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Revitalizing Public Health Policy and Legislation for Effective Management of Sickle Cell Disease

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This is to certify that the doctoral dissertation by

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Abstract

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MPhil, Walden University, 2021

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Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
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Abstract

The transition of care from childhood to adulthood can impact young adults with chronic conditions. U.S. public health policy and legislation can mitigate the challenges with the transition of care through education and policy guidelines. There was a lack of information on the public policies that evaluate continuing care practices, education, and the competence of young African American (AA) adults with sickle cell disease (SCD) living in Pennsylvania. The purpose of this generic qualitative study was to explore the experiences of 10 AA adults ages 18–25 with SCD to understand what education was necessary for policymakers to reform legislation and public policies to enhance quality of life. The theoretical framework for this study was the policy feedback theory and the narrative policy framework. Data were collected via semistructured interviews with a researcher-developed interview guide. The data were analyzed using descriptive coding and thematic analysis. Five themes emerged: responsibility for health and wellness, SCD education, challenges associated with SCD, the impact of SCD on mental health, and the benefits of support systems. Findings may be used for positive social change by policymakers to evaluate the personal factors that impact the transition of care to promote public policy reformation for individuals living with SCD.

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Dedication

All thanks be to God for enabling me to reach this academic goal and milestone in my life. His love and mercy endures forever. I am humbled to make it to the finish line, and I recognize that by faith “I can do all things through Christ, who strengthens me” (Philippians 4:13). This dissertation is dedicated to my wonderful parents, Evelyne Beaubrun and Henock Beaubrun. Thank you for your love, compassion, support, and encouragement throughout my life. After God, I am the strong woman I am today, because of you both. I am so grateful for the greatest blessing that God gave me to have amazing parents like you and the privilege of being your daughter.

I would also like to dedicate this dissertation to my wonderful sister, Samantha Beaubrun. Thank you for being not only my sister but also my best friend and my biggest cheerleader. I am incredibly grateful for your love, kindness, and support. In addition, I would like to dedicate this dissertation to my late and dear grandmother, Jeannette Lambert. Thank you for being such a wonderful and caring grandmother to me. I love you beyond what words can express. You were full of love and brought so much joy to my heart. I am so grateful for your support throughout my life. Thank you for the positive impact that you made on my life, your love, and your legacy. May you rest peacefully in heaven, in all your beauty, love, kindness, and profound affection. To my late and beloved grandmother, Roosevelt Woeche, thank you for your love and strong foundation of faith that has been a source of inspiration. I am so grateful for the wonderful memories that we have shared. Heaven has gained a beautiful angel.

In addition, I dedicate this accomplishment to my former speech coach, the late and great Sister M. A. Hawes, who saw something special in me and supported me as a student competing, excelling in forensic public speaking tournaments, and receiving multiple championships. I also dedicate this dissertation to the late and great Dr. K.O.F., my former hematologist who made a positive impact on my life and served as a mentor, educator, and advocate for sickle cell disease.

I dedicate this dissertation to the wonderful health care workers, nurses, doctors, hematologists, providers, researchers, and educators who made an impact on my life and those living with sickle cell disease. Finally, I dedicate this milestone to every person living with sickle cell disease and the community of people worldwide impacted by this condition, who put on a brave face each day despite the obstacles and challenges associated with this condition. May you continue to be strong, let your light shine bright, believe in yourself, and aim high. May your stories continue to serve as a source of inspiration to individuals with sickle cell disease and other debilitating illnesses.

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Chapter 1: Introduction to the Study

Sickle cell anemia (SCA) is a form of the inherited blood disorder, sickle cell disease (SCD). According to Cushman et al. (2021), SCD is a genetic, red blood cell disorder that affects individuals of African, Mediterranean, or Asian descent, with a worldwide estimated prevalence of 200,000 children born with SCD each year. Clinical features of this condition include acute and chronic pain, multiorgan injury, or shortened life span (Cushman et al., 2021). SCA is one type of SCD. There are many forms and types of SCD, which can be severe or mild classifications of the disease, including hemoglobin SS disease (SCA), hemoglobin SC disease, hemoglobin SB+ (beta) thalassemia, hemoglobin SB 0 (beta-zero) thalassemia, hemoglobin SD, hemoglobin SE, and hemoglobin SO (Centers for Disease Control and Prevention, 2023b).

According to Aleluia et al. (2020), SCA is the most severe form of SCD. In addition, SC hemoglobinopathy (HbSC) is thought to be a milder form of SCD. The transition of care from childhood to adulthood can be a vulnerable stage affecting disease management and effective continuing care practices. Successful transitions and collaboration among health care providers, nurses, and clinicians are a priority to ensure positive disease management and independent lifestyle implementations. Public health policy is central to defining a scope of practice and enacting guidelines to foster an effective transition through education for young AA adults with SCD.

As defined by the Center for Healthcare Transition and Improvement (Hankins et al., 2019), there are six core elements of transition. The elements of transition include policies that foster the transition of care, monitoring progress, conducting assessments for transition readiness, coordination, planning for adult care, transferring patients from childhood to adulthood care, and ensuring a successful integration process. These elements are critical to public health and promotion and self-management guidelines for young adults with SCD. Researchers are investigating interventions in comparative effectiveness trials to promote health-related quality of life. The goal is to reduce acute care utilization among adults with SCD (Hankins et al., 2019).

