchers, the high unemployment status and low income of SCD patients was indicative of impediments to earning power caused by the disease (dos Santos & Neto, 2013). Of all the domains measured, vitality was the most highly rated. This was a substantial finding, because “although sickle cell anemia patients have pain, fatigue and depressive symptomatology, they seek the best coping strategies against feelings of tiredness and exhaustion” (dos Santos & Neto, 2013, p. 244), which may contribute to better coping skills.

According to Schlenz, Schatz, McClellan, and Roberts (2012), assessing HRQoL in children can be complicated by the large number of variables linked to child well-being, such as age, gender, disease severity, caregiver education, locus of control, and medical comorbidities. Further, many instruments are limited to assessment of a short duration, whereas assessment of chronic illnesses requires measures during longer periods of time. Schlenz et al. examined the responsiveness of caregiver reports of pain factors related to physical, psychosocial, and overall HRQoL indicated by the PedsQL, a HRQoL assessment instrument. Study participants included 94 SCD patients between the ages of 2 and 19 years. Schlenz et al. designed the study to assess the responsiveness of the PedsQL to changes in pain related to HRQoL in children and adolescents with SCD.

Schlenz et al. reported that caregiver assessments were predictive of HRQoL related to pain caused by SCD. This was an important finding for children with the disease who are too young or too ill to self-report. Although previous researchers indicated that caregivers may be unable to detect and report accurate psychosocial changes effecting HRQoL (Dampier et al., 2010; Panepinto et al., 2009), Schlenz et al. found the PedsQL to be responsive to such measures. Schlenz et al. explained, “Although proxy reports cannot replace self-reports, caregiver perspectives are considered an integral part of HRQoL assessment” (p. 804).

Additional research has been conducted on the HRQoL of children and adolescents with SCD. Dale et al. (2011) conducted a study including 124 children and adolescents with SCD who were between the ages of 8 and 18 years. The researchers used the PedsQL 4.0 to assess QoL in the SCD participants. Dale et al. compared results of the patient population against data from a study of 10,241 healthy participants published by Varni, Burwinkle, Seid, and Skarr (2003). Self-report measures for both children and parents on the PedsQL 4.0 included physical health, psychosocial health, emotional functioning, social functioning, and school functioning. Dale et al. noted that the overall HRQoL was significantly lower for the SCD population than it was for healthy children. Notably, children with SCD exhibited similar HRQoL scores to those observed in children with other chronic conditions. Similar to findings reported in an earlier study by Varni, Seid, and Kurtin (2001), Dale et al. noted the discrepancy between patient and parent self-reports on the PedsQL 4.0, with patients consistently reporting better HRQoL than parents.

Another interesting finding by Dale et al. (2011) was that parents of SCD patients and those of healthy children perceived the HRQoL of their children differently. Dale et al. reported that “parents of children and adolescents with SCD rated the overall HRQoL, as well as all of the subdomains, lower than did their healthy counterparts” (p. 212). The researchers also posited that more than half of the SCD population (53–63%) would be considered at risk for reduced HRQoL based on item scores that were at least one standard deviation below the healthy population. The domains within which SCD children would be considered at risk for reduced HRQoL included overall HRQoL, physical health, and school functioning. Because HRQoL seemed to be affected across various domains in children with SCD, Dale et al. suggested treatments “such as CT, hydroxyurea, or SCT and even more importantly to provide psychosocial interventions such as assistance with school work, counseling, or play therapy” (p. 213). By better understanding the ways HRQoL subdomains are affected, interventions can be “tailored to address the specific QOL need or needs of each child with SCD” (Dale et al., 2011, p. 213).

Quality of Life (QoL) Inventories

Many HRQoL inventories have been developed to assess QoL in individuals with chronic illnesses. In the following sections, I describe a few of the most recognized tools.

Adult Sickle Cell Quality-of-Life Measurement Information System (ASCQ-Me)

Developed by Treadwell, Hassell, Levine, and Keller (2014), this HRQoL instrument is specific to SCD. Treadwell et al. developed the ASCQ-Me as a supplement to the Patient-Reported Outcome Measurement Information System (PROMIS; Cella et al., 2010). The conceptual model for the ASCQ-Me incorporates a number of factors that affect SCD patients, including stigma, quality of care, living environment, pain, social cognitions, emotional distress, coping skills, social role functioning, and other physical effects (Treadwell et al., 2014). The aim of the instrument is to “provide clinicians with an improved understanding of the lived experience of adults with SCD upon which they can draw to improve their practice” (Treadwell et al., 2014, p. 911).

Child Health Questionnaire

Landgraf, Abetz, and Ware (1999) developed the Child Health Questionnaire to compare the HRQoL of chronically ill children to that of healthy children. The Child Health Questionnaire is a valid predictor of physical and psychosocial well-being (McCullough & Parkes, 2008) and is one of the most widely used measures of HRQoL in children and adolescents (Wrotniak, Schall, Brault, Balmer, & Stallings, 2012).

KIDSCREEN-52

This self-report QoL questionnaire was designed for both healthy and chronically ill children between the ages of 8 and 18. This tool consists of 52 items that assess the following domains, physical well-being, psychological well-being, moods and emotions, self-perception, autonomy, parent relation and home life, financial resources, social support and peers, school environment, and bullying. The instrument has demonstrated satisfactory reliability, validity, and internal consistency (Ravens-Sieberer et al., 2008). Hijmans et al. (2010) noted that because the KIDSCREEN-52 only detects HRQoL for the week prior to assessment, it may not provide the best measure of HRQoL in children with SCD because of the long-term and unpredictable course of the disease.

Life Satisfaction Questionnaire-Short Form (LSQ-SF)

The Life Satisfaction Questionnaire Short Form (LSQ-SF) contains items designed to measure three scales: health, personal relationships, and everyday life. Participants answer items using a Likert scale, and the scores from each group are coded and transformed into a final score between 0 and 10. According to Kristofferzon, Lindquist, and Nilsson (2011), Cronbach's alpha values for the LSQ-SF range from .80 to .90.

Pediatric Quality of Life Inventory (PedsQL)

The Pediatric Quality of Life Inventory (PedsQL) is a caregiver proxy instrument designed to assess the HRQoL in children between the ages of 2 and 18. It includes 23 items that measure four domains of functioning, including physical, emotional, social, and school (Varni et al., 2001). Caregivers use a Likert scale to indicate responses to each of the measures, and averaged scores produce final scores.

General Health Barriers

Chronically ill children and adolescents often experience health-related barriers that healthy children are not exposed to. Agrawal et al. (2012) conducted a study to investigate pediatrician perceptions of barriers faced by children and youth with special health needs. Specifically, Agrawal et al. aimed to assess barriers to care, pediatricians' preparedness to provide care to these patients, and what types of patients' primary care pediatricians felt comfortable seeing. The researchers followed a cross-sectional, descriptive design using mailed surveys (Agrawal et al., 2012). Participants included 376 primary care pediatricians listed on the Illinois Chapter of the American Academy of Pediatrics address list. The survey consisted of three parts: personal characteristics, practice characteristics, and perceptions of 16 barriers, 14 tasks, and 16 types of technologies all related to caring for youth with special needs (Agrawal et al., 2012).

The top five barriers to primary pediatric care for youth with special needs, as perceived by primary care pediatricians, included "insufficient time to care for patients' needs (72%), insufficient reimbursement for time (68%), lack of support services such as case management and social work (59%), lack of knowledge about services available (55%), and lack of understanding of coding/billing (53%)" (Agrawal et al., 2012, p. 40). Of all the potential barriers assessed, a lack of interest in youth with special health care needs was the least indicated. According to Agrawal et al. (2012), the results of this study raise questions about ensuring that the health care needs of special needs youth and children are met. Of particular concern, according to the researchers, is reimbursement for services that improve care for this patient population, "and whose insufficiency impedes" (p. 44) physician care.

Barriers for SCD Patients

While chronically ill patients often experience similar general barriers, patients with SCD may experience those barriers differently, or face additional challenges. One such challenge is the transition from pediatric to adult care. Bryant and Walsh (2009) performed a comprehensive literature review on the transition of chronically ill youth to adult care. The researchers identified 17 empirical studies of analysis, including five that focused on SCD (Bryant & Walsh, 2009). The studies revealed three main categories of obstacles, including lack of transitional support, limited transitional programs, and resistance to transitioning into adult care. Lack of transitional support was indicated by difficulties locating adult care providers, abrupt transfers, lack of transfer resources and personnel, and poor communication between pediatric and adult providers. The researchers also indicated that few of the programs designed to aid SCD patients with transitions from pediatric to adult care exist, although such programs are critical to transition success (Bryant & Walsh, 2009). Clinical recommendations by the researchers included establishing comprehensive goals, educating all stakeholders on transfer issues, providing adult doctors with medical summaries from patients' pediatric physicians, and collaboration between adult and pediatric health care providers (Bryant & Walsh, 2009). Resistance to transition was identified among physicians, parents, and SCD patients, as all parties tended to have mixed feelings about patient transition.

In conclusion, the clinical recommendations made by Bryant and Walsh (2009) included establishing a buddy system with other patients going through similar transition experiences, and forming collaborative relationships between pediatric and adult care providers. An important finding was that few qualitative studies regarding the perceptions of the transition to adult care by youth with SCD exist. Most of the 17 studies that the researchers analyzed employed quantitative or mixed methods, and did not provide an in-depth look at patients' experiences with transition. Researchers called for further research to better understand these experiences in order to create and establish more effective transition programs. Further, they noted that most of the recommendations made were based on "speculation and experience rather than empirical evaluation" (Bryant & Walsh, 2009, p. 48). Because of this, Bryant and Walsh posited that further research was needed to evaluate the clinical outcomes of such programs.

Bryant, Young, Cesario, and Binder (2011) conducted a phenomenological investigation of the experiences and expectations of chronically ill youth with SCD who transferred from pediatric to adult care. The sample included 14 sickle cell patients between the ages of 19 and 25. Bryant et al. tape-recorded, transcribed, and analyzed semistructured participant interviews lasting approximately 45 minutes. The following four major themes emerged during analysis: reactions to the adult care transition, concerns about transition experiences, being forced into adult care, and general adult care transition. According to the researchers, these themes indicated the adjustment process that SCD patients are forced to undergo, despite reported reluctance (Bryant et al., 2011). "All the participants in the study stated either that they did not want to leave pediatrics or they were not ready to leave pediatrics" (Bryant et al., 2011, p. 281). Many participants expressed concerns about what type of care they would receive from new providers and reported feelings that they were being “put out” (Bryant et al., 2011, p. 279). Participants explained that they eventually accepted having to leave pediatric care. This acceptance included being introduced to adult care, interacting with their new care provider, and recognizing that participants were now to be treated as adults (Bryant et al., 2011). For most patients, once accepting the transition, patients found the adult care environment to be welcoming and informative. Participants also expressed feeling greater control of their care, which helped improve their attitudes toward transition (Bryant et al., 2011)

While most researchers studying transitional care of SCD patients point out associated challenges, Bryant et al. (2011) were the first to acknowledge that the benefits of transition, including being treated as an adult and increased control and independence of health care decisions, can outweigh the difficulties. Researchers suggested further studies examining transitional preparation are needed to help patients with SCD successfully move into adult care. Some of the interventions that should be examined include early and ongoing programs for transition preparation, or the effectiveness of educational programs designed to reduce barriers and resistance to transition (Bryant et al., 2011).

Youth Transition Programs

As health care advances, a greater number of youth with special health care needs (YSHCN) now survive into adulthood (Bloom et al., 2012; Perrin, Bloom, & Gortmaker, 2007). According to the American Academy of Pediatrics (2002), nearly 500,000

YSCHN in the United States transition into adult health care each year. The goal of the transition process is to maximize patient functioning and potential by providing quality, developmentally appropriate, and uninterrupted health care from adolescence into adulthood (American Academy of Pediatrics, 2002). Transition programs for youth with chronic illnesses should be flexible, developmentally appropriate, and support emerging autonomy among patients (Rosen, Blum, & Britto, 2003).

Bloom et al. (2012) conducted a literature review to examine the general outcomes and best practices of existing health care transition programs. Fifteen studies met the researchers' inclusion criteria, and included research regarding the health care needs of transitioning patients with cystic fibrosis, developmental disabilities, diabetes, and congenital heart defects. Bloom et al. found that although youth with milder conditions and no physical limitations appeared to transition with relative ease, those with more complex conditions experienced greater transition barriers. Youth with special health care needs of racial or ethnic minorities experienced greater difficulties obtaining access to care, and for some, transition to adult care resulted in health insurance gaps or reduced service quality. Researchers concluded that, while existing literature provided information on how well YSHCN transition from pediatric to adult care, details about transition programs that may assist were sparse. Bloom et al. stated, "the dearth of evidence regarding transition for YSHCN indicates the need for rigorous research into the elements of effective programs to facilitate transition to adulthood" (p. 218). The researchers suggested that better understanding of these key elements could lead to improved outcomes and more efficient care models for transitioning YSHCN (Bloom et al., 2012).

Some researchers also indicated that YSHCN receive deficient assistance in navigating the move from pediatric to adult care (Lotstein, Ghandour, & Cash, 2009; Lotstein, McPherson, Strickland, & Newacheck, 2005). This is often because providers are not adequately equipped to provide effective transition care. Nishikawa, Daaleman, and Nageswaran (2011) analyzed responses from the 2005–2006 National Survey of Children with Special Health Care Needs (NS-CSHCN) to explore the connection between the scope of physician practice and the quality and effectiveness of transition services provided to YSHCN. The researchers specifically analyzed caregiver responses to the following three questions: (a) "Have your child's doctors or other health care providers talked with you or your child about his/her health care needs as he/she becomes an adult?"; (b) "Has anyone discussed with you how to obtain or keep some type of health insurance coverage as your child becomes an adult?"; and (c) "How often do your child's doctors, or other health care providers encourage him/her to take responsibility for his/her health care needs, such as taking medication, understanding his/her diagnosis, or following medical advice?" (Nishikawa et al., 2011, p. 210).

An analysis of caregiver responses to the three questions of interest revealed that youth with lifespan-oriented providers were more likely to review transitional health needs and adult health insurance coverage with patients than child-only providers were. Data did not indicate any significant differences in encouragement toward autonomy.

While the researchers acknowledged that no simple solution improved the quality of transition care for YSHCN, care from lifespan-oriented providers who took a life course approach may provide better transition assistance than sole assistance from pediatric providers. Researchers called for future researchers to consider the effects of training provided to health care providers to help YSHCN identify effective approaches and planning to optimize transitions from pediatric to adult care.

In response to the general paucity in the literature on transition programs, Grant and Pan (2011) analyzed five Canadian transition programs designed to help youth with chronic illnesses transition from pediatric to adult care. These programs included ON TRAC, Good2Go Shared Management Model, The Maestro System Navigator, Be Your Own Boss Program, and Young Adults with Rheumatic Diseases (Grant & Pan, 2011). Grant and Pan reported that some programs demonstrated effectiveness in helping ease patient frustrations, establish regular follow-up visits, and reduce overall adult care dropout rates. The researchers revealed similar themes during the analysis of different programs; however, the researchers varied in their reflection of recommended policies and practices (Grant & Pan, 2011). The researchers concluded that a need exists to further evaluate the effectiveness of transition programs to ensure that transition goals are met.

Although the number of studies regarding the process of transition from pediatric to adult health care in children and adolescents with chronic illnesses has steadily risen during the last decade, many of these researchers focus on the perspectives of health care providers and caregivers. Betz, Lobo, Nehring, and Bui (2013) recognized the apparent lack of studies that gauged the perspectives of SCD patients, and performed a systematic review to analyze data that had already been obtained. Betz et al. analyzed 144 studies for adolescent perspectives on health care transition. Five themes emerged from the analysis, including adolescents' and emerging adults with special health care needs' (AEA-SHCN) reflections on transition services received, recommendations for transition program development, identified transition obstacles, expectations related to transition, and issues related to self-management of health care needs.

Studies that Betz et al. (2013) analyzed which investigated youths' perspectives seemed to focus on the transfer aspect of care, gathered retroactively. Further, most of the studies that the researchers reviewed were international and reflected "health care systems that are very different from those in the United States" (Betz et al.,, 2013, p. 332). Just 29% of the studies were conducted within the United States. This particular revelation was unsettling because, as Betz et al. noted, the voice of transitioning patients within the unique social, cultural, and health care organizational factors of the United States must be identified in order to create programs that maximize transition effectiveness at home. Further, larger and more diverse studies are needed to account for differences in factors such as socioeconomic status, disease-specific conditions, and ethnicity. Betz et al. concluded that "Additional research is needed to develop and implement evidence-based approaches to HCT care" (p. 333). Without further research, challenges to provide effective health care transition services to youth with chronic illnesses will "remain elusive" (Betz et al., 2013, p. 333).

Much of the research regarding transition involved quantitative methods, and failed to provide a deeper understanding of challenges from the perspectives of chronically ill patients. In a recent synthesis of qualitative studies, Fegran, Hall, Uhrenfeldt, Aagaard, and Ludvigsen (2014) explored the experiences of adolescents and young adults with chronic illnesses when transitioning from pediatric to adult hospital care. Researchers analyzed 18 studies regarding patient transition experiences, and emerging themes were synthesized into the following four categories: “facing changes in significant relationships, moving from a familiar to an unknown ward culture, being prepared for transfer and achieving responsibility” (p. 129). Researchers discovered that the transition experiences of chronically ill youth often involved more than just a ward transfer; it represented complex changes in developmental, health, situational, and organizational factors.

The analysis by Fegren et al. (2014) revealed a couple of interesting points. Researchers indicated that while increasing autonomy was crucial to effective patient transitions from pediatric to adult care, “it is hard for young adults to become independent if their parents have difficulty letting go of their responsibility” (Fegren et al., 2014, p. 132). However, because emotional separation from parents and increased identification with peers typically occurs during mid-adolescent years, peer support during the transition could help young adults adapt to the changes in health care. Another interesting finding was that despite the emphasis on chronological age for determining developmentally appropriate stages for transition, adolescents in the studies tended to cite individual maturity as more critical to transition readiness than chronological age (Fegren et al., 2014). According to McDonagh and Kelly (2010), the age of transition onset was typically around 16; however, the best time for young adults to transition is after the age of 18, because brain development continues into the early 20s (Rutishauser et al., 2011). Ultimately, Fegren et al. discovered that transition programs need to reflect a holistic approach to adolescents' experiences in order to maximize the effectiveness of health outcomes.

Transition Readiness

One of the challenges with transition from pediatric to adult care in children and youth with chronic illnesses is "the lack of a validated, patient-centered instrument to assess youths' ability to make appointments, understand their medications and other skills needed for transition" (Sawicki et al., 2011, p. 161). According to Sawicki et al. (2011), a number of inventories exist to assess transition programs, but do not consistently measure stages of readiness for each skill needed to ensure smooth transition to adult care. In response, the researchers conducted an evaluation of the formulation, development, validity, and internal reliability of the Transition Readiness Assessment Questionnaire (TRAQ), a transition-readiness scale. Sawicki et al. adapted the stages of change model to design the TRAQ, and testing indicated that the instrument may help identify the developmental stages of transition readiness, which would assist health care providers with identifying appropriate transition interventions based on individual skill development. The final instrument assessed skills within two broad domains of self-management and self-advocacy. Although Sawicki et al. acknowledged that this two-domain structure may evolve as further studies take place; it provided a crucial first step toward creating a tool to assess the development of patient skills critical to successful health care transition.

Because much of the literature related to transition readiness involved specific diseases from the perspectives of physicians, a gap exists on the broad, common experiences of adolescents with chronic illnesses from the perspectives of the patients. In response, Staa, van der Stege, Dedeloo, Moll, and Hilberink (2011) conducted an investigation on adolescent perspectives of transition readiness in relation to sociodemographic characteristics, disease-related factors, effects of the health conditions, self-management abilities, and overall attitude toward transition. The study population included 954 patients between the ages of 12 and 19 who suffered from a variety of chronic illnesses, including congenital anomalies, neoplasms, endocrine disorders, metabolic diseases, immunity disorders, and musculoskeletal diseases (Staa, van der Stege, et al., 2011). Participants responded to a questionnaire that measured each of the five factors under investigation.

Overall, Staa, van der Stege, et al. (2011) found 56% of respondents perceived themselves as “probably” or “definitely” ready to transfer to adult care (p. 299). A positive association between transition readiness and sociodemographic characteristics was indicated in that older participants exhibited higher transition readiness, and boys were more prepared for the transition than girls were. Researchers also reported that attitude toward transition and self-efficacy in managing daily care needs were correlated with transition readiness (Staa, van der Stege, et al., 2011). Because disease-specific variables were not strong indicators of transition readiness, Staa, van der Stege, et al. posited "transition issues are not unique to any disease process, but are instead universal among all those growing up with special health care needs" (p. 300). Staa, van der Stege, et al. stressed the need for early preparation for the transition to adult care so that the process was not abrupt. Overall, because the data indicated that children and adolescents with chronic illnesses experience many of the same aspects related to transition readiness, a general assessment tool, such as the TRAQ, may be useful for implementing generic transition readiness assessments.

Staa, Jedeloo, Meeteren, and Latour (2011) conducted another study based on the perspectives of young adults with chronic conditions. The researchers wanted to assess the experiences of transfer and identify ways to improve the transition from pediatric to adult care in those with chronic illnesses (Staa, Name, et al., 2011). The qualitative investigation consisted of semistructured interviews and included a sample of 65 participants between the ages of 15 and 22. Seven patient populations were included, although no differences related to conditions seemed to influence attitudes and concerns assessed by the investigation. As other researchers have indicated, Staa and Jedeloo et al. (2011) reported that young adult patients perceived the transition from pediatric to adult care to be one of challenges, and that early preparation for the transition was essential to maximizing transition success. An interesting finding was the existence of cultural and organizational differences between pediatric and adult care providers that can impede transition success. Staa and Jedeloo et al. suggested that better communication between health care practitioners may improve transition experiences for young adults. "The directions emerging from this study are clear: better preparation for transition, early start and involvement of adolescents and parents. The focus should be on strengthening adolescents' independency and changing parents' roles" (Staa & Jedeloo et al., 2011, p. 830), and these actions should begin in early childhood.

SCD Transition Programs

Transition planning for SCD patients must take the developmental changes of patients into account, and not solely focus on clinical needs (Musumadi, Westerdale, & Appleby, 2012). According to Watson (2000), many challenges can be found in connection with transitioning adolescent SCD patients from pediatric to adult care. Such challenges include excessive patient dependence on caregivers, developmental problems, stunted psychosocial development, disruptions in care, disengagement from care, elevated health care costs, and increased morbidity and mortality (Watson, 2000). Children and adolescents with SCD often experience diverse issues caused by a variety of factors, such as socioeconomic status, immigration status, education, and familial breakdown (Musumadi et al., 2012). The ultimate goal of a health care transition program for SCD patients is "competence and emotional readiness to cope with the move to adult services" (Musumadi et al., 2012, p. 38). Accordingly, patient-centered planning that acknowledges individual patient differences and their evolving needs is critical to program success (Department of Health, 2008). A gradual transition process should be set in motion for SCD patients that details a plan for care, outlines existing and potential health issues, and provides direction for managing such issues (Musumadi et al., 2012).

Researchers have designed and tested many transition programs for SCD patients in recent years. Hankins et al. (2012) created a transition pilot program to help adolescents with SCD identify and establish care with adult providers. The pilot program consisted of three components: a tour of adult SCD programs, a discussion with pediatric staff, and scheduling initial appointments with their new adult care providers. Participants included adolescents between the ages of 17 and 19 and their parents. Hankins et al. conducted the tour every 3 months, depending on the availability of adult care providers, and lasted about 45 to 60 minutes. After each tour, patients and their parents would return to their home pediatric facilities, where they had the opportunity to discuss the transition process, particularly their "fears and expectations, insurance coverage, and future educational and vocational goals" (Hankins et al., 2012, p. 46). A few days later, a nurse case manager contacted each patient to help them make their first appointment with an adult care provider (Hankins et al., 2012).

According to Hankins et al. (2012), all of the program participants and their parents rated the transition program as helpful or very helpful. Seventy-four percent of the transition program participants completed their first appointment with an adult care provider within three months of participating in the program, compared to 33% of patients who were not in the program (Hankins et al., 2012). Hankins et al. concluded that the program, which was an innovative approach to improving the transition from pediatric to adult care for SCD patients, “was feasible and well accepted by adolescents, their parents, and health providers” (p. e47). Hankins et al. also explained that a large portion of program participants went on to fulfill appointments with their new adult care providers. Hankins et al. posited that participation in a structured program could bridge the transition from pediatric to adult care for SCD patients, and highlighted the need for more research regarding such programs about behavioral and medical outcomes.

Similarly, Doulton (2009) reported on the success of a SCD transition program employed in two Texas hospitals. The program provided adult physicians with detailed patient health and contact information prior to initial meetings with them. During the last meeting with pediatric providers, the differences between pediatric and adult providers were explained to patients. After the last pediatric visit, a transition celebration was held for patients, pediatric staff, and patient families (Doulton, 2009).

A pediatric sickle cell nurse was available to attend the first adult provider appointment with SCD patients. After the first appointment, a follow-up call was made to patients to assess their concerns and experiences (Doulton, 2009). Doulton (2009) noted, “with each transition, something new was learned and the process was adapted to incorporate that experience” (p. 121). After transition was complete, it was the patient’s responsibility to manage appointments and care. Doulton pointed out that when developing transition programs, it is important to consider the uniqueness of each individual, especially differences in education, socioeconomic status, coping strategies, health, maturity, and education. Further, Doulton explained that despite the best efforts of health care providers, “you cannot change anyone’s behavior if they do not see their behavior as a problem” (p. 121) and that some patients simply do not understand that it is not in their best interest to obtain health care on an as-needed basis. While the focus of this program was on the actual transition process, energy was also put into preparing patients for transition from the time they first entered the program. This was done by encouraging education and active patient participation from an early age, with the hopes that they would become involved in their health care as they grew older (Doulton, 2009). At age 13, SCD patients were provided with a transition binder to help them begin to take active roles in their care. Between the ages of 14 and 16, a program called Coaching Through the Emergency Department was offered to help patients learn to advocate for themselves, from triage through discharge (Doulton, 2009).

While several pilot transition programs for youths with SCD exist (Doulton, 2009; Hankins et al., 2012), the use of different evaluative measures and inconsistent outcomes has failed to lead to a theoretical framework to guide program development. Griffin et al. (2013) examined recent programs and selected one particular program to critically analyze—the Sickle Cell Disease-Age Based Curriculum (SCD-ABC; Treadwell et al., 2011). The evaluation focused on the components, challenges, and suggestions for applicability of the SCD-ABC program as a framework for the development of other programs. The SCD-ABC program utilized a development framework that incorporated biosocial and ecological transition (Griffin et al., 2013). Transition readiness began at the time of diagnosis, and several methods were used throughout the program to provide education to caregivers and patients, as appropriate. Four program components designed to improve transition readiness included: (a) a community needs assessment roundtable that incorporated stakeholders; (b) patient and family education days that provided education and mentoring; (c) monthly teen clinics that offered individualized care, education, and support; and (d) a quarterly transition day event which served as the final event prior to transition (Griffin et al., 2013).

The SCD-ABC program was administered to the SCD community in the metro-Atlanta area, which has a population of more than 1,700 children and adolescents with the disease. Griffin et al. (2013) reported that the developmental-ecological framework of the SCD-ABC program demonstrated increased transition success. The researchers noted that the preplanning phase of the program was particularly helpful to identifying potential challenges, and although such issues are likely to vary by region and culture, the general framework of the SCD-ABC program “can be modified to suit individual needs” (p. 260). While preliminary results from the program indicated increased knowledge and improved transition among SCD patients, Griffin et al. acknowledged that longitudinal research is necessary to adequately measure the program’s overall success.

Cerns, McCracken, and Rich conducted a comprehensive literature review of SCD transition programs in 2013. Findings echoed themes reported by individual studies previously discussed in this section, including encouraging self-management, independence, access to skilled adult providers, adequate communication, follow-up challenges, and patient apprehension related to transition (Cerns et al., 2013). In response to needs discovered by their review of existing studies, the researchers partnered with a 500-bed teaching hospital and constructed an interdisciplinary team of health care professionals. The team consisted of direct-care nurses, a nurse educator, a nurse manager, doctors, social workers, pharmacists, emergency workers, and case managers (Cerns et al., 2013). The goal of the transition program implemented by the interdisciplinary team was to provide a seamless transition from pediatric to adult care and prepare SCD patients to take responsibility for their health care needs.

The interdisciplinary team worked together to provide inpatient hospital tours to familiarize patients with differences in pediatric and adult emergency departments, triage processes, admission processes, and hospital layouts. The tours included all members from the interdisciplinary team, and were followed by informational sessions that addressed health care expectations and gave patients the opportunity to ask questions related to pain management. At the conclusion of the informational session, patients were transported back to their pediatric facility for follow-up appointments. Researchers concluded that patients “indicated they had less apprehension about entering the adult health care system, and recognized their responsibilities as patients and their expectations during an inpatient stay” (p. 255). The interdisciplinary team reported that the program provided a great opportunity to meet with patients and their families, encouraged collaboration between departments and hospitals, and helped them provide better care to incoming transitioning SCD patients.