However, defining transition outcomes also plays an integral role in promoting the success of interventions for productive transition processes. Health care systems experience barriers in the context of specialized training and education with individuals and healthcare providers working with this population. Challenges can arise with care coordination within the pediatric and adult health care systems. Challenges can also impact the continuity of care that young adults receive. Patient factors also contribute to the gaps in the transition of care including disease knowledge and management, self-efficacy skills, and a lack of preparation. Best practices for the care of these patients require systematic approaches to health care transitions. Although guidelines for health care transitions are prevalent, gaps in care remain a challenge. Data are limited on the outcomes of the health care transition processes (Hassell et al., 2018).

The current study was needed to fill a gap in the literature that considers public policies for the continuation of care from childhood to adulthood and education to increase competence among specific populations. Findings from this study may assist health care providers and legislators in helping young AA adults with SCD to utilize cultural competence education materials to promote self-management guidelines.

Education materials and cultural competence have long been a force for social change by promoting resources for individuals with chronic conditions. According to Brookshire et al. (2020), patient education and materials from a health care provider increase patients' understanding and adherence to medical instructions. In return, this helps to improve patient health outcomes. Young adults with SCD need better health care guidance, and supporting their successful attainment of cultural competence materials allows for increased knowledge to self-manage health care needs and promote quality of life.

The current study may revitalize public policy by offering a fresh perspective on how an existing policy can promote new health care initiatives for individuals with SCD. For example, the Sickle Cell Disease Control Act of 1972 could add or reform an educational component for young adults with SCA or SCD (American Society of Hematology, 2024). The current study provided insight into how young adults with SCD understand their experiences and educational journey. This information could offer an analysis of current laws for individuals with SCD and encourage more legislative guidance for organizations to follow protocols during the transition of care. In addition, current study findings may be a helpful resource for public administrators, health care providers, and professionals to help young adults receive the necessary education to effectively self-manage their condition.

The results of this study offered insights into the processes by which cultural competence education materials can help individuals with SCD to self-manage this condition. According to U.S. Department of Health and Human Services Office of Minority Health (2021), national standards have been created for culturally and linguistically suitable health care services. The national culturally and linguistically appropriate services standards offer guidelines to implement these services to improve health care in the United States. These standards encompass many areas including governance, leadership, communication, and language services organizational engagement and improvement (Agency for Healthcare Research and Quality, 2019).

Insights from the current study could assist health care providers in providing support to young AA adults with SCD to utilize cultural competence education materials to promote self-management guidelines. Education materials and cultural competence serve as a resource for individuals with chronic conditions. This is also important for the patient, provider, and organizational level to inform appropriate policies that offer culturally competent education.

Chapter 1 provides information regarding the background of the study, problem statement, purpose of the study, research question, and theoretical framework for the study.

In addition, this chapter offers insight into the nature of the study and provides concise definitions of key concepts, assumptions, scope, and delimitations. A brief examination of this study’s limitations related to the overall design and/or weaknesses in the methodology is explored. Lastly, this chapter identifies the significance of this study and contributions that may advance knowledge in the field of public policy and administration. This chapter includes a summary of the main points discussed in this chapter.

Background of the Study

The literature review included primary sources such as peer-reviewed, scholarly articles, publications, and official government sites. These articles were accessed via the Walden University research databases EBSCO Discovery Service, PubMed, and Thoreau Multi-Database Search. Database searches were conducted using keywords and phrases including *sickle cell disease*, *sickle cell anemia*, *sickle cell*, *young adults*, *African American*, *cultural competence*, *transition of care*, *public policy*, and *education*.

Ayers et al. (2017) focused on utilizing a community-based participatory research to evaluate cultural competency training and improve culturally appropriate care among Marshallese and Hispanic communities. The study found that participants at 25 organizations reported higher levels of knowledge after completing a cultural competency training; this was important to my study to help me understand how providers can utilize cultural competency training to improve culturally appropriate care. Crosby et al. (2021) focused on factors that activate patients' knowledge, motivation, self-efficacy, and social support to self-manage SCD by using Sickle Cell Thrive, a mixed in-person and online technology-enhanced mobile app for self-management. The study found that Sickle Cell Thrive was highly feasible and helped participants with SCD manage their condition. This was important to my study to help understand self-management interventions that can be useful in educating the younger adult population. Davies et al. (2019) focused on the health care experiences of individuals with chronic conditions like cancer and asthma in New Zealand. Findings indicated that chronic illnesses disrupt the trajectory of one's life and health care professionals require effective cultural competence training. This was important to my study to help in understanding how young people with chronic conditions experience the health system. This is also helpful to understanding the methods necessary to include young adults during the decision-making process.

In 1972, Congress passed the National Sickle Cell Disease Control Act, which provided an obligation to establish educational information, screening, testing, counseling, research, resources, and treatment programs for SCD (Manley, 1984). According to Manley (1984), under the administration of the National Institutes of Health, sickle cell research and treatment centers were established. Under the administration of the Health Services Administration, sickle cell screening and education clinics were also created.

It can be challenging for young adults living with a chronic condition such as SCD, which requires lifestyle changes and implementations to manage, control symptoms, and prevent potentially life-threatening complications (Hamilton et al., 2016). Hamilton et al. (2016) conducted a qualitative study to describe the perceptions of young adults between the ages of 18 and 35 with SCD. The study recognized self-care management, lifestyle modifications, understanding how to cope with a chronic illness, developing as an individual, and incorporating the illness into the overall context of one's life. Because self-care management plays an important role, the theory of self-care management for SCD provides an outlook on the factors that can impact self-care. These aspects have been found to mediate vulnerable factors and health outcomes for individuals with SCD (Jenerette et al., 2014).

Hamilton et al. (2016) sought to identify whether the study's participants would report self-management resources in the theory because resources are important to disease management processes, which may be physiologic, psychological, and provider-related treatment or guidance. Hamilton et al. (2016) used a sample of 29 young adults with SCD, which consisted of 79.3% females, 35.6% employed full-time or part-time, 71.6% single or never been married, and 57.8% with SCA. Among the participants, the mean age was 25.8 with approximately 13.2 years of education. The study found four major themes. According to Hamilton et al., young adults face many challenges living with this disease including (a) struggles to maintain or achieve a good quality of life; (b) struggles to maintain self-care; (c) interruptions to family, work, and social roles to maintain or achieve good quality of life; and (d) difficulties accessing health care required. This was important to my study to help understand the appropriate interventions, emerging themes, and self-management resources identified with theoretical application to improve health education for young AA adults with SCD.

Chronic disease self-management interventions focus on equipping patients with tools and skills to manage their health. Britto et al. (2017) evaluated the practicality of a group self-management intervention, Chronic Disease Self-Management Program (CDSMP) at Stanford, for adolescents and young adults (AYAs) with SCD. The widely utilized intervention is a six-week group-based intervention directed by lay leaders with a chronic health condition (Britto et al., 2017). The program seeks to help patients comprehend acute and chronic disease by teaching skills that include action planning and problem solving. All of these aspects can help patients manage health conditions, associated symptoms, and resulting emotions (Britto et al., 2017).

The CDSMP is connected to improvements in self-reported health, exercise, symptom management, patient–provider communication, functioning, and long-term improvements in health behaviors (Britto et al., 2017). Britto et al. (2017) focused on evaluating the feasibility of the self-management intervention, (CDSMP), for adolescence and young adults (AYAs) with SCD. The study recruited 22 AYA participants with SCD, ages 16 to 24 years, who completed self-efficacy and quality of life measures before and after CDSMP, and three and six months later. Britto et al. (2017) found significant improvements for AYAs self-efficacy following the intervention. Analyses of follow-up data provided additional information on the medium effects of the CDSMP on patient activation three months after, although this was not sustained. Participants were highly satisfied; however, only 64% completed the program. This study provided insight to understand the impact of group self-management interventions that have been helpful for young adults with SCD.

There has been an increase in medical nonadherence and morbidity for individuals with SCD (Andemariam et al., 2017). Mortality has been associated with health care transition and the transfer from pediatric to adult care in individuals with chronic illnesses. Understanding the transition to adult care for individuals with SCD and self-management strategies is essential to decreasing the morbidity and mortality associated with this critical stage of development (Andemariam et al., 2017). Andemariam et al. (2017) focused on a study to explore the meaning of transition to self-management in SCD. The study included semistructured interviews with a sample of young adults between the ages of 21 and 25 recruited from a comprehensive sickle cell center in the Northeast region of the United States. To develop the age criteria, the researchers considered Arnett's theory of emerging adulthood. This theory formed the basis for a culturally constructed stage of identity development and exploration of focus for young adults ages 18 to 25 (Andemariam et al., 2017). This age group also corresponded to the transition period from pediatric to adult care for SCD. Andemariam et al. (2017) found that the meaning of transition to self-management was found in lived time, space, body, and human relationships.

Andemariam et al. (2017) found transition to self-management as an evolving process as participants struggled with developmental issues involving emerging adulthood and the challenge associated with learning to live with a chronic illness. Overall, SCD requires variability in self-management and evaluation by young adults on the adaptation to new roles and responsibilities, as family caregivers let go and young adults begin to master self-management of the disease (Andemariam et al., 2017). For the study's participants, this progression meant becoming an adult. The results also emphasized the cultural meaning of transition to self-management for SCD and integrating transcultural perspectives into nursing practice. This was important to help me understand cultural perspectives in promoting better self-management practices and how young adults with SCD perceive continuing care norms and transitions.

The transition from pediatric to adult health care services for adolescents with chronic conditions has been widely recognized by the Office of Disease Prevention and

Health Promotion, the Society for Adolescent Medicine, and by a consensus of the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians (Shapiro & Weissberg-Benchell, 2017). Shapiro and Weissberg-Benchell (2017) focused on studies developed that addressed interventions to facilitate the transition of care process. These interventions and strategies were utilized to help with the transition of care for young adults with chronic illnesses to adult programs during the past decade (Shapiro & Weissberg-Benchell, 2017). Shapiro and Weissberg-Benchell (2017) evaluated the impact of transition coordinators and found that the most successful results occur when coordinators meet with patients before the transition of care, encourage them as young adults negotiate the adult programs, and facilitate keeping appointments.

Positive outcomes during this phase resulted from having patients foster trusting relationships with adult providers before fully transitioning under their care. Shapiro et al. (2017) found that changing the system of care for young adults and adolescents with chronic diseases can help navigate the challenges of transition in care. Hankins et al. (2012) provided a comparison of a multicomponent transition program, 34 with standard care and 49 for adolescents ages 17 to 19 with SCD. The participants in the transition program were offered a tour of the adult program, a luncheon and discussion with pediatric staff to discuss transition planning, and assistance with scheduling the first adult clinic along with the nurse case manager. Similar conclusions can be made regarding the transition of care programs (Shapiro et al., 2017). The opportunity for patients to discuss and plan transitions with a pediatric provider over time and connect with both the pediatric and adult providers simultaneously can promote a successful transition to adult care (Shapiro et al., 2017).