Lebensburger, Bemrich-Stolz, and Howard (2012) also conducted a comprehensive literature review of the status of current SCD transition programs, factors critical to effective transition, and patients' readiness for transition. Lebensburger et al. noted that while substantial research existed on transition programs in general, the current literature on transition care of SCD patients was extremely limited. Based on Lebensburger et al.'s review of current programs, the researchers recommended the following direction for future research of transition care programs aimed specifically at children and adolescents with SCD: (a) additional research to address barriers to transition from all stakeholders (i.e., patients, physicians, and advocacy groups); (b) evaluation of outcomes associated with various transition programs to assess the effect on patients' morbidity, mortality, health care costs, and QoL; and (c) investigation of effective strategies that promote provider expertise and commitment to patient care.

Role of the Family

Many researchers have examined patient and caregiver perspectives of transition (McPherson, Thaniel, & Minniti, 2009; Telfair et al., 2004), but Porter, Gaff, Lopez, and Hankins (2014) recognized that transition experiences from the perspectives of family members (other than caregivers), such as siblings, was lacking. In response, the researchers conducted a qualitative examination of transition experience perspectives of patients with SCD, their close siblings, and caregivers in order to identify further recommendations for improving transition (Porter et al., 2014). Porter et al. conducted focus groups with 15 SCD patients and their families. During analysis of transcriptions from the focus group interviews with patients, four core themes emerged, including "awareness of transition, feelings about transitioning, concerns about adult care providers, and recommendations for pediatric teams" (Porter et al., 2014, p. 161). Focus groups from the sibling interviews revealed two core themes: concerns about siblings' abilities to care for themselves, and transition recommendations. Among caregivers, the themes that emerged included "preparation for the transition, concerns about transition, and recommendations for transition" (Porter et al., 2014, p. 163).

Porter et al. (2014) noted that patients and family members both indicated a desire to understand what to expect when transitioning from pediatric to adult care. Caregivers and siblings wanted to better understand how to prepare for transition challenges so they could foster independence and support SCD patients. Porter et al. noted, "even though siblings were not the direct recipient of care, they were exposed to and, in some cases, directly involved in efforts to prepare the adolescent for the transition to adult care and adult responsibilities" (p. 164). Porter et al. concluded that adolescent SCD patients, their siblings, and caregivers all play a unique role in the transition preparation and planning process, although perceptions regarding transition appeared to be similar. The results of this investigation indicated that assessing the perspectives of adolescent SCD patients and their family members may provide researchers with better insight into the transition process and assist in the development of tailored, effective transition plans.

Summary

As more children with chronic illnesses progress into adulthood, thanks to advances in medical technology, an increased awareness of the challenges associated with transitions from pediatric to adult care has occurred. Research regarding the topic has shed light on a variety of factors that may influence transitioning SCD patients; however, studies are still in their infancy. For this reason, continued research regarding the transition experiences of children and adolescents with SCD is essential to improving the effectiveness of programs aimed at helping these patients move from pediatric to adult care.

In the following chapter, I discuss details of the study's methodology. This includes the study's design, rationale, and participant selection. In addition, I detail the data collection and analysis procedures, as well as issues of trustworthiness and ethics.

Chapter 3: Research Method

The purpose of this phenomenological study was to explore the lived experiences of 12 patients living with SCD who were within the first 3 years of leaving transitional care from a medical center in the Southwest United States and who are now receiving adult care. The findings from the study increase understanding of factors critical to successful care transition programs and quality of life for patients with SCD. In this chapter, I describe the study's design, sample, and sampling procedures. In addition, I detail data collection and analysis protocols, potential issues regarding ethical research, and the steps taken to prevent harm to participants.

Research Design

This study involved a qualitative methodology to examine the lived experiences of SCD patients between the ages of 18 and 21 who made the transition from pediatric to adult care within the last 3 years. All participants were treated at a medical center in the Southwest United States. Qualitative methods are particularly useful when attempting to understand the nature and essence of a phenomenon. Using Husserl's tenets of transcendental phenomenological design, I examined participants' lived experiences (Moustakas, 1994) to explore thoughts and perceptions related to their shared experiences.

Transcendental phenomenology refers to the identification and exploration of a particular phenomenon through the lived experiences of participants (Moustakas, 1994). Using transcendental phenomenology, I was able to capture and reflect participants' personal experiences. I addressed the following research questions.

RQ1: How do individuals who have transitioned from pediatric to adult care describe their lived experiences in pediatric care?

RQ2: How do individuals who have transitioned from pediatric to adult care describe the transition process?

RQ3: How do individuals who have transitioned from pediatric to adult care describe their experiences in adult care?

Participants filled out a short demographic questionnaire prior to the interview. Data gathered included participants' gender, current age, date of original diagnosis, and race (see Appendix B). A description of the participants in the study is presented in Chapter 4. I conducted semistructured interviews with a sample of 12 SCD patients who recently experienced the transition from pediatric to adult care. Face-to-face interviews were conducted with 12 participants.

I asked a series of open-ended interview questions designed to answer the research questions. This allowed for unstructured and spontaneous data collection. I asked participants to provide a desired pseudonym prior to audio recording. I then noted this pseudonym and created a key to match these pseudonyms back to the participants. During the course of the interview, only the pseudonym was used when referring to the participant by name. I then transcribed de-identified responses. The qualitative analysis software program, NVivo 11, aided in the organization and analysis of the interviews.

After examining participant responses, I determined thematic commonalities among the interviewees using Colaizzi's (1978) six procedural steps for thematic analysis: (a) reading of the written responses; (b) extraction of significant statements or phrases that directly pertain to the transition to adult health care; (c) formulation of meaning from these significant phrases; (d) organization of meanings into clusters, which are then referred to as *themes*; (e) description of the results of the thematic analysis and integration of the phenomenon of interest; and (f) validation of core themes through member checking (Colaizzi, 1978).

Rationale

I employed a phenomenological research design. I selected a qualitative method because qualitative research allows for the study of a phenomenon in its natural setting. Qualitative methods allow researchers to gather data that are unique to each individual experience, which helps improve overall understandings of a phenomenon (Patton, 2007). Data are subjective and based on each individual's personal experience, making the data interpretative or personalistic. Because individual experiences do not occur simultaneously, the information is also situational.

Data from the study were used to understand the transition experiences of SCD patients who moved from pediatric to adult health care services. The data also helped to identify areas of excellence and areas where opportunities to change or improve services exist.

Context of the Study

I considered other qualitative designs before selecting a phenomenological design.

These included ethnography, grounded theory, narrative inquiry, and case study. A description of each of these methods and rationalization for their not being selected follows.

Ethnography is generally used to investigate culture and may focus on elements such as language, rituals, relationships, and ceremonies (Tracy, 2013). The researcher gathers data through researcher immersion as an unobtrusive observer. This long-term immersion leads to thick description that the researcher can mine for information. This type of research would not have been effective for this study because the focus pertained to specific transitions and reactions, not a broad understanding of culture.

Another qualitative research design called narrative inquiry involves participants' stories as the basis for inquiry. Researchers examine these stories for information to answer the research questions. Researchers implement narrative inquiry to examine stories in three dimensions: place, time, and social interaction (Clandinin, 2006). With this method, the story is the focus, not themes based on individual experiences. Therefore, this method would not have provided information needed to answer the research questions of the study.

The case study is a qualitative design that researchers use to describe, assess, and evaluate an area of interest through the use of cases (Yin, 2014). When using more than one case, a common thread or theme must exist. Cases may include data gathered though fieldwork and secondary resources, such as government data, organizational records, or online data. The researcher organizes and analyzes all data to develop a deeper understanding of the case(s). The case study model is applied when a researcher seeks to understand how and why phenomena occur (Creswell, 2007). This method was not appropriate because I focused on the lived experience rather than the case itself. Case study research is useful to gain a comprehensive understanding of a situation (Yin, 2014), but it did not align with the purpose of understanding the phenomenon of SCD patients' transition to adult care.

Grounded theory is another well-known qualitative design. However, it was not appropriate for the study because the goal of a grounded theory study is to develop new theories (Moustakas, 1994). In grounded theory, a researcher conducts interviews or gathers data, analyzes them, and returns to gather more data before beginning analysis. This cycle is repeated until data begin to reveal a theory. Understanding the data involves constant reflection and analysis by the researcher. The theory is said to be grounded in the data (Creswell, 2007). I aimed to understand a phenomenon rather than to create a theory. Therefore, grounded theory was not appropriate.

I selected a phenomenological design as the appropriate choice to explore participants' lived experiences. Phenomenology allows the researcher to develop a richer understanding of the perceptions and meanings ascribed to participants' experiences (Moustakas, 1994). A phenomenological lens allowed me to examine data without bias or judgment. An essential element of this approach is for the researcher to bracket personal biases and preconceptions prior to and throughout the study. This helps the researcher to separate preconceptions so they do not affect the coding and thematizing of data, and to arrive at unbiased results (Moustakas, 1994).

Applying a transcendental phenomenological design enabled me to hone in on the lived experiences of participants (Moustakas, 1994). I explored SCD patients' perceptions of care transition from pediatric to adult care. I also explored participants' quality of life during the care transition. Participants were SCD patients who had had recently transitioned (within 3 years) from pediatric to adult care. Working across participants enabled me to analyze and reduce the interview responses to an essence representative of the sample's overarching experience. Open-ended face-to-face interviews allowed for the exploration of a variety of experiences and perceptions (see Appendix A). Following the Colaizzi (1978) method of analysis, I pinpointed noteworthy statements, from which meaning units were produced and a description of the essence of the phenomenon was generated.

Role of the Researcher

My role was to design the study, collect the data, analyze the data, and present the results. I maintained an open mind to objectively interpret multiple experiences and unexpected occurrences. I encouraged participants to speak openly of their experiences and to elaborate on responses when necessary. Participants were encouraged to provide honest answers to each interview question. I created a climate in which participants felt comfortable so they would be more likely to provide honest and comprehensive responses.

I recorded and transcribed interview exchanges into textual data. I created a separate Word document for each interview. I then assessed each response to ensure that they were accurate. Prior to transcribing with the raw data, I de-identified interviewees. Participants were assigned a pseudonym during the introduction, and actual names were not spoken during the interview (see Appendix A). Pseudonyms were compiled into a master identification list, where names were matched to corresponding pseudonyms so that transcripts could be identified at a later date, if necessary. Only I have access to this master list.

Additionally, I searched for any discrepancies within the responses; any irregularities were presented so all angles were accurately reported. I focused on Husserl's concept of *epoché*, also known as bracketing. *Bracketing* refers to setting aside personal experiences as much as possible to take a fresh perspective toward the phenomena under study (Moustakas, 1994). I exercised bracketing to mitigate personal biases or beliefs.

I did not have any personal relationships with the participants or have authority over them. As such, no issues of power differentials were expected. I did not provide any tokens of appreciation to participants, monetary or otherwise. In addition, I had no personal relationship with any participants, so no conflicts of interest or bias was expected.

Participant Selection

Sample Size

Guest, Bunce, and Johnson (2006) determined that a sample size of 12 was typically appropriate to achieve both data and thematic saturation in qualitative interview-based research when the participants are similar. I recruited interviewees based on identical inclusion criteria, and 12 participants were invited to participate in the study.

Recruitment Strategy

Purposeful criterion sampling was used to identify potential participants. The inclusion criteria required that participants were individuals living with SCD. They were required to have transitioned from pediatric to adult-centered health care within the previous 3 years, to have utilized the services of the study site hospital, and to be 18 years of age or older.

Permission was requested from the Southwestern U.S. hospital to post a flyer to recruit potential candidates for participation. The flyers described the study and identified the inclusion criteria. The flyers instructed potential candidates to contact me using information listed on the flyer for further information or to express interest in participating in the study.

I posted fliers in the Southwestern United States. When interested individuals contacted me, I reviewed the criteria for participation and determined their eligibility. I then answered any questions they had regarding their inclusion in the study. I scheduled a time at the site to meet for the interview. Prior to beginning the interview process, I reviewed the informed consent form with the participant and ask that he or she provide consent in the form of a signature. Once informed consent was gathered, the interview began.

Instrumentation

The interview protocol used in the study was developed using the research questions and literature review. A series of semistructured open-ended questions were designed to elicit information about the phenomenon under study. The questions were vetted by an expert panel before being used to collect data.

The interview questions allowed me to explore participant experiences regarding their transition to adult-centered health care and to examine the barriers and facilitators participants faced, as well as the perceived effect on their health-related quality of life. Table 1 presents the RQs and the interview questions used to answer them.

Table 1

Research and Interview Questions

Research Question	Interview Questions
RQ1: How do individuals who have transitioned from pediatric to adult care describe their lived experiences in pediatric care?	1. I would like to go back to when you first received care after being diagnosed with sickle cell disease and talk with you about the care you received. Can you describe the different types of care you received as a child? (Prompt: care in hospital, care in doctor’s office, care in urgent care, care in emergency department, and the frequency of the different types of care) 2. Can you talk about the different providers you had and what your experience with each type was like for you? (Prompt: nature of care, frequency of care, helpfulness of care, nature of relationships developed with health care providers)

Table 1 Continued

Research Question	Interview Questions
RQ1: How do individuals who have transitioned from pediatric to adult care describe their lived experiences in pediatric care?	3. Thinking about your experiences in pediatric care in terms of hospitalizations and the providers you worked with and received care from, what was it like for you as you approached the time when you had to leave pediatric care? (Prompts: feelings experienced? Barriers/challenges faced? Relationship with pediatric care providers? Positive or negative? Difficult or easy? Why or why not?)
RQ2: How do individuals who have transitioned from pediatric to adult care describe the transition process?	1. As you began to think about moving from pediatric care to adult care what kinds of things did you think about? (Prompt: hospitalization changes, health care provider changes, issues of concern, support through transition). 2. What kinds of support did you receive and from whom as you began to think about and make the transition from pediatric to adult care? (Prompt: nature of support, challenges experienced, helpfulness of support) 3. What was the actual process of transitioning from pediatric to adult care like for you? (Prompt: age transition took place? Challenges experienced, issues of concern)
RQ3: How do individuals who have transitioned from pediatric to adult care describe their experiences in adult care?	1. When you made the transition to adult care what was the experience like for you? (Prompt: differences/similarities to pediatric care – hospitalization, support from health care providers, care provided, challenges faced)

Table 1 Continued

Research Question	Interview Questions
RQ3: How do individuals who have transitioned from pediatric to adult care describe their experiences in adult care?	2. As you think about the experiences you have been having in adult care what stands out as the biggest changes from pediatric care for you? (Prompt: nature of hospitalization, health care provided, participation in decisions about health care) 3. What about the experiences you have had now that you are receiving adult care would you share with others who are about to make the transition from pediatric to adult care? (Prompt: issues you faced, recommendations for smoothly paving the transition process, what questions would you have asked back then) 4. What significant events and experiences that stand out for you when receiving adult care? (Prompt: differences/similarities between pediatric and adult care, support received during transition process, challenges faced in receiving support or help, differences in care received from pediatric and adult physicians, what were the similarities/differences in care from pediatric and adult physicians?