A transition coordinator can help with making decisions for adult clinics and peer support groups to ensure the well-being of individuals with chronic conditions and promote an effective transfer. This was important for my study to help me understand the strategies utilized for adolescents transitioning to adult care. This includes how establishing self-management protocols for providers and programs can prepare young adults with SCD, with better self-management resources to help manage this chronic condition throughout their lives. According to the social-ecological model of readiness for transition by Ginsberg et al. (2011), many channels should be evaluated for interventions that affect a patient's transition readiness and successful outcomes for adult care. The intervention studies reviewed in the study highlighted the importance of changing the system of care for adolescents and emerging adults, by developing a relationship with a transition coordinator who can help patients navigate many challenges of adult care services (see Shapiro et al., 2017).

The transition of medical care from pediatrics to adulthood can be a challenging process. Until the 1970s, only half of patients with SCD reached adulthood (Jacobs et al., 2018). As a result of patients living longer with increased medical advancements and research, there is an increased need to understand factors that influence readiness to transition. Jacobs et al. (2018) examined age specific SCD knowledge and understanding, self-management skills of patients, and educational goals in connection with a sample of patients and parents. Jacobs et al. (2018) distributed 183 transition surveys during scheduled hematology clinic visits. The surveys were evaluated with descriptive statistics to determine the differences in SCD knowledge concerning age groups, self-care expertise, vocational support, and educational goals. Jacobs et al. (2018) found that patients and parents both had adequate knowledge regarding SCD. However, adolescents and young adults lacked disease knowledge to transition from receiving care from a parent to independent care. An evaluation for transition readiness should be promoted as ongoing efforts to incorporate disease-specific knowledge and self-management skills (Jacobs et al., 2018). This was important for my study to help understand the knowledge regarding SCD among young adults and parents, the barriers adolescents and young adults face when transitioning to more independent care, and the self-management strategies necessary to foster a better quality of life.

In addition to transition of care measures for young adults with SCD, prior studies demonstrated that long-term engagement and involvement can be increased when health interventions offer clear utility, personalization, feasible use, and seamless integration in daily life. Recent studies indicated that using conversational agents (i.e., software that mimics communication with humans) including chatbots could support behavior changes and improve health outcomes (Hardy-Dessources et al., 2021). Hardy-Dessources et al. (2021) focused on the use of chatbots to support SCD self-management, improve self-efficacy, and reduce disease severity. Hardy-Dessources et al. (2021) sought to understand the usefulness of conversational agents to achieve better outcomes and facilitate user experience with specific agents. The study included recruiting a small convenience sample of adults and young adults with SCD to evaluate the usability and usefulness of TREVOR, a conversational agent created to support individuals with SCD self-management. Hardy-Dessources et al. (2021) utilized a mixed-methods approach to assess quantitative and qualitative data. The quantitative results showed high usability and usefulness scores, and the qualitative findings provided information on usability issues, usefulness, and ideas for improvements and new implementations. The results of the study contributed to the limited body of knowledge of chatbots for chronic disease, health management, and coaching.

The research also suggested that conversational agents are welcomed by AYAs with SCD (Hardy-Dessources et al., 2021). However, to have a clear picture of whether chatbots for AYAs with SCD can be a valuable complement to clinical care, controlled studies will need to evaluate other aspects including clinical utility, clinical safety, acceptability, usage, or engagement (Hardy-Dessources et al., 2021). This was important for my study to help understand different channels and agents that could be used for AYAs with SCD. This includes methods to support self-management strategies and how receptive the population is to explore these options. Individuals with SCD require effective management of vaso-occlusive crises, which is integral to the provision of care (Baer et al., 2019). A systematic review of technological developments and interventions to improve self-management in the care of SCD confirmed that electronic health has the potential to promote better care outcomes (Baer et al., 2019).

Baer et al. (2019) focused on assessing the value of an electronic teaching module to educate adult patients with SCD on vaso-occlusive crises and self-management treatment. The findings indicated that knowledge scores among 20 adults enrolled improved from pretest to posttest. In total, 18 out of 20 participants agreed that knowledge was enhanced from the electronic teaching module experience. In addition, 12 out of 20 would recommend the module to a friend or family member with SCD. This was important for my study to help understand how technology can be used more effectively with the young adult sickle cell population to promote better self-management for vaso-occlusive pain crises and other treatment options.

Effective management of policy narrative is important to reduce ambiguity, a vital challenge concerning policy implementation, and to increase the chance that citizens will adequately interpret the policy measures conducted and take actions to support those policy measures (Mintrom & O'Connor, 2020). The spread of the Coronavirus pandemic during the first half of 2020 posed an unprecedented challenge to governments worldwide. The first case was reported by China to the World Health Organization on December 31, 2019 (Mintrom & O'Connor, 2020). According to Mintrom and O'Connor (2020), the Coronavirus (COVID-19) pandemic and government responses offered an open platform regarding policy learning. Traditional policy analysis tools could explain policy variation regarding the population size, ease of closing jurisdictional borders, governance arrangements, available resources, and system capacity.

Mintrom and O'Connor (2020) reviewed the national context and cases and noted differences in state-level policy narratives and how it influences policy development and implementation. The researchers found compelling reasons for policy designers to regularly integrate narrative development and control into their advising practices. In addition, Mintrom and O'Connor (2020), discovered that the narrative policy framework played a key role in the relative efficiency of rapid responses to COVID-19. This was important to my study to help me understand how public policy learning and efforts can be enhanced through the implementation of the narrative policy framework. In addition, this framework can be used to inform policies and practices through legislation for self-management guidelines during the transition of care. This can also be beneficial for individuals with SCD. Throughout the literature review conducted, none of the studies examined the importance of public policy implementation and self-management guidelines during the transition of care from childhood to adulthood for young AA adults with SCD. My study contributed to a body of scholarly research and provided insight for guidelines to help patients transition from childhood to adulthood care.

Problem Statement

There was a problem in the public health education and promotion efforts to consider public policies for continuing care from childhood to adulthood, and the competence of young adults with chronic conditions. The problem was insufficient information regarding public policies that evaluate continuing care practices, education, and competence of AA adults with SCD in Pennsylvania to effectively self-manage this condition throughout their lives. This problem impacts young AA individuals because this group of individuals has a mortality rate 6%–20% higher than the same age groups of White and other racial minority patients suffering from any chronic disease. Young AA adults also experience more emergency visits and are at risk for silent strokes and other complications resulting in a decreased quality of life (Crosby et al., 2021). According to Braun et al. (2013) “racial/ethnic minorities are 1.5 to 2.0 times more likely than whites to have most of the major chronic diseases” (p. 1). To help this population, it is essential to understand what cultural guidelines can be created through public policy planning to inform best practices for transition of care outcomes.

The literature reviewed for this study indicated that others have investigated this problem by focusing on sociocultural barriers related to quality health care and language barriers (Centers for Disease Control and Prevention, 2017). Other themes found in research included the knowledge, motivation, and self-efficacy of young adults (Crosby et al., 2021). Researchers had also examined this from interviews with parents (Jacobs et al., 2018). None of the literature examined this from a public policy standpoint and the perspectives of young AA adults between the ages of 18 and 25, living with SCD in Pennsylvania. This includes analyzing what appropriate content regarding the disease and self-management would help increase young AA adults’ understanding and ability to follow the self-management recommendations.

My research filled this gap by contributing knowledge to the literature for health policymakers to use when revising Healthy People 2030 and offering cultural competence educational guidance designed to promote self-management. Healthy People 2030 offers 10-year, measurable, public health goals, and resources to help track progress toward achieving them (Office of Disease Prevention and Health Promotion, n.d.). The results of the current study offered insights into the processes by which cultural competence education materials can help individuals with SCD to self-manage this condition. Insights from this study could assist health care providers in helping young racial minority adults with SCD to utilize cultural competence education materials to promote self-management guidelines. Educational materials and cultural competence have been helpful for promoting resources for individuals with chronic conditions. Because young adults with SCD need better health care guidance, supporting their successful attainment of cultural competence materials allows for increased knowledge to self-manage health care needs and promote quality of life. According to the Centers for Disease Control and Prevention (2023a), preparation during the transition of care for young adults can increase success in transferring care to an adult care provider and to receive adequate, regular care to improve overall health.

Purpose of the Study

Research was limited in understanding what policies and laws for SCD can be enacted or reformed based on existing policies that incorporate a subcomponent of transition of care guidelines. The transition of health care services from childhood to adulthood can be a sensitive time and predisposes this group to challenges. According to the Centers for Disease Control and Prevention (2023a), transition refers to the process by which young adults with SCD are learning to become more responsible for their health care needs and switching to another hematology care provider. The Centers for Disease Control and Prevention (2023a) raised awareness regarding the transition of care for this population.

It is important for young people with SCD to be educated and prepared for this important transition. The goal is to ensure success during this phase through effective continuing care and routine care to remain healthy. The responsibility of transition of care is placed on these individuals to be well informed to effectively manage their condition and ensure the reliability of keeping up with necessary services. Although health care organizations and clinic practices may implement resources as part of their protocol to inform guidance, there is not enough information on public policy reform to establish state or federal regulatory requirements for public administrations and health care organizations to follow based on the lived experiences of individuals with SCD.

H.R.7177 - Sickle Cell Care Expansion Act of 2022 was passed by Congress to promote access to treatment and enhance the quality of life for people with SCD (Sickle Cell Disease Association of America, 2022). This legislation sought to enable the National Health Service Corps to offer scholarships and loan repayment assistance for individuals studying benign hematology. The objective was to ease financial concerns and make this specialized field attract more providers to the workforce (Sickle Cell Disease Association of America, 2022). The bill provided competitive grants to increase awareness and resources to patients. Likewise, the senators' legislation built on the need for health care organizations to further fund support services for young adults transitioning from pediatric to adult care (Sickle Cell Disease Association of America, 2022). Research was necessary to understand the lived experiences of people with SCD to inform health promotion guidelines during the transition of care from childhood to adulthood. The purpose of this qualitative study was to explore the experiences of young AA adults with SCD and to provide policymakers with insight and an understanding of what education is required to reform legislation, public policies, and health promotion to enhance quality of life.

Research Question

What are personal factors and the experience with education on SCD from existing legislation for young adults living with SCD that public health policymakers should know so legislators are better able to reform policy, update care guidelines, and promote disease management? This qualitative study was conducted to understand the SCD experience of young AA adults living with this condition to inform public policies for effective transition of care protocols. The research purpose was to explore the impact of young AA adults' transition from childhood to adulthood, readiness, and transition of care protocols in preparation to self-manage their condition throughout adulthood.

The research question provided support for a generic qualitative inquiry. According to Patton (2015), the generic qualitative inquiry involves various qualitative methods to answer questions without a specific theoretical, philosophical, epistemological, or ontological tradition. Conducting a generic qualitative inquiry provided multiple qualitative channels for obtaining insight regarding the experience of young AA adults living with SCD.