Data Collection

Upon meeting with the participant for the interview, I carefully reviewed the study and explained the informed consent form. After obtaining consent, the participant received a brief demographic form to complete. Once the consent form was signed and the demographic form was completed, I began the interview. Interviews took place in a room at the hospital that was neutral, quiet, and isolated. This setting was meant to be comfortable for the participant and allow for privacy. The interview setting minimized the possibility of interruptions during the interview process. Interviews were expected to take approximately one hour. Participants were notified that they could choose to be removed from the study at any point during or after data collection. I transcribed the recorded interview sessions into a Microsoft Word document. Only I had access to identifying features for any participant. Upon completion of each interview, I thanked participants for their time.

Data Analysis

Unit of Analysis

In a research study, the unit of analysis represents the smallest unit from which information may be gathered in the study. Since I intended to gather experiences from sickle cell disease patients, these were the individuals sought for data collection. Thus, the participant was the unit of analysis in this study. Each interview was coded separately then all codes were joined to be compared, contrasted, and build themes.

Data Management

I utilized the qualitative analysis software program, NVivo 11, to assist with data analysis. NVivo helped me categorize data according to identified commonalities or themes among participant responses. The use of NVivo also facilitated the categorization of supportive excerpts for identified themes.

Method of Analysis

In this study, I used Colaizzi’s (1978) method of analysis of phenomenological data. Through this process, I endeavored to create an interpretation of the deeper meaning of the data with an emphasis on health-related quality of life during this transition. The steps prescribed by Colaizzi are:

1. The first step in the data analysis was the process of familiarization with the subjects' oral or written descriptions. This step involved a careful review of each transcript.
2. In the second step of this process, I identified significant statements and phrases that pertained to the transition to adult health care.
3. In the third step of this process, I formulated units of meaning from the significant statements.
4. In the fourth step of this process I clustered core themes from the formulated meanings of the experience. The units of meaning, as labeled in Step 3, were clustered so that similar or identical units were clustered into an overarching response or experience.
5. In the fifth step, I created a textural and structural description of the experience, then created a composite description. I then created an amalgamation of the descriptions to form a synthesized presentation of the essence of the phenomenon.

I validated other core themes of the experience, through the process of member checking.

Issues of Trustworthiness

Credibility

The goal of credibility in qualitative research is to ensure that findings are accurate and valid (Lincoln & Guba, 1985). A number of methods were used to improve the credibility of the study. Anomalies or contradictory data were identified using a negative case analysis and any such cases were analyzed with other results to ensure that the breadth of participant perspectives was represented (Lincoln & Guba, 1985).

Finally, I used member checking to further bolster credibility. The member checking process involved sending resultant themes to consenting participants, and requesting that participants confirm or deny that the themes accurately represented their experience. Participants who indicated that their experiences were miss-represented were asked to provide details to guide me in reanalyzing any identified inconsistencies. This method was an effective way to ensure that findings were accurate and valid (Rolfe, 2004).

Transferability

Transferability lies with the reader and his or her interpretation as to whether or not the findings are applicable to other settings (Lincoln & Guba, 1985). To allow the reader ample information from which to infer the result's transferability, the sample's demographic composition was explained prior to discussion of the study findings. In addition, a rich, detailed description of the thematic findings and significant statements was included. I also discussed the transferability of the findings, including suggesting the applicability to other settings.

Dependability

Dependability in qualitative research refers to the reliability, or repeatability, of the findings within the study (Lincoln & Guba, 1985). In this study, dependability was ensured using an inquiry audit. This step occurred following data analysis and consisted of a review of the findings with a researcher who was not involved in the current study.

Confirmability

Confirmability is the endeavor to discount researcher subjectivity based on biases (Lincoln & Guba, 1985). I maintained an audit trail to provide a detailed outline of the conscious and physical steps taken throughout data collection and analysis. I maintained epoché, or bracketing, to identify and isolate any biases (Moustakas, 1994). Bracketing enabled me to approach each participant's experiences with an open mind in capturing the essence of participants' lived experiences (Hycner, 1999).

Ethical Procedures

I obtained Institutional Review Board (IRB) approval for research involving human subjects prior to the collection of any participant data. I went through a second IRB from the site I selected. Participants had opportunities to stop for breaks or to completely drop out of the inquiry at any time and with no penalty at any point before, during, or after data collection. Participants learned, prior to beginning the study, of any known risks associated with participation. Because this study involved consenting adults who spoke about a past experience, the only risk to participation was the possibility of discomfort of recollecting their experience of going from pediatric to adult care during the interview process. To minimize this risk, I reminded participants that they could choose to leave the study at any time with no explanation and would suffer no penalty.

Participants also received a list of local counselors and the numbers for a no-cost telephone counseling (i.e., The Crisis Call Center) on the consent form. This significantly lowered the risk of harm to participants, as they had the opportunity to reach out for counseling if the interview process made them uncomfortable. Then, I asked participants to sign the consent form for their participation in the study. I endeavored to support participants in providing honest and candid information throughout the interviews. I encouraged participants to elaborate on responses that warranted additional explanation and reminded participants that they could leave at any time.

All recorded data were de-identified and transcribed to maintain participant confidentiality. I assigned participants pseudonyms throughout the presentation of the results. Raw data were only available to me. All data were kept in a locked filing cabinet when not in use. I will retain the data for 5 years, after which time it will be destroyed by permanent deletion.

Following analysis, participants were asked to review findings through the process of member checking. Participants received a typed 1- to 2-page summary of the key findings from their interview and could comment on whether or not their perceptions were accurately captured. If a participant determined that any of the findings were unrepresentative of their experiences or provided responses, they could amend incorrect interpretations through email. UTSW served as primary IRB and Walden University served in the role of secondary IRB during this study. Any such alterations were reported in the audit trail and data interpretation in Chapter 4.

Summary

This chapter presented a detailed explanation of the methodological procedures I applied in the present study. In addition, Chapter 3 provided procedures for the collection and analysis of data. The objective of this phenomenological study was to explore the lived experiences and perceptions of patients regarding the transition to adult health care, with specific examination of the effects of their experiences on their quality of life. Through this inquiry, knowledge concerning SCD transitional programs was illuminated with the goal of improving patient services. Chapter 4 presents the results of the qualitative research. The follow chapter presents a description of the data analysis process with examples, and the findings from the study.

Chapter 4: Results

In this phenomenological study, I investigated the lived experiences of 12 patients with sickle cell anemia (SCA) who were within the first 3 years of completing transitional care at the study site hospital. The aim of this research was to explore SCA patients' perceptions about their experiences of care transition programs and their quality of life during care transition. The results of this study provide increased insights on the care transition process and lead to the creation of interventions to improve survival rates.

The following questions guided the study:

RQ1: How do individuals who have transitioned from pediatric to adult care describe their lived experiences in pediatric care?

RQ2: How do individuals who have transitioned from pediatric to adult care describe the transition process?

RQ3: How do individuals who have transitioned from pediatric to adult care describe their experiences in adult care?

Setting

I conducted interviews in a room at the study site medical center. The room was quiet and isolated for comfort, privacy, and to minimize the possibility of interruptions during the interview process. The thermostat was set on a temperature that was comfortable for the study participants and me. The room was set up with comfortable chairs and appropriate lightning.

Demographics

The sample for this study consisted of 12 African American youths diagnosed with SCD. Participant demographics are shown in Table 2.

Table 2

Participant Demographics

Participant Demographics	*n*	%
Gender		
Male	6	50
Female	6	50
Age		
20	6	50
21	2	17
22	3	25
25	1	8
Age of transition		
18	10	83
21	2	17

Data Collection

Data collection consisted of a screening process during routine office visits to the hematology-oncology clinic at the study site medical center. Advertisement of the study was sent via email to potential participants. Individuals who expressed interest in participating were screened via telephone or during a face-to-face meeting using a screening script, to ensure they were age 18 or older, spoke English, and were diagnosed with sickle cell anemia prior to the transition to adult care. Once participants were confirmed eligible for inclusion in the study and agreed to participate, I filled out a participant screening and enrollment log, a demographic sheet, and basic demographic and contact information on the authorization form and consent form. First, I carefully reviewed and explained all study procedures with participants, and allowed time for questions and to enable the participants to make an informed decision about participating in the study. I asked the participants to sign the consent form and HIPAA authorization prior to the interview. Participants signed all forms before interviews began. After consent was obtained, participants completed a short demographic questionnaire addressing their gender, age, ethnicity/race, and year of sickle cell diagnosis.

The interviews were semistructured and addressed the three guiding research questions, with the addition of 10 follow-up/probing questions when necessary. These questions were included in the interview protocol (see Appendix A), which allowed me to ask for additional details or clarification when necessary. Interviews were expected to last approximately 60 minutes; however, the length of the interviews varied from participant to participant, with no interviews lasting longer than 60 minutes. The semistructured interviews were the only form of data collection used for the study, and the interviews were audio recorded. Participants were reminded that they could leave the interview at any time or have their data withdrawn if they so decided. All participants completed the interview, and none asked to have their data redacted. When the interview process was completed, participants were thanked for their time and informed that they could contact me at any time to request withdrawal from the study, ask any questions, or voice any concerns.

I transcribed all interviews, and all participants were de-identified using a pseudonym such as Participant 1. Once de-identified, participants' pseudonyms were matched to their actual names in a separate secured document (the subject masking log) so that participants could be removed if necessary.

Data Analysis

I used Colaizzi's (1978) method of analysis of phenomenological data. After interview data were collected and transcribed, I read and reread the transcribed interviews several times to gain an understanding of the predominant messages shared in the interviews, as well as implicit nuances within the participant responses. The first step in the data analysis was the process of familiarization with each participant's transcript.

In the second step of this process, I identified and highlighted significant statements and phrases that pertained to the lived experiences in pediatric care, the transition to adult health care, and the lived experiences in adult care. This process required me to review the data to recognize and isolate noteworthy statements.

In the third step of this process, I formulated units of meaning from these significant statements. In this step, each extracted statement from the textural data was given a summative explanation that described the excerpt in a few words. Using Nvivo 11, the data fragments were assigned to a node. The data fragments were organized under the appropriate research question. Each node was assigned a summative explanation. Table 3 presents examples of this process.

Table 3

Selected Examples of Significant Statements of SCA Patients Transition Into Adult Care and Corresponding Formulated Meanings

Significant Statements	Formulated Meanings
1. It’s like they pay more attention to what was going on with what I have. When I transitioned towards the adult side it was more so they were not paying attention or listening to what’s going on.	1. Level of care is different at the pediatric level.
2. I also went to church with one of my nurses, so yeah, I knew everybody there, I went to church with... Oh one of the doctor’s was friends with my aunt too, they went to the same church so Dr. McAbbott.	2. Had a personal relationship with providers.
3. They saw... I guess that maybe they saw a lot of their patients weren’t transitioning as well, so they brought in Dr. [name redacted] as a transition person.	3. Doctors noticed patients were not transitioning well and a transition physician was hired
4. Transition that was probably one of the worst times in my life, just medically [chuckle] as well as just transitioning from them	4. Transition was the worst time in the participant’s life.

The fourth step in this process was the creation and clustering of core themes from the formulated meanings of the experience. The purpose of this step was to arrange the data into themes that represented the essence of the experience. In this step, the units of meaning, as described in Step 3, were clustered so that similar or identical units were gathered into an overarching response or experience. Using Nvivo 11, I organized the similar statements into clusters of themes. Associated clusters were gathered to form the themes that described the lived experiences. A tabulation was used to show the clustering of meanings to indicate how these were grouped to lead to each formulated theme. Table 4 presents examples of this tabulation, including the number of significant statements included in each theme.

Table 4

Examples of Two Theme Clusters With Their Subsumed Formulated Meanings

Theme Clusters with Subsumed Formulated Meanings and Number of Significant Statements
Building relationships with new health care providers.
1. Meeting a new physician for before the transition process was completed (5).
2. Meeting the new physician after transition (11).
3. Worried about the relationship with new physician (12).
4. Creating positive relationships with health care providers (16).
Unwillingly beginning the transition process.
1. Patients did not want to transition out of pediatric care (13).
2. Patients worried about the transition (18).

In the fifth step, the results of the data analysis were integrated into an exhaustive description of the phenomenon under study. The sixth step of the process involved my validation of the core themes of the experience. Throughout this process, I confirmed the accuracy of the themes and their representativeness of the participants' experiences through the process of member checking. I consulted the participants and had them review a summary of the themes and the composite descriptions of the lived experience that arose from the data analysis process. The participants who were available to review the summary believed that the results of the analysis and the themes generated reflected an accurate representation of their lived experiences.

A tabulation indicated significant statements and delineated meanings behind them. Table 5 provides an example of this tabulation. A second tabulation was used to show the clustering of meanings to indicate how they were grouped to lend to each formulated theme. Table 6 provides an example of this tabulation. In order to make the results easily understandable, a table was included with each theme that identified the significant clusters and groups associated with the theme.

Table 5

Example of Significant Statements and Corresponding Meanings

Significant Statements	Corresponding Meanings
The transition process was difficult; I found my pediatric care to be more involved and comprehensive than my adult care.	Pediatric care was more comprehensive than adult care.
I did not notice any remarkable changes to my health as I transitioned between pediatric and adult care.	Quality of life was not affected by the transition from pediatric and adult care.

Table 6

Example of Themes and Corresponding Significant Statements

Themes and Significant Statements
Sickle cell patients perceived that they received more support in pediatric care.
Pediatric care was more comprehensive than adult care.
Pediatric doctors were more attuned to the needs of their patients.
Quality of life was not affected by the transition from pediatric to adult care.
Level of comfort remained constant during transition.
There were no major sickle cell events while patients were in their transition.