Theoretical Framework for the Study

The theoretical base for this study was the narrative policy framework by Caress et al. (2018) who utilized an integrative narrative review to understand adolescents' experiences of living with SCD and to make suggestions for practice and research. Results revealed nine themes: (a) knowledge and understanding of the condition, (b) symptom experiences, (c) self-management, (d) attitude to treatment, (e) health care experiences, (f) social relationships, (g) difference and striving for normality, (h) school experiences, and (i) emotional well-being and coping. This research provided knowledge for providers and nursing care to consider the well-being of sickle cell patients and to promote peer support network groups. This theory was appropriate to understand the lived experiences of diverse individuals regarding the cultural competence of their condition to promote better self-management interventions.

The narrative policy framework begins with the claim that the power of policy narratives is something worth exploring. Policy narrative learning could be a method to link policy processes to policy change (Sabatier & Weible, 2018). This framework was appropriate for the current study because the target population was young adults. Digital media as policy narrative data can be beneficial in disseminating information and collecting data. This theory could also be used to examine policy learning initiatives or educational programs that may provide more education regarding SCD to the younger adult population.

According to Mintrom and O’Conner (2020), policy narratives may be perceived as general storylines that are developed to hold value in policy and communities concerning a phenomenon. An important aspect of policy narratives is how narratives can condition the thoughts and actions of larger populations. Thoughts and actions can impact the effectiveness of policies (Mintrom & O’Connor, 2020). I applied this framework to my qualitative study to understand the thoughts and perceptions of individuals with SCD and how young adults view transition of care protocols. The research question addressed what young adults experienced with continuing care practices, the education (if any) provided during the transition, and how equipped the young adults felt to effectively manage their chronic disease. Findings provided themes to inform evidence-based research and policies that foster health and wellness.

Nature of the Study

The research design that was used in this study was a generic qualitative approach. According to Patton (2015), the generic qualitative approach focuses on descriptions of what individuals experience to understand how people process their experiences. This approach is used to understand a phenomenon, a process, or the perspectives and worldviews of the people involved. Coleman (2015) applied this type of analysis to understand how patients with SCD understand and experience their pain. My purpose was to understand how these individuals experienced the policy firsthand.

This type of analysis may also be beneficial to understanding how the integration of culturally competent education materials can help this population with effective disease management. Generic qualitative inquiry can be applied in unique ways. Using this approach in the current study fostered opportunities for information to be gathered from participants through various qualitative methods. Generic qualitative inquiry may combine several qualitative approaches, draw on a single approach, and deviate from its intent, guidelines, or rules, which can be beneficial for the study (University of Nottingham, n.d.).

I used purposive sampling and recruited 10 young AA adults with SCD between the ages of 18 and 25. Data were collected using a researcher-developed interview guide to conduct individual semistructured interviews. Data were analyzed using descriptive coding and thematic analysis.

Definitions

The following terms were used as defined in this study:

African American: Black people living in the United States who are descendants of families that originated from Africa. Blacks/African Americans are the second largest minority population in the United States, following the Hispanic/Latino population (U.S. Department of Health and Human Services Office of Minority Health, 2021).

Cultural competence: The ability to understand and interact with people from different cultures and beliefs than one's own (American Psychological Association, 2024).

Health promotion: The process of enabling individuals to improve their overall health (World Health Organization, 2024).

Legislation: The provision and enactment of laws by a legislative and governing body through its lawmaking process (Cornell Law School, n.d.).

Policymaker: A person who is a member of a government department, legislature, or other organization and is accountable for enacting rules, laws, and mandates (Cambridge University Press, 2024)

Public policy: A set of laws, regulations, and guidelines or actions decided and taken by governments to work in the interest of the public. Public policy can govern specific areas including laws enacted, where funding goes, and which topics concern the public (University of the People, 2024).

Self-management: The responsibility and management of oneself, behavior, and well-being. Self-management is referred to as an individual's ability to manage the symptoms and treatment, consequences, and lifestyle modifications integral to living with a chronic condition (Fonagy et al., 2023).

Sickle cell anemia (SCA): A form of SCD characterized by the effects on the shape of red blood cells, making them sickled-shaped, which carry oxygen to all areas of the body (Mayo Clinic, 2024).

Sickle cell disease (SCD): A serious group of conditions that are inherited (genetic) and affect red blood cells in the blood (Mayo Clinic, 2024). There are many types of SCD including hemoglobin SS disease, hemoglobin SC disease, sickle beta-plus thalassemia, sickle beta-zero thalassemia (Sickle Cell Disease Association of America, 2021).

Transition of care: The movement of a patient from one setting to another, which may include pediatric care to adult care (Agency for Healthcare Research and Quality, 2018).

Assumptions

Leedy and Ormond (2015, as cited in Burkholder et al., 2020) defined an assumption as “a condition that is taken for granted without which the research project would be pointless” (p. 322). One assumption of the current study was that the implementation of transition of care guidelines for young adults from childhood and adulthood has been established as a trend. Although health organizations and clinics may have protocols in place to facilitate the transition of care efforts, there was not enough research to understand how well patients have been prepared for transitions and the effectiveness of self-management guidelines. Current literature has also not reviewed this from a public policy, governance, and legislation perspective from the experiences of individuals with SCD. Assuming there are existing protocols in place for the transition of care for patients, does not necessarily mean the readiness and preparation for transition has been provided. I assumed that all participants would be honest in the information provided and would offer a clear understanding of personal perceptions during the transition of care from childhood to adulthood.

Scope and Delimitations

According to Burkholder et al. (2020), the scope of the study focuses on the group to which the study may apply. Delimitations narrow the study in the context of the participants, time, or location, by providing a statement of what the study will not include. Limitations refer to weaknesses as part of the study design or methods (Burkholder et al., 2020). It is essential to declare foreseeable weaknesses in the study and explain what has been done to overcome them or what has prevented overcoming them (Burkholder et al., 2020). I analyzed the extent to which the transition of care affects young AA adults with SCD. The study focused on this population of young adults living with SCD and the transition from pediatric to adult care. The purpose was to understand the lived experiences of these adults and health promotion efforts or self-management guidelines provided.

This study was delimited by focusing on the population of sickle cell young adults between 18 and 25 years of age who had experienced a transition from childhood to adulthood care. The study included men and women participants; however, I did not address other topics concerning SCD. Transition of care for this population was the focus of this study. Validity may be difficult to achieve because the realities may vary.

Reflexivity refers to the need for researchers to be transparent (Burkholder et al., 2020). It is essential to consider the overall position of the researcher in relation to the study and examine potential biases concerning cultural and socioeconomic factors (Burkholder et al., 2020).

Limitations

Limitations to my study may include an agreement to conduct the study in a particular setting, recruiting participants, and separating my role affiliated with this group as a professional and researcher. In addition, there are ethical issues to consider when working with vulnerable populations. It is essential to provide a thorough informed consent process, obtain approval from the institutional review board (IRB) prior to conducting the study with participants, and ensure the confidentiality of participants (Walden University, 2024). A researcher should maintain integrity and follow all protocols necessary to offer anonymity or confidentiality to participants. This includes safely storing files, creating a unique code for each participant, and offering a safe environment.

Two issues that may arise when collecting data and using sampling methods include dependability and credibility. Triangulation can help to verify the basis of a claim and audit trails. Other limitations included the location of the study, which was conducted virtually in Pennsylvania. It is unknown how the study would be applied in other states or regions (see Burkholder et al., 2020). In addition, the study was limited to the individuals included in the problem statement and focused on the experiences of young AA adults with SCD.

The study was limited to this group of individuals and population to (a) influence appropriate practice, (b) impact policy, and (c) contribute to future research regarding SCD (see Burkholder et al., 2020). There are challenges and limitations to consider with respect to data collection. Trust plays a major role in research involving human participants and is often considered essential to the success of the research enterprise (Allen et al., 2018). Researchers and institutions need to be mindful of this to appreciate the importance of institutional processes related to and in preparation for executing appropriate ethical research practices (Allen et al., 2018). Lack of trust or transparency between the participants and researcher can impact the study, especially if the participants are not completely open and honest about their experiences.

Significance

The current study may revitalize public policy by offering a fresh perspective to understanding how certain legislation (e.g. the Sickle Cell Disease Control Act) could reform or add an educational component for young adults living with SCD. The research provided insight into how young adults with SCD understand their experiences and educational journey. This study offered an analysis of current laws for individuals with SCD and may encourage more legislative guidance for organizations to follow during the transition of care. In addition, findings may provide a resource for how public administrations, health care providers, and professionals can help young adults receive the necessary education to effectively manage their condition.

This study may be significant in that it offered insights into the processes by which public health promotion and policies can improve legislation and culturally competent education materials to help people self-manage this condition. SCD has long been an invisible global health concern, especially in regions of high incidence, attributed to a lack of awareness among local health policymakers and the public (Mburu & Odame, 2019). Policymakers, leaders, and officials may enact transition of care guidelines to help individuals with SCD. In addition, insights from this study may help health care providers offer guidance to young adults with SCD. This includes the utilization of cultural competence education materials to facilitate health promotion and self-management.

Public–private partnerships for sustainable program development and effective interventions should be integrated into existing health systems (Mburu & Odame, 2019). Health promotion, educational materials, and cultural competence have long been a force for social change by promoting resources for individuals with chronic conditions. Because young adults with SCD need better health care guidance, providing support and successful attainment of cultural competence materials allows for increased knowledge to self-manage health care needs and promote quality of life.

Potential Implications for Social Change

SCD is an inherited blood disorder in the United States, which impacts approximately 70,000 to 100,000 Americans (Centers for Disease Control and Prevention, 2023b). The transition of care from childhood to adulthood poses significant challenges including increased mortality rates among this population. According to

Banks et al., (2019), SCD can lead to poor disease outcomes and disparities in the life span of individuals with SCD. The mortality rate for individuals with SCD was 0.6 per 100,000 adolescents ages 15–19, and 1.4 per 100,000 between the ages of 20 and 24. Mortality rates for young adults with SCD increased two-to-threefold as this population of individuals transitioned from childhood care to adulthood care (Banks et al., 2019). Implications for social change during the transition of care include the implementation of public policies, legislation, and self-management guidelines to address health disparities.

Summary

Chapter 1 introduces the study and provides the existing research problem. This chapter also included a review of the research purpose, research question, theoretical framework, research design, assumptions, scope and delimitations, limitations, significance of the study, and implications for social change. Chapter 2 provides a synopsis of the current literature and establishes the relevance of the problem. This chapter includes the integration of concepts that formed the basis for the study, the literature search strategy, and the theoretical foundation.

Chapter 2: Literature Review

The purpose of this qualitative study was to understand the experiences of young AA adults with SCD and to determine what continuing care guidelines can be enacted via public policy efforts to improve their quality of life. Findings may also help providers understand how to foster health care education, promotion, and policies for young adults between the ages of 18 and 25 who experience health care transitions from childhood to adulthood (see Clayton-Jones et al., 2021). This time frame can be challenging for young adults living with SCD because young adults often experience pain and frequent hospitalizations (Clayton-Jones et al., 2021).

Due to medical advances in disease management, mortality rates of children with SCD have decreased significantly. Social and psychological factors are critical to understanding the health care transition process among young adults (Clayton-Jones et al., 2021). There is a problem in public health education and promotion efforts to consider public policies for continuing care from childhood to adulthood and the competence of young adults with chronic conditions.