Each theme constitutes a separate subsection of the results, and each of these sections follows a similar presentation. Each theme is followed by a summary of the significant statements related to the theme. Examples of these significant statements are provided as verbatim quotes where applicable and are described as they relate to each overall theme.

No discrepant cases were noted during the analysis. A variety of experiences was expected and incorporated into the themes to provide a complete and rich description of the participants' experiences.

Results

Research Question 1

How do individuals who have transitioned from pediatric to adult care describe their lived experiences in pediatric care?

Theme 1: Participants formed close personal relationships with their providers. The participants in this study formed very close bonds with their health care providers. They relied on them for medical care, emotional support and guidance. The relationships they formed were personal and, for some, likened to family. The participants indicated that the level of care and concern was extraordinary, which enabled them to feel safe and secure in spite of their SCA diagnosis. Many of the participants had formed relationships with the health care providers from early childhood. The one participant who did not identify a close relationship with a provider, had multiple changes throughout childhood. The relationships formed the basis of their ideas surrounding long term care for chronic conditions and quality of relationship between health care provider and patient.

Table 7

Theme and Theme Clusters for Theme 1: Relationships Formed with Health Care Providers

Theme Clusters with Subsumed Formulated Meanings and Number of Significant Statements
Relationships formed with health care providers (84).
1. Consistent health care provider (9).
2. Emergency room care (13).
3. Hospital care (4).
4. Infusions and transfusions (13).
5. Initial care was not good (1)
6. Laboratory practices (1).
7. Level of care is different at pediatric level (9)
8. Had many different providers (1).
9. Neutral relationship with a physician (3).
10. Parents were in control of medical care (10).

Table 7 Continued

11. Participated in a study (1).
12. Positive relationship with physician (27).
13. Too many medications (1).
14. Treatment options dictated living situations (2).
15. Creating positive relationships with health care providers (16).

Most of the participants had relationships with their providers that spanned many years. The same physicians, nurses, and other medical professionals had cared for them for most of their lives. Two of the participants in the study indicated that their families had relocated to receive optimal care. Accessing quality care was important to the families of the participants. They wanted to ensure they could access the best care possible for their children.

The participants reported their families moved because the level of care available to them was less than optimal as the medical professionals in the area where they lived were not as familiar with SCA. Because of this they made the decision to return to Texas and access the best medical care they could find.

The participants spoke about the importance of the long-term relationships they built with their health care providers. Because they could form these relationships, they were comfortable with their care and felt safe and secure. One of the hallmarks of their care was the relationships that were built over years. Being able to go to the provider's offices and see the same face every time increased their sense of security and trust. Participant 2 said, "Brandon. I mean, every single time I got an infusion he was there. It was never anybody else, it was always Brandon."

The participants were young and often frightened. Having professionals who they knew cared made a difference in their feelings. They believed their providers were invested in their wellbeing and cared about them as individuals. This was displayed by the amount of care that was offered and the health care providers desire to make them feel comfortable as possible.

Another important aspect of this consistency was that the participants and their families could get the knowledge that they needed to understand the details of their care. This coordination of care enabled the participants to receive services in an organized and planned manner. By working together, the medical team was able to make decisions that were in the best interest of their patients, which lead to a higher quality of care. The participants and their families did not worry about having to educate or inform the health care providers because they had been involved in their care from the beginning. Participant 11 spoke about his health care provider's office and stated, "I loved it there. I got to know all the nurses, all the doctors. It was like home away from home really, a lot of the times." The level of support made him feel as the provider's office was an extension of his family.

Participants described the closeness they felt to their physicians. They felt as if they were important and cared for as individuals. They believed they were treated as members of their physicians' families. They found their health care providers cared for all aspects of their lives: social, emotional, physical and medical. Participant 8 spoke about the person centered care and said she appreciated the holistic nature of the care provided. Because the health care providers asked questions about her life outside of the medical, she felt as if they cared for the whole person and not just the condition they were treating.

Only one participant did not have the same closeness to his provider as the other participants. He indicated that he had many different doctors while he was young, and believed the many changes prevented him from creating close bonds. Despite the fact he did not develop a strong relationship with a specific provider he remarked, “I would say the pediatric side did pretty good.” He was satisfied with the level of care he received and did not feel anything was lacking.

One of the primary factors the participants spoke about was the level of care they experienced when under the auspices of the professionals who practiced pediatric medicine. The participants compared their pediatric and adult care experiences and found some differences. They believed the level of care they received was different. Unlike their pediatric caregivers, the participants felt their adult providers were not emotionally involved and they did not listen as well to the information they wished to share. One of the participants summed up the difference and said, “I don't know, it's. . . they cared more on the pediatric side.”

The only area of any complaint when it came to pediatric care was in the emergency room. Most of the participants were fairly neutral in their evaluations of the emergency services they received stating, “the care was usually well” (Participant 10), “we had to wait a while to get to the emergency room, but other than that everything was fine" (Participant 9) and "yeah, the emergency room people they were okay" (Participant 1). The adjustment to emergency care could be jarring because the participant went from a medical situation where they were known to their caregivers to one where little information could be available to the medical professionals providing care. They were used to accessing care and having their needs met in the physician's office with little explanation needed and minimal time before any issue was addressed. In the emergency room, the challenges they faced could be frustrating and upsetting.

Overall, the participants formed close bonds with their health care providers. They could lean on them for support and felt cared for and loved. These relationships were an essential part of their care and engendered great trust between the participants, their families, and the health care providers.

Theme 2: Communication with health care providers was mediated through the participants' parents. Communication was an important part of the participant-physician relationship. However, the communication discussed was mainly how their parents mediated conversations or information for them. Most of the participants shied away from directly sharing information with their health care providers and expected their parents to take on this task.

Table 8

Theme and Theme Clusters for Theme 2: Communication Was Mediated Through the Parents

Theme Clusters with Subsumed Formulated Meanings and Number of Significant Statements
Communication was mediated through the parents (13). 1. Don’t want to talk (8). 2. Mom could talk for me (4). 3. I was involved in talking to the physician (1).

Participant 12 was very clear on how communication about her care occurred. She said, “My mother was more of the one who really just was kind of took control over everything when I was younger.” She did not have the need to communicate directly because her mother was there handling and managing her care. Other participants indicated that they did not like to speak up and advocate for themselves and were more comfortable letting parents ask questions and communicate with caregivers. They felt that it was not important to share information because their parents were available. Some of the participants believed their parents were better at communicating than they were and expected their parents to handle that aspect of their care.

Participant 4 was the one participant who spoke about communicating directly with her physician and said, “I'm not the type of person to talk to my doctor. I was always with my mom's help.” However, Participant 4 also indicated that she did communicate with her physician. She spoke about her doctor and said, “My doctor talked to me about everything I needed to know, even though I didn't really understand when I was younger." She was included in the conversations about her care. Even if she did not fully understand everything that was said, she could be a part of the conversations about her care. Like the other participants, she preferred to have her mother handle communication, but because of her physicians' actions, she also had to participate in the conversations about her care.

Theme 3: Reluctance to begin transition process. Eleven of the twelve participants were reluctant to transition into adult care. They were fearful of the change and anxious about taking full responsibility for their own care. When they initially realized the change was going to occur some of the participants expressed anger. They felt safe and secure in the relationships they had formed and did not want them to change.

Table 9

Themes and Theme Clusters for Theme 3: Reluctance to Begin the Transition Process

Theme Clusters with Subsumed Formulated Meanings and Number of Significant Statements
Unwillingly began the transition process (20). 1. Did not want to transition (7). 2. Kept past transition age (3). 3. Worried about transition (8). 4. Eager to begin the transition process (2).

The participants in the study reported negative reactions when first informed that they would need to prepare to transition over to adult services. The idea of leaving their pediatric health care providers behind was frightening. They were dealing with the fear of becoming an adult which was compounded with the fear of assuming full responsibility for their health care decisions. Participant 5 said, “I felt like I was in the first day of school, again.” The participants worried they would have to start all over again and have to create new relationships. The participants were comfortable and secure in the care of their health care providers and did not see a reason to have to change. They felt their physicians were more than capable of continuing to care for them and were fearful of the proposed change.

The participants described a range of emotions when it came to thinking about the transition. The participants were used to having someone to lean upon, and the idea they would have to be solely responsible for their own care was intimidating. The participants indicated that many of their parents were also fearful. This compounded their anxiety because the person they depended upon was also frightened.

The participants found the idea of transition difficult at first. Initial reactions included sadness and fear. The participants felt unprepared for the transition and were overwhelmed by the idea of transition because of managing many different changes including beginning college.

Participants experienced feelings of anxiety. They had many issues that worried them from who their new caregivers would be to how to manage paperwork and insurance. They also worried about losing the emotional support they received from their health care providers. They worried that adult caregivers would not provide the same levels of support and engagement.

Unlike the other participants, Participant 3 was eager to make the transition. Although, she admitted to some trepidation, she wanted to be an adult. She said, “I'm one of those people, I [want to] be independent so it was [kind of] finally, yes.” Her main concerns were focused on where she needed to go. She did not want to get lost while trying to find her new health care providers, or be unsure of where to go to access different services.

Most of the participants in this study were reluctant to face the transition process. They were comfortable and happy with their pediatric care and did not see a reason to move to different providers. They had formed strong emotional bonds with their health care providers and were fearful that new providers would not provide the emotional care and support that they were accustomed to receiving.

Research Question 2

How do individuals who have transitioned from pediatric to adult care describe the transition process?

Theme 1: Patients faced many barriers and challenges during their transition to adult care. The participants faced a host of barriers and challenges throughout the transition to adult care. Most of the participants had an abrupt transition into the adult care setting. They indicated that there was little planning or forethought that went into the process. They reported dealing with many transitions at once. Many of the participants dealt with graduating from high school, preparing to start college, starting college, and transitioning into the adult care system all at once. They felt overwhelmed at the number of changes that were occurring in a short period.

The transition was a confusing time for many of the participants. They were unsure of how to handle their care and experiencing a wide variety of changes. They were surprised by some of the barriers and challenges they faced. They found the transition of information to be problematic. Often their adult providers did not have access to their medical records making access to appropriate medical interventions challenging. Participant 2 reported, “I remember being in the hospital in the first time, in the adult hospital, nobody knew what my orders were, nobody knew anything.” The lack of communication between computer systems and providers made the transition very difficult for many of the patients. The quality of care they received was compromised.

For many of the participants, one of the biggest challenges they faced was finding an adult physician. The participants indicated that did not have a planned transition, and instead were given a referral to a new physician and left to handle the details of the transition on their own. Participants had difficulties locating doctors who were qualified. Some patients were told, “You're the only sickle cell patient I have in my clinic. I think you should just find somewhere else to go." When referrals to new practitioners were appropriate many of the participants in the study found they had to wait for long periods of time to before they could have an initial visit. This break in care caused high levels of anxiety and worry about how to handle any medical crises. This lack of planning was accompanied by difficulty accessing appropriate care in a timely manner

Another challenge faced by the participants during the transition period was learning to find their voice. The participants had to learn how speak up and become an advocate for themselves. Up to this point, parents or other adults accompanied the participants and interacted with the health care system. It was now their responsibility to handle their own care. To do so effectively, they needed to learn how to speak to health care providers. They needed to learn how to provide accurate information, make informed decisions about their care, and ask questions. Many of the participants in the study were reluctant to speak. Up to this point they had relied on the adults around them to be their advocate and were not involved in managing their own care. Some of the participants indicated they did not pay attention to conversations at the physician's office, because they thought it was not necessary. They felt safer letting the adults manage their care and make the decisions. This situation created a steep learning curve for the participants in this study. They found it challenging to speak up and felt as if they were not prepared to manage their own care.

Participants believed they could an adult handle the details of their care and not have to communicate with health care providers. Many of the participants were ill and felt that all they could manage was themselves. They indicated managing the symptoms of SCD took all their energy, leaving no desire to be involved in communicating with others or managing their own care. One participant said, "learning how to do everything for myself. That was the biggest challenge for me."

In addition to finding their voices, the participants had to learn to navigate new systems. They had to learn where to go to receive care, how to handle insurance claims, and manage their appointments. Some of the new systems were more cumbersome than the ones they were used to using. The process to access care became longer and more elaborate, which was a challenge for them to manage. Participant 4 reflected the viewpoint of others and said, “Concerns that I had were knowing where to go . . . . I guess knowing where the new buildings were going to be.” Many of the participants were uncertain and felt intimidated by everything they had to learn. The participants understood they needed to assume this responsibility, but did not feel prepared to do so. Many of the participants were fearful of the unknown, and created the barriers for themselves. Once they began to actively manage their care they found themselves capable and indicated taking on the responsibility for their own health was empowering.

The participants indicated that their parents also expressed concerns about transitioning their children to adult care. Their parents were deeply involved in managing the participants care throughout childhood. The parents worried about how the participants would manage the myriad pieces that were involved in ensuring they received proper care. Participant 11 who described the fear she felt at the thought of transitioning spoke about her mother’s reaction and stated, “My mom was even more afraid than I was.” Her mother worried about finding a good adult health care provider and how Participant 11 would manage her own care. The remaining parents were concerned but at the same time pushed their children to manage their own care. The participants in the study indicated that their parents knew that managing their own care was a skill the participants needed to learn. Many of the parents understood that the participants needed to learn to manage their care and tried to help their children assume the responsibilities.

The participants indicated that their parents began to step back and push them forward. Participant 8 spoke about his mother's actions and said, "The older I got, the more she started not going with me, and I started going with my uncle. He was just playing on his phone while I was answering all the questions and all that." Although for some a transitional safety net was provided where participants reported that they had an opportunity to practice and learn. For the majority of the participants however, there was ~~reported~~ little transitional preparation before they had to assume responsibility for themselves.

Theme 2: Participants experienced many emotions during transition. There were many emotions expressed by the participants during the transition to adult care. They were worried, anxious, and fearful throughout the transition. They were uncertain of how to handle the changes, and needed to learn a host of new skills including managing their own care and communicating with a variety of providers.

Table 10

Themes and Theme Clusters for Theme 2: Participants Experienced Many Emotions During Transition

Theme Clusters with Subsumed Formulated Meanings and Number of Significant Statements
Participants experienced many emotions during transition (26). 1. Felt unready for transition (8). 2. Negative emotions associated with transition (12). 3. Nervous about transition (3). 4. Thoughts during transition (3). 5. Worried care would not be individualized (1). 6. Worst time of my life (1).

The participants were very emotional as they spoke about the transition process. They said they had been worried about the changes that would arise and were ambivalent about the change. They had established long-standing relationships with their health care providers who had been there for them throughout their lives. The seemingly abrupt sundering of those relationships left the participants feeling lost. Participants were upset during the transition and reported feelings of sadness and loss that were ongoing, with Participant 2 saying, “I still get really sad.” Other_emotions the participants spoke about included fear of the unknown, nervousness, and anxiety. These emotions were all connected with facing an unknown situation. Most of the participants worried about how they would establish new relationships.

Some participants entered the transition feeling as if it was unfair to ask them to make the transition to adult care while they faced other challenges and transitions such as graduation from high school, beginning college, or entering the workforce. They felt overwhelmed by the myriad changes they faced. One observation made by a few participants was a feeling of being unfairly treated. They spoke about other individuals they knew who did not transition until the age of 21. These participants wondered why they were not offered that option.

Participants noted a change in the emotional connections they felt with their caregivers. They felt as if their adult health care providers were competent and would look after their best interests, however, they missed the emotional connections they felt with their pediatric health care staff. One of the participants stated, “In terms of when you're switching over, those are all the things you're thinking of. I had such great doctors beforehand, and you've got to say goodbye to those people, those people that you grew up with.” The participants in the study understood that the transition to adult care was significant and they were dealing with ending long-term relationships. The participants all reported relationships that were very positive and many worried that adult caregivers would not be as committed and caring.

Theme 3: Participants had to build relationships with new health care providers. The participants were very worried about establishing new relationships with health care providers. They had long established relationships with their current providers and were reluctant to change. They were uncertain that their new providers would be as caring and compassionate and worried that the quality of their care would decrease.

Table 11

Themes and Theme Clusters for Theme 3: Building Relationships With New Health Care Providers

Theme Clusters with Subsumed Formulated Meanings and Number of Significant Statements
Building relationships with new health care providers (13). 1. Met new doctor before transition (5). 2. Positive relationships with physicians (5). 3. Worried about relationship with physicians (3).

One of the most important parts of the transition was the creation of relationships with their new health care providers. The participants needed to create adult relationships and learn to interact with health care providers in a new way. They had to oversee their own health care and advocate for themselves. The basis of this shift was the relationship with their health care provider.

Many of the participants worried about establishing the relationship with their new health care providers. Although Participant 9 identified his transition as easy he still had some anxiety about the relationship with his new provider. A prime concern was the building of a new relationship with a stranger. They worried about how to build trust and communication in order to convey their thoughts and feelings. They were aware their new providers would have control over their health care and understood that this relationship was of utmost importance. Participants were concerned with the quality of care that would be offered. They wanted to receive the same care and commitment as they had while in pediatric care but felt unsure of the future.

The concern with quality of care was at the forefront of many participants concerns. Some had had early negative experiences with providers and they worried they would no longer have access to good quality care. Participants worried that a new physician would see them as just another patient and not consider the fact that they were unique individuals with unique needs. Some participants also worried that their knowledge would be disregarded because they were not a physician; they were simply a patient.

For other participants in the study, the transfer to adult care was very straightforward. Many of these participants met their new health care provider before they made the shift into adult care. They began to form a relationship with the physician who would be responsible for their care before the shift to adult care.

The participants with these experiences could meet their adult physicians in their pediatric health care provider's office, a place where they felt safe. This enabled this group of participants to enter adult care believing they had a physician they could depend upon. Participant 10 said, "I was able to meet my doctor before I was moved over to the facility, so that was something that helped ease my mind, helped me through the transition." It was evident that knowing exactly who would be responsible for their care and having the opportunity to form a relationship with them before the transition was essential in making their entry into adult care less stressful. The participants felt as if they were in good hands and, because they established the relationship before the transition was complete, were less fearful of all the changes ahead.

Theme 4: Participants needed support throughout their transition process. One area that the participants identified as essential to a smooth transition was the support they received. All the participants in the study indicated the support they received from their mothers and families was essential in keeping them calm and helped to make it easier to deal with the transition. When speaking about support a few indicated their pediatric caregivers were also helpful, but the major form of support was from their parents.

Table 12

Themes and Theme Clusters for Theme 4: Having Support During Transition

Theme Clusters with Subsumed Formulated Meanings and Number of Significant Statements
Having Support during transition (18).

Participant 1was the one of the few participants who had a formalized support process during the transition. She spoke about the many different forms of support available to her and listed a variety of services which included psychologists, groups, parents and caregivers. She credited this level of support for a smooth and easy transition. Although she did not access all the forms of support available, she found the psychological support important. In addition, she indicated her mother was also very supportive, since her mother was a nurse and knowledgeable about working within health system. This support was invaluable and helped ease her transitions.

Although the participants reported different levels of support throughout their transitions, the support they received was essential. Parent support was described by all the participants. They relied on their parents to see them through the process and to help decipher the intricacies of the adult health care system. Support form pediatric caregivers was also seen as important. One participant said, “So, even in my transition, my [pediatric] doctors, my [pediatric] nurses, they were still there for me. They were obviously supporting that transition.” Having caregivers who were familiar with their SCD and who could share information with their new medical team created a sense of safety and security for the participants.

Only one participant spoke about a lack of support during transition support during transition. He spoke about that period:

> None, [no support from pediatric health care providers] . . . except the referrals. That was about it. It was the same thing [with my parents]. I guess the only thing they could do was just help find referrals with me. They couldn't really do anything about it.

Participant 11 felt as if the support he needed was not available to him. His pediatric health care providers gave him referrals but little else and his parents attempted to help but did not know any more than he did when it came to the transition. This participant’s difficulties underscored the importance of support for these participants as they transitioned to adult care.

Theme 5: Many participants reported differences in the transition process. There were three main ways the participants described the transition process itself. It was structured, had some support or had no support. A few participants underwent a 2 to 3-year transition process that attempted to prepare them for the switch in providers and participant responsibilities because they were beginning the steps early on, some by the age of 16 or 17. Some participants had some support, while others simply received a referral. Interestingly, the idea of an easy transition was not necessarily linked to the type of transition the participant underwent.

Table 13

Themes and Theme Clusters for Theme 5: The Transition Process

Theme Clusters with Subsumed Formulated Meanings and Number of Significant Statements
The transition process (37). 1. Thoughts during transition (5). 2. Transition process was easy (8). 3. Transition was very hard (3). 4. Transition process (21).

Some participants underwent a very formal transition process, which began 2 to 3 years before transition occurred. They were guided step-by-step through their transitions. They gradually assumed responsibility for their own care starting by working with psychological staff who ensured the participants were educated about SCD and offered emotional support when necessary. The participants were then taught to make appointments, introduced to their new adult physicians, and offered group support. Some participants reported meeting their new adult caregivers several times before their final transition. Once the time for transition arrived they were familiar with their adult caregivers and were then gradually shifted over to adult care. This eased the transition and enabled the participants to feel comfortable as they switched over. For participants who had formal support available throughout the process, the transition was smooth and almost seamless. Meeting their adult caregivers while still in pediatric care seemed to be particularly important in creating a sense of safety for the participants.

Many of the participants indicated they had no real transition process between adult and pediatric care. Several simply received a referral and were left to their own resources to find a physician. Some referrals were appropriate while others were not. Incidents such as referrals to unqualified providers occurred, which left the participants on their own to locate a practitioner.

Participant 6 spoke about this and remarked that the only support he received was a vague referral to the adult side of the pediatric practice where he was a patient. The adult side did not have a specialist for SCA and he was left on his own seeking a new health care provider. He shared that “we (his familial unit) had to try to figure out the doctors ourselves.” When speaking about the transition process itself he said, “I didn't think we had support whatsoever.” He reported that his search for an adult health care provider lasted 3 months.

One group of participants who also had no transition process managed their transitions with ease. They indicated for them transition was an easy process involving some paperwork and a shift over to new health care providers. They did indicate they found the entire process very straightforward. One participant reported that there was a great deal of information that could have been offered during the transition process. Having this information would have made functioning as an adult much easier. Although the transition seemed easy, this participant came to realize how much information was lacking as he learned about the adult system.

Overall, the participants had a range of experiences when it came to the transition process. The experiences they had covered a wide spectrum from planned and organized to nonexistent. Despite the varied experiences, they all managed to find care and located adult health care providers who could give them support and care.

Research Question 3

How do individuals who have transitioned from pediatric to adult care describe their experiences in adult care?

Theme 1: Participants face some barriers and challenges in the adult care system. The participants described a variety of barriers and challenges that they faced as they became adults. One of the difficulties mentioned by many of them was juggling multiple transitions at the same time. They spoke about a difference in the caring displayed by the health care providers and perceptions that had changed.

Table 14

Themes and Theme Clusters for Theme 1: Participants Faced Some Barriers and Challenges

Theme Clusters with Subsumed Formulated Meanings and Number of Significant Statements
Participant faced some barriers and challenges (13). 1. Bad experiences (1). 2. Barriers in adult care (4). 3. Challenges in adult care (8).

Participants had to learn how to juggle scheduling their health care along with other responsibilities. They needed to be able to manage many responsibilities including college, work, and their health. Participant 4 had to be careful how she juggled appointments and getting her lab work completed with her responsibilities as a college student. Finding the time was often challenging because the schedules they had often conflicted with health care appointments. Participants reported their care to be very different and believed they were not as well cared for as they had been when they were children. Coordination of care became their responsibility as well, and was often challenging. The community and wrap around care they had received as children were ~~was~~ not offered to them as adults. Communication could be challenging and frustrating, and for some, coordination of care was seen as almost impossible. The challenge they faced was to learn to work within a new system and to get their health care needs met.

The major barrier that Participant 6 note was the time it took to be seen by the adult health care practitioner. He spoke about his appointments and stated:

> When I was a child. . . I just think they moved a little quicker with me. . . . finding me an appointment faster. Now that I'm an adult I noticed that I'll have to take a month or two months out, before I can get in when I go."

Participants realized they needed to learn how to plan ahead as much as possible.

Generally, the challenges and barriers the participants experienced once in adult care focused around learning the system, and the amount of care shown by health care providers. They were all able to successfully navigate the barriers they faced and get their medical needs met.

Theme 2: Becoming an adult was perceived as being challenging for many participants. The participants shared information about what it was like to function as an adult. They found new responsibilities and came to realize how much their parents had done for them when they were children. They were universally amazed at the amount of information they needed to learn and know to manage their SCD.

Table 15

Themes and Theme Clusters for Theme 2: Being an Adult

Theme Clusters with Subsumed Formulated Meanings and Number of Significant Statements
Being an adult (30). 1. Taking on responsibilities (12). 2. I wish I knew (4). 3. Needs to improve communication (5). 4. Managing your care (9).

The participants indicated that there were many responsibilities associated with becoming an adult. They needed to learn about their disease in depth, manage appointments, be compliant with all medical recommendations, remember to take medications, manage paperwork, and deal with insurance. Participants understood that just switching to adult care was not enough to be an adult. It was necessary for them to take responsibility for living with SCA. They were required to learn to be on top of everything associated with their condition to stay healthy and to keep receiving the necessary health care.

When speaking about being an adult, the participants needed to be able to speak up and share information with their health care providers. They had to learn how to advocate for themselves and make sure their concerns were addressed and that they shared important information with their providers. They could no longer rely on their parents to remember everything for them, they had to take on that role for themselves. Participant 4 spoke about being an adult and said one of her biggest realizations was, “I realizing how much information you have to know yourself. . . . You have to know when to come in or when not to come in, and when to contact your doctor on your own." In being an adult she, came to understand that she was ultimately responsible for understanding her medical condition and sharing that information with others. Participants had to spend the time necessary to learn the information they needed and they indicated they needed to learn this quickly.

The participants had learned to function as adults. They took responsibility for their own care and committed themselves to learning the information necessary to manage their SCA. They learned that they needed to be advocate for themselves and had to speak up when necessary.

Theme 3: Relationships with health care providers. The participants began to form new relationships with their adult health care providers. They became independent and no longer expected their parents to handle the details of their SCA. Some participants felt close to their new providers while others felt they had competent physicians but did not have the emotional connection that they had with their pediatric caregivers.

Table 16

Themes and Theme Clusters for Theme 3: Relationships With Health Care Providers

Theme Clusters with Subsumed Formulated Meanings and Number of Significant Statements
Relationships with health care providers (20). 1. Relationship with doctor (4). 2. New medical professionals (4). 3. Medical professionals are supportive (10). 4. Medical professional roles the same (2).

Participants generally reported good relationships with their providers. They believed they were competent and provided quality care. Some participants reported good relationships with physician but found the other relationships lacking. The participants felt pediatric caregivers including nurses and social workers cared more than their counterparts in the adult health care system. Participant 10 reported a good relationship with his providers. The main difference he noticed in adult care was, “I guess I would say the time. There are still a few that seem to rush, just because they have several patients, but sometimes they tend to rush a bit more. It's not exactly as personalized.” Many of the participants reported that the relationships with health care providers were more formal and less personal. The participants made the transition into adult care and generally liked their physicians. Some of the supporting staff were identified as less caring, but the main relationship with their physicians was good.

Participants were concerned with the competence of health care providers who did not specialize in SCA. Participant 2 stated that many people often were afraid to make decisions because they were unfamiliar with SCA, and defaulted to the standard protocol rather than trying to understand what was best for the patient. She felt as if she needed to be an agent of change to make things better for others who followed.

Participants felt that open communication was the key to creating a working relationship with their providers. They had to speak up for themselves and share information. Participants reported gaining confidence in their ability to share information and interact health care providers without support from parents. They became confident they could manage their care and communicate information effectively.

Issues of Trustworthiness

Credibility

Credibility in a qualitative study refers to the degree to which results reflect the true and accurate experiences of the participants. A number of methods were utilized to improve the credibility of this research study. Any anomalies or contradictory data were identified employing negative case analysis, and the resulting information was incorporated into a discussion of the results to ensure that the breadth of all the participant perspectives were represented in this study. In addition, a part of the data analysis process, member checking was employed to further bolster credibility. The member checking process involved sending the resultant themes to consenting participants, and requesting that participants confirm or deny if the identified themes accurately represented their experience. No participants responded and requested any changes in the themes

Transferability

In qualitative studies, transferability lies with the reader and their interpretation as to whether or not the findings are applicable to other settings. To ensure that any reader had ample information from which to infer the transferability of this study, I included information about the demographic composition of the sample, as well as, an explanation of the setting for the study. In addition, a rich, detailed description of the thematic findings was included in the results section of this study.

Dependability

Dependability was ensured using an inquiry audit. This step occurred upon completion of the data analysis. It consisted of a review of the findings with a researcher who was not involved in the study.

Confirmability

I maintained a detailed an audit trail in order to provide a complete outline of the conscious and physical steps taken throughout data collection and analysis process. Before beginning interviews and data analysis, I maintained epoché to fully enter into the lifeworld of the participants. Before interviews and data analysis commenced, I employed bracketing to reflect on any preconceived notions, ideas or biases, in order to set these thoughts to the side. Bracketing enabled me to approach each participant’s experiences with an open mind in order to identify the essence of participants’ lived experiences (Hycner, 1999).

Summary

The transition from pediatric to adult care was a challenging period in time for these participants. They faced many changes in addition to the transition to adult care. Other transitions that occurred included, graduating from high school and beginning to attend college. For some the transition seemed to be overwhelming, while for others with was described as easy. The range of experiences these participants described painted a full picture of the different paths that could occur. For most of the participants, little forethought or planning had occurred before the transitions. The change felt very abrupt, and many struggled to find their footing amidst the difference changes and challenges they faced.

Overall, the participants had a range of experiences when it came to the transition process. The experiences they had covered a wide spectrum from planned and organized to nonexistent. In spite of the varied experiences, they all managed to find care and located adult health care providers who could give them support and care.

The participants all reported being satisfied with their health care providers. They made the transition into adult care and generally liked their physicians. Some of the supporting staff were identified as less caring, but the main relationship with their physicians was perceived positively.

Summary Research Question 1

The answer to this research question was made up of three distinct themes. The themes encompassed the participants' experiences in receiving treatment while in pediatric care. The majority of the focus for the participants at this time revolved around the relationships that formed with their physicians. The participants also spoke about looking towards the upcoming transition period and their thoughts and feeling regarding this change. The final theme focused on the quality of communication that occurred with the health care providers during this stage. Over all, the participants indicated high levels of satisfaction with the care they received, and their relationships with the health care providers. They noted some communication issues, more on their side than the providers, and they universally indicated that they were very satisfied with their pediatric care with 11 of 12 participants indicating they were reluctant to leave the physicians and other professionals who had formed their support network. The one participant who was not reluctant to transition was eager to be thought of as an adult. Her desire for change did not reflect the quality of the relationship with her health care providers, and was a result of her desire to move forward in her life.

Summary Research Question 2

The answer to this research question revealed 10 of the 12 participants transitioned into adult care at the age of 18. The other two participants transitioned at the age of 21. This was a challenging period for these participants. They faced many changes in addition to the transition to adult care. Other transitions that occurred included graduating from high school and beginning to attend college. For some the transition seemed to be overwhelming, while for others the transition was described as easy. The range of experiences these participants described painted a full picture of the different paths that could occur. For most of the participants, little forethought or planning had occurred before the transitions. The change felt very abrupt, and many struggled to find their footing amidst the changes and challenges they faced.

Summary Research Question 3

The participants all reported being satisfied with their health care providers. Generally, the participants indicated that they had formed good relationships with their new health care providers. Once the transition into adult care was complete, some of the participants found that the care was equivalent to the care they received from their pediatric health care providers. Many formed strong relationships with their new physicians and were pleased with the relationships. Areas of difference pointed out by the participants were in ancillary areas, such as treatment in the emergency room. Overall, they felt that health care providers displayed lesser degrees of empathy and compassion, but also reported that they were satisfied with their physical care.

Chapter 5: Discussion, Conclusions, and Recommendations

The continuity of care is essential to health maintenance among individuals living with SCD (Jordan et al., 2013). Pediatric patients who are unprepared to transition to adult care are more likely to return to their pediatric providers, utilize emergency rooms, and fail to keep follow-up appointments with their health care providers (Bryant & Walsh, 2009). SCD patients demonstrate alarming increases in mortality during the transition period (Brousseau et al., 2010; Cadario et al., 2009; Debaun & Telfair, 2012; Quinn et al., 2010); therefore, more effective transition support is needed among this patient population. Prior to the current investigation, few researchers had explored the transition process from the perspectives of successfully transitioned patients.

Although health care transition for adolescents with chronic and disabling conditions is a national priority (Reiss & Gibson, 2002), debate remains on best practices for structuring SCD transition programs and measuring program effectiveness (Treadwell et al., 2011). The purpose of the current study was to investigate the lived experiences of 12 patients with SCD who were within the first 3 years of completing transitional care at the study site facility. Specifically, I explored SCD patients' perceptions and experiences of care transition programs, as well as their perceptions of quality of life during care transition.

Analysis of data related to the first research question addressing how individuals described their experiences in pediatric care revealed three themes: (a) relationships formed with health care providers, (b) communication was mediated through the parents, and (c) unwillingness to start the transition process. Because of the continuity of care and consistency of personnel with whom participants interacted, they were able to develop close bonds with pediatric health care providers including physicians, nurses, and other medical professionals. The development of long-term trusting relationships with health care providers helped participants feel safe and comfortable in pediatric care. Because they interacted with the same medical professionals throughout the duration of their pediatric care, participants did not have to worry about informing care providers of their health histories or individual needs. These relationships improved the quality of health care delivered to participants, which was important to them. In addition, participants described high levels of coordination among pediatric care providers, which helped ensure holistic high-quality patient-care decisions.

Participants revealed that much of the patient-provider communication was facilitated through their parents. Although participants described feeling safe and comfortable with their health care providers due to the strong bonds developed over the course of treatment, they were reticent to engage directly with providers. Participants also described a general unwillingness to begin transition to adult care due to fears of losing the relationships they had established with pediatric care providers and uncertainty with establishing new bonds with adult providers. Participants also described feelings of stress and anxiety. Had they been given the opportunity, most participants would have remained in pediatric care rather than transition into adult care.

Participants described many barriers and challenges related to the transition process. The process felt abrupt, and participants described it as an overwhelming undertaking during a period in their lives when they faced many other big changes (i.e., graduating from high school, moving to start college, etc.). The biggest challenge described by participants was locating adult providers. Participants also had a difficult time adjusting to speaking up and becoming their own advocates, especially when they were accustomed to having parents speak for them while in pediatric care. They also had to figure out where to go to receive care, how to handle insurance, and how to make and manage appointments—all factors that parents previously handled. Participants reported their parents were also concerned about the transition process and ensuring care continuity as participants learned to manage their SCD care. Although participants understood that learning to manage their health care was a skill they would need to develop to transition into adult care, they did not describe having received much preparation for that transition. Participants reported many negative emotions associated with the transition process, including worry, fear, anxiety, stress, and paranoia.

Much of the fear, stress, and anxiety reported by participants regarding the transition process was related to establishing relationships with new health care providers. Participants' fears related to the establishment of new relationships were primarily based on the unknowns of new settings and new care providers. Participants were also uneasy with creating adult relationships and interacting with care providers as adults because they had not developed the self-efficacy to feel confident managing these communications while in pediatric care. Participants who were afforded opportunities to meet with their adult providers prior to transition, to begin the process of establishing relationships with them, described less stressful transition processes. As for the organization of the transition process, some participants described a structured and supportive process, while others described processes with little to no support. Participants who experienced longer, more structured transitions described less challenging transitions than those who simply received physician referrals.

In response to the third research question addressing participants' experiences in adult care, participants discussed challenges they faced juggling other life challenges during the time of their transition and learning to navigate the adult care system. Participants also described not realizing how much work went into scheduling their appointments and managing care, or the amount of information they needed to know to manage SCD. Finally, although most participants were satisfied with the care they received as adults, they did not have the same emotional connections with adult care providers that they had experienced in pediatric care. Although they were generally satisfied with the transition process, participants described more caring and nurturing interactions with pediatric care providers than with adult providers.

Interpretation of the Findings

Findings from this study are largely reflective of findings from previous studies. In this section, I compare findings from the current study to those from previous studies. This section includes the following subsections: (a) resistance to transition; (b) inadequate transitional programming; (c) lack of autonomy; (d) fear, anxiety, and stress; (e) lack of education; (f) simultaneously managing other life changes; and (g) experiences after transition. Table 17 details how these topics were confirmed by previous researchers.

Table 17

Confirmation of Study Findings by Previous Researchers

Topic	Findings from previous research that confirm those of the current investigation	Findings from current study
Resistance to Transition	In Bryant et al.'s (2011) study, participants resisted the transition process because they felt unprepared and anxious.	Participants discussed a variety of reasons for resisting transition, including poor preparation for transition, lack of self-efficacy/ autonomy, fear, inadequate education, and coping with simultaneous changes in other areas of their lives.
Inadequate Transitional Support Programming	Bryant and Walsh (2009) reported disjointed transition programs for SCD patients. Nishikawa et al. (2011); Lotstein, Ghandour, et al. (2009); and Lotstein, McPherson et al. (2005) also reported deficiencies in the levels of support provided to patients transitioning from pediatric to adult care.	The transition support described by participants varied; some participants experienced formal transition support lasting years, while others did not even receive referrals to adult providers.
Lack of autonomy	Bryant et al. (2011) reported that autonomy was essential to successful care transitions.	

Table 17 Continued

Topic	Findings from previous research that confirm those of the current investigation	Findings from current study
Lack of autonomy	Rosen et al. (2003) reported that emergent autonomy must be fostered to improve patients' transitions to adult care settings. Fegran et al. (2014) found that poor autonomy was a barrier in the transition to adult care.	Poor autonomy and self-efficacy were transition barriers discussed by many participants in the current investigation.
Fear, anxiety, and stress	Researchers of health care transitions among emergent adults with chronic health conditions reported on patients' related fears, anxieties, and stresses (Bryant et al., 2011; Hankins et al., 2012; Jordan et al., 2013; Telfair et al., 2004).	Participants in the current study expressed significant fear, anxiety, and stress related to care transition.
Lack of education	Because of poor knowledge among transitioning patients, previous researchers emphasized the need to integrate education related to disease management as part of patients' transitional programming (Bryant et al., 2011; Doulton, 2009).	Participants described feeling overwhelmed by the thoughts of taking responsibility for their own health care, especially due to the lack of knowledge related to management of their SCD upon transition.

Table 17 Continued

Topic	Findings from previous research that confirm those of the current investigation	Findings from current study
Lack of education	Hankins et al. (2012) and Nishikawa et al. (2011) recommended that care transition programs provide patients with information needed to navigate these other aspects of their health care management to improve transition.	
Simultaneously managing other life challenges	Musumadi et al. (2012) and Watson (2000) reported that unrelated challenges of emergent adulthood can make chronic disease management more difficult for transitioning patients. Musumadi et al. (2012) recommended that transition programs consider patients' various social and developmental needs, not just their clinical needs.	Participants discussed simultaneously managing a variety of significant changes associated with emergent adulthood (i.e., graduating from high school, moving away from home, starting college, joining the workforce, etc.) while also becoming responsible for the management of their SCD.
Experiences after transition	Bryant et al. (2011) reported that once accepting the transition process, SCD patients usually found adult care settings to be informative and welcoming.	Participants in the current study generally expressed satisfaction with the care they received after coming to terms with the changes and completing transition.

Resistance to Transition

Resistance among SCD patients to transfer to adult care was a prominent theme in the current study, which previous researchers also reported (Bryant et al., 2011; Bryant & Walsh, 2009). For example, Bryant and Walsh (2009) reported that patients' transition resistance was reflected in the mixed feelings that patients, parents, and health care providers expressed regarding transition to adult care. During an investigation of 14 SCD patients who had transitioned into adult care, Bryant et al. (2011) reported that all participants expressed an unwillingness to transition out of pediatric care. The three themes that emerged relative to transition resistance were concerns about the transition experience, feeling forced out of pediatric care, and reactions to the transition process. Participants in the current study had a variety of reasons for resisting transition, including poor preparation for transition, lack of self-efficacy/autonomy, fear, inadequate education, and coping with simultaneous changes in other areas of their lives.

Inadequate Transitional Support Programming

The lack of transitional support was a prominent theme in the current investigation. The transitional support described by participants varied; some participants experienced formal transitional support lasting years, while others did not receive referrals to adult providers. To ensure smooth transitions to adult providers and care continuity, SCD patients must receive formal support (Bryant & Walsh, 2009). Findings from the current study echoed those from previous studies, which indicated disjointed transitional programs for SCD patients (Bryant & Walsh, 2009). For example, in their evaluation of 17 empirical studies on SCD transition, Bryant and Walsh (2009) reported that few programs existed to help SCD patients transition to adult care. The lack of adequate programming was indicated by patients' difficulties locating adult providers, abrupt transfer experiences, and lack of access to transfer resources.

Other researchers investigating youth care transition reported deficiencies in the levels of support provided to patients transitioning from pediatric to adult care (Lotstein, Ghandour, et al., 2009; Lotstein, McPherson, et al., 2005). Findings from Nishikawa et al.'s (2011) study indicated that lack of transitional support might occur because health care providers are not equipped to provide transitional assistance. In addition to ensuring patients have access to adequate support, it is also necessary to ensure that the length of supportive transitional programs is adequate. Staa, Name, et al. (2011) reported that transitional programs that prepared patients for transition over time were necessary for improving transition and preventing the process from being abrupt. Further, Staa, Jedeloo, et al. (2011) reported that early preparation was key to ensuring effective transitions.

Lack of Autonomy

Poor autonomy and self-efficacy were issues expressed by many participants in the current study. Previous researchers also reported this barrier. For example, after accepting and adjusting to transition, participants in Bryant et al.'s (2011) study reported greater feelings of autonomy in managing their health care, which improved their overall attitudes toward transition. Bryant et al. found that the benefits of autonomy, control, and independence afforded to patients in adult care settings outweighed the challenges and barriers associated with care transition. Although patients are often resistant to transition, such reticence may relate to emerging adulthood rather than concerns about their future care. If family members and health care providers can develop ways to foster autonomy while SCD patients are in pediatric care, patients may perceive the care transition process in a far more positive light.

A fundamental aspect of youth transition programs, according to Rosen et al. (2003), is the fostering of emergent autonomy. Failure to foster autonomy was reported as a transition barrier by previous researchers (Fegran et al., 2014). A potentially significant barrier to autonomy among participants in the current study may have been well-meaning parents. Participants discussed not feeling comfortable speaking directly with their care providers, preferring to allow their parents to ask questions and speak for them. Although this was likely because parents were caring and concerned about their children's health, acting as their children's mouthpieces may have prevented participants from becoming comfortable talking with doctors, discussing their health, and learning to manage their own health. Thus, highly involved parents may actually foster a barrier to autonomy among SCD patients. As Fegren et al., 2014) explained, it can be difficult for emergent adults to become autonomous and learn to manage their health care independently if their parents are reluctant to let go of their responsibilities.

Fear, Anxiety, and Stress

Participants in the current study expressed significant fear, anxiety, and stress related to care transition. These sentiments were reflected by previous researchers on SCD transition. For example, Bryant et al. (2011) reported that participants expressed fear and anxiety over the unknowns related to care transition, especially regarding who their care providers would be and what types of care they would receive. Many other researchers of health care transitions among emergent adults with chronic health conditions reported on patients' related fears, anxieties, and stresses (Bryant et al., 2011; Hankins et al., 2012; Jordan et al., 2013; Telfair et al., 2004). While participants in the current investigation discussed their transition fears, anxieties, and stressors as related to the unknowns of transition, such as working with new doctors, a deeper analysis revealed that these negative emotions may be more related to emergent adulthood and lack of knowledge/preparation for transition. For example, many participants discussed feeling uncomfortable speaking for themselves or interacting with their pediatric doctors. They were accustomed to having their parents ask and answer questions for them; however, as they assumed responsibility for their own care and transitioned into adult settings, they were expected to communicate with doctors on their own. These may have been uncomfortable experiences for participants who were not accustomed to having to speak with their doctors, themselves, thus creating feelings of intimidation or anxiety. Similarly, patients may have felt stressed or anxious about transition because they lacked adequate knowledge regarding their disease management and health care processes.

Lack of Education

A significant factor in the lack of autonomy reported by participants in this study, as well as those in previous investigations, may be inadequate knowledge related to disease management. Participants described feeling overwhelmed by the thoughts of taking responsibility for their own health care, and many described a lack of knowledge related to management of their SCD upon transition. Without fully understanding their disease and care requirements, patients may have experienced reduced autonomy and low levels of self-efficacy, which led to fears, stress, anxiety, and resistance related to care transition. Accordingly, previous researchers emphasized the need to integrate education related to disease management as part of patients' transitional programming (Bryant et al., 2011; Doulton, 2009).

The education and knowledge needed by transitioning SCD patients may extend beyond management of the disease processes. Participants in the current investigation discussed feeling overwhelmed by other factors related to their care, such as understanding insurance and payment processes, and figuring out how to obtain physical referrals. Accordingly, previous researchers recommended that care transition programs provide patients with information needed to navigate these other aspects of their health care management, which may help to improve transitioning patients' feelings of autonomy (Hankins et al., 2012; Nishikawa et al., 2011).

Simultaneously Managing Other Life Changes

Another challenge reflected by participants in the current investigation was simultaneously managing a variety of significant changes associated with emergent adulthood (i.e., graduating from high school, moving away from home, starting college, joining the workforce, etc.) while also becoming responsible for the management of their SCD. Previous research indicated that unrelated challenges of emergent adulthood can make chronic disease management more difficult for transitioning patients (Musumadi et al., 2012; Watson, 2000); thus, transition planning should account for these various life changes. Accordingly, Musumadi et al. (2012) recommended that transition programs consider patients' various social and developmental needs, not just their clinical needs.

Experiences After Transition

Despite trepidation associated with transition to adult care, participants in the current study generally expressed satisfaction with the care they received after coming to terms with the changes and completing transition. Although they missed the caring and nurturing relationships they developed with pediatric providers, they found the care from adult providers to acceptable. Similarly, Bryant et al. (2011) reported that once accepting the transition process, SCD patients usually found adult care settings to be informative and welcoming.

Limitations of the Study

Possible limitations of the current investigation included recall bias and selective responses. This study may have been subject to a degree of recall bias in older participants, which I attempted to limit by narrowing the age range of participants and only including participants who were within their first 3 years of transition. Despite confidentiality, it is also possible that participants may have been reticent to share information that would cast a negative light on those who assisted them during the care transition process.

Another limitation is that all participants received care from the same hospital. Thus, this study did not account for facility-related variances in the care transition process. It is possible that transitioning patients who received care at other facilities may have had different transition experiences. Finally, this study only focused on the experiences of transitioning patients. The experiences and perspectives of care providers and parents may have shed additional light on patients' transition processes.

Recommendations

The transition from pediatric to adult care settings is a complex process that simultaneously involves changes in developmental, health, situational, and organizational factors (Fegran et al., 2014). Thus, many factors should be considered when making recommendations for practice and future research. For example, Bryant and Walsh (2009) recommended the establishment of buddy systems to help SCD patients transition into adult care. Buddy systems may be an effective way to reduce SCD patients' reliance on their parents, while still providing peer support and fostering autonomy (Fegren et al., 2014). Similarly, Bryant et al. (2011) suggested the development and implementation of interventions designed to provide ongoing transition preparation and health care education to young SCD patients. Because most of the existing research conducted on the efficacy of SCD transition programs is not based on empirical evaluation, Bryant and Walsh called for future research to evaluate the clinical outcomes of such programs. This is an important direction for future research echoed by Grant and Pan (2011). Additionally, it is important that research on the effectiveness of SCD transition programs consider the perspectives and experiences of patients, rather than just focusing on feedback from parents and health care providers (Betz et al., 2013).

Findings from the current investigation also support the need for research on more comprehensive SCD transition programs; however, in order to understand critical factors of transition programs, empirical research is needed to investigate the clinical outcomes of different program factors. For example, future researchers may study the effects of programs aimed at improving patients' self-efficacy and developing patient-provider communication skills. Similarly, future study could center on the effects of targeted educational programs designed to improve SCD patients' understandings of their diseases and improve their feelings of self-efficacy related to managing their health care.

Future researchers may also explore sociodemographic differences in transition readiness among SCD patients. Previous researchers found that patients' transition readiness tended to vary based on demographic characteristics. For example, Staa et al. (2011) reported that boys and older patients were typically more prepared to transition than girls and younger patients were. Although sociodemographic considerations were beyond the scope of the current investigation, such research could help health care providers create tailored programs designed to improve successful transition into adult care settings.

Implications

Positive Social Change

Results from the current study may help health care providers and the family members of SCD patients develop a better understanding of patients' transitional needs. These findings may be used to develop and implement transition programs, or improve the effectiveness of existing programs. While health care transition is an experience that many people with chronic health conditions undergo, successful transition among SCD patients is especially crucial for reducing mortality rates and helping patients live longer, healthier lives.

Stakeholders, including doctors, health care administrators, and health insurance companies may use the findings from this study to inform policy and improve patient care transition. In addition, findings may be used to inform the development and implementation of transition programs for children suffering with other chronic illness, besides SCD. Research indicates that poor care transition is a problem for youth suffering with a variety of other chronic illnesses, such as (diabetes) Vaks et al., 2016) and spinal bifida (Lewis & Slobodov, 2015).

Another potential implication for positive social change from the current study relates to the bedside manners of adult practitioners. Participants consistently discussed the warm and nurturing care provided to them by their pediatric doctors and nurses.

However, most participants discussed receiving much more cold and sterile care after transitioning to adult providers. The caring bedside manner demonstrated by pediatric caregivers should be fundamental to all levels of patient care. As Farooq et al. (2015) explained, “It is not possible to effectively address a medical concern without addressing the anxiety, concern, and fears that come with a disease. So, technical solutions are only half the answer” (p. 179). Thus, it is possible that adult care providers need to be trained to develop better bedside manners. Not only may this reduce the stress and anxiety experienced by youth transitioning to adult care, but improved bedside manners may also benefit all adults receiving medical attention (Swing, 2007).

Theoretical Implications

Results from this investigation supported use of the biosocial-ecological systems model (Treadwell et al., 2011) to explore transition from pediatric to adult care among SCD patients. The model also provides a comprehensive framework for evaluating existing SCD transition programs and developing new ones. The five systems that can influence SCD transition, according to the biosocial-ecological systems model, are the microsystem, mesosystem, exosystem, and macrosystem (Griffin et al., 2013). According to Treadwell et al. (2011), the microsystem involves the immediate environment; including family, peer groups, school, and neighborhood. The mesosystem refers to connections between microsystems, while the exosystem includes external factors that affect the development indirectly. Finally, the culture of an individual is encompassed by the macrosystem (Treadwell et al., 2011). Results from the current study indicated that factors within the microsystem are significant factors in SCD patient transition. Specifically, patients' experiences in their immediate care environments, interactions with doctors and family members, and the communication between pediatric and adult care providers may all affect patients' transition experiences. The biosocial-ecological systems model can provide a valuable framework for the development of comprehensive transition programs that improve independent self-care, disease knowledge, and long-term health outcomes among SCD patients (Dale et al., 2011).

Practical Implications

Based on findings from the current investigation, practical recommendations can be made. For example, adult care providers should be equipped with the knowledge and skills needed to foster more effective transition among SCD patients. Similarly, Nishikawa et al. (2011) urged for research on the effects of training provided to health care providers to assist youth with chronic health problems during the transition from pediatric to adult care in order to identify effective approaches and to optimize transitions.

Another recommendation can be made regarding the scope of transition programs. A common reason participants cited for reticence to transition was concerns about leaving the comprehensive care provided by their pediatric care team. Participants described less holistic care and disjointed communication between medical professionals in adult care settings. Previous researchers reported this finding (Staa, Jedeloo, et al., 2011). However, effective transition programs must take a holistic approach in order to provide transitioning patients with the greatest health outcomes (Fegren et al., 2014). Accordingly, when designing and implementing transitional care programs, caregivers should emphasize communication across patients' care teams. Not only may this lead to better transition, but also more effective long-term care for adult SCD patients.

Conclusion

In this chapter, I compared findings from the current study to those from previous researchers, as arranged in the following subsections: (a) resistance to transition, (b) inadequate transitional programming, (c) lack of autonomy, (d) fear, anxiety, and stress, (e) lack of education, (f) simultaneously managing other life changes, and (g) experiences after transition. I also reviewed the study's limitations and recommendations for future research. Theoretical, practical, and positive social change implications were also discussed.

Ongoing care is critical to health maintenance among individuals living with SCD (Jordan et al., 2013). Prior to the current investigation, few researchers had explored the transition process from the perspectives of successfully transitioned patients. In this study, I investigated the lived experiences of 12 patients with SCD who were within the first 3 years of completing transitional care at the University of Texas Southwestern (USTW) Medical Center. This study shed new light on some of the challenges associated with care transition among SCD patients. Much of what was reported by participants was reflective of findings produced in previous investigations, indicating that significant challenges exist for transitioning SCD patients.

Addressing the challenges reported in this study is critical to ensuring successful transition for SCD patients, which is necessary to reduce mortality rates and help patients live longer, healthier lives. While many young adults with chronic illnesses experience the transition from pediatric to adult care, the impact of transition on young SCD patients can be much more profound than for other illnesses; for SCD patients, transition can significantly influence their mortality. Thus, successful transition among SCD patients is critical for reducing mortality rates and helping patients live longer, healthier lives.

Findings from this study may be used by stakeholders, including doctors, health care administrators, and health insurance companies, to inform policy and improve the well-being and quality of life among transitioning SCD patients. There is currently no cure for SCD, but through continuous managed care, many individuals can live longer, healthier lives. We must address the transitional care needs of SCD patients to ensure every young person living with SCD has the opportunity to live fullest life possible.

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Appendix A: Semistructured Interview Guide

Brief Introduction

Hello, my name is Karen Haynes and I am in pursuit of a Doctoral Degree in General Psychology with Walden University, School of Psychology. I am conducting a research study titled: Health care Transition and Patient-Perceived Quality of Life in Sickle Cell Disease. I am very passionate about my topic of research because my family has been affected by the painful disease of sickle cell. To begin, I would like to thank you for volunteering your time to participate in this interview.

The purpose of these interviews is to gather data regarding the transition from pediatric to adult care for Sickle Cell Disease patients. Please make yourself comfortable and remember that you may leave the interview process at any time. In addition, your responses will remain confidential, and any information from this interview will be de-identified using a pseudonym. Full, honest, and comprehensive responses are greatly appreciated, now let's begin!

Interview Questions for Research Question 1

Lead in: To gain a better understanding of your health, I would like to go back to when you first received care after being diagnosed with sickle cell disease and talk with you about the care you received.

- Can you describe the different types of care you received as a child?

        - Care in hospital
        - Care in doctor's office
        - Care in urgent care
        - Care in emergency department
    - What were the frequencies of the different types of care?

- Can you talk about the different providers you had and what your experience with each type was like for you?
        - Nature of care
        - Frequency of care
        - Helpfulness of care
    - What was the nature of relationships developed with health care providers?

- Thinking about your experience in pediatric care in terms of hospitalizations and the providers you worked with and received care from, what was it like for you as you approached the time when you had to leave pediatric care?
        - Feelings experienced
        - Barriers/Challenges faced
        - Relationship with pediatric care providers?
        - Positive or negative
    - Was the transition process difficult or easy? Why or why not?

Interview Questions for Research Question 2

Lead in: As you began to think about moving from pediatric care to adult care what kinds of things did you think about? (Prompt: hospitalization changes, health care provider changes, issues of concern, support through transition).

- ❖ What kinds of support did you receive and from whom as you begin to think about and make the transition from pediatric to adult care?
    - ♦ Nature of support
    - ♦ Challenges experienced
    - ♦ Care in urgent care
    - ♦ Helpfulness of support

- ❖ What was the actual process of transitioning from pediatric to adult care like for you?
    - ♦ Age transition took place
    - ♦ Challenges experienced
    - ♦ Issues of concern

Interview Questions for Research Question 3

Lead in: When you made the transition to adult care what was the experience like for you? (Prompt: differences/similarities to pediatric care – hospitalization, support from health care providers, care provided, challenges faced)

- As you think about the experiences you have been having in adult care what stands out as the biggest changes from pediatric care for you?
    - Nature of hospitalization
    - Health care provided
    - Participation in decisions about health care

- What about the experiences you have had now that you are receiving adult care would you share with others who are about to make the transition from pediatric to adult care?
    - Issues you faced
    - Recommendations for smoothly paving the transition process
    - What questions would you have asked back then

- What significant events and experiences that stand out for you when receiving adult care?
    - Differences/similarities between pediatric and adult care
    - Support received during transition process
    - Challenges faced in receiving support or help
    - Differences in care received from pediatric and adult physicians
  - What were the similarities/differences in care from pediatric and adult

physicians?

Closing statement: Do you have any final comments on about your experience that I have not previously asked?

Appendix B: Demographic Questionnaire

Please provide your birth name: ___________________________

Please provide a desired pseudonym: ___________________________

(This is to protect your confidentiality. If you do not respond to this section, you will be assigned a pseudonym before the interview begins.)

Please indicate your gender:

Male: ___

Female: ___

Other (please specify): __________________

Please indicate your current age: ____

When were you first diagnosed with sickle cell disease?

Please respond with an approximate date: _____________

What is your racial identity?

American Indian or Alaska Native: ___

Asian: ___

Black or African American: ___

Hispanic/Latino: ___

Native Hawaiian/Pacific Islander: ___

White: ___

Other (please specify): ____________________