Literature Search Strategy

The in-depth literature review process consisted of primary sources that included peer-reviewed journal articles, books, Walden University research, and publications, dissertations, doctoral studies (ScholarWorks), professional and governmental websites, associations, and publications. The articles were retrieved via the Walden University Library and research databases. These include EBSCO Discovery (Advanced) Search, Thoreau Multi Database Search, SAGE Journals and PubMed education, and research from The Sickle Cell Disease Association of America. Comprehensive searches were performed using keywords, phrases, medical conditions, and topics such as SCD, sickle cell, SCA, chronic conditions, transition of care, transition of care guidelines, public policy, continuum care practices, young adults, and young African American adults. Additional phrases included *self-management guidelines* and *interventions*, and *childhood to adulthood care*. The specific types of SCD were also searched such as hemoglobin SS disease, hemoglobin SC disease, hemoglobin SB+ (beta) thalassemia, hemoglobin SB 0 (beta-zero) thalassemia, hemoglobin SD, hemoglobin SE, and hemoglobin SO. Other phrases included *sickle cell* and *healthcare practices*, *healthcare reform*, *sickle cell patients* and *providers*, *sickle cell patients*, and *parents of children with SCD*. I also searched for literature to support my selected theoretical framework, which included the narrative policy framework and policy feedback theory. The search strategies also involved prominent government sites such as the Centers for Medicaid and Medicare Services, The Department of Health and Human Services, the Centers for Disease Control and Prevention, the Agency for Healthcare Research and Quality, and Congress.Gov.

Conceptual Framework

Narrative Policy Framework

The theories and concepts that grounded this study as cited by Sabatier and Weible (2018) included the narrative policy framework by Jones, Radaelli, and Shanahan. The policy feedback theory by Mettler and Sorelle as cited by Sabatier and Weible (2018) also grounded this study. There is an increase in recognition among scholars and experts in the field of public policymaking regarding the importance of narratives as a central part of the broad evidence base necessary to inform complex policymaking processes (Arif et al., 2019). Policy decisions tend to be value driven and political, not merely evidence-based choices. In addition, policymakers, lawmakers, and public health professionals' function on a different pyramid of evidence compared to researchers (Arif et al., 2019). Engagement in evidence-based policymaking requires practicality, the alignment of scientific evidence with governance principles, and persuasion to translate complex evidence into simple stories (Cairney & Oliver, 2017). By providing narratives, I incorporated both frameworks in my study.

Arif et al. (2019) examined the increased interest in using narratives for storytelling to influence health policies and inform complex policymaking processes. Arif et al. conducted a study focused on a systematic review of the evidence on the use of narratives to foster healthy policymaking process. Policy decisions tend to be not only evidence-based but also value-driven and political choices (Arif et al., 2019). Marcus et al. (2010) analyzed the educational and behavioral effects of an NBC drama narrative, which addressed cancer patient navigators. The segments of the television episode were used by congressional staffers to raise awareness regarding patient navigators in a congressional committee meeting (Arif et al., 2019). Congressional staffers reported how this storyline provided an example of how patient navigator programs work.

This contributed to a policy discussion that led to the enaction of U.S. Law or House Resolution 1812, the Patient Navigator Outreach and Chronic Disease Prevention Act of 2005 (Arif et al., 2019). This mandate provides funding to model programs that help patients when accessing health care services (Arif et al., 2019). The findings of this study indicated that although narratives may have a positive influence on health policy change, narratives may sometimes lead to undesirable outcomes. Findings also alluded to potential pitfalls and ethical concerns that should be taken into consideration when using narratives. Despite an increased interest in using narratives and storytelling, the existing evidence base precludes any robust suggestions about the impact of narrative interventions on health policymaking. More research supporting the impact on public health policymaking is necessary.

The logical connections between the framework presented and the nature of my study included the understanding of lived experiences of young AA adults with SCD, the competence of their condition to promote better self-management interventions and facilitating better practices during the transition of care. According to Sabatier and Weible (2018), the narrative policy framework begins with the declaration that the control of policy narratives is something worth understanding. The narrative policy framework and the policy narrative learning is a start to begin the connection of policy processes to policy change (Sabatier & Weible, 2018). This framework was appropriate for the current study because the target population was young AA adults with SCD. Digital media as policy narrative data can be beneficial in disseminating information and collecting data.

This theory was also used to examine policy learning initiatives or educational programs that could provide more education regarding SCD to the younger adult population. The Sickle Cell Disease Control Act passed by Congress in 1972 and the

Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018 fostered the advancement of research, education, screening, and testing (S.2465 - 115th Congress (2017-2018). The National Institutes of Health fostered a comprehensive approach to sickle cell research, and treatment centers were established. The objective was to develop sickle cell screening and education clinics for the treatment of patients (Manley, 1984).

Policy Feedback Theory

The policy feedback theory offers a new dimension to the study of the policy process (Sabatier & Weible, 2018). This theory highlights how previously enacted regulations and legislative laws form future policy creations (Sabatier & Weible, 2018). In addition, the policy feedback theory can help lawmakers build on previously enacted policies to better meet the needs of a specific population. The idea of policy feedback was developed in the 1980s as a broad approach to politics and public policy. Both are different from two other contemporary types of new institutionalism: organizational institutionalism and institutional development of organizations. Organizational institutionalism focuses primarily on cultural validity. In addition, the institutional development of organizations and rational-choice institutionalism focuses on institutional limitations and individual choice (Béland et al., 2022). Existing policies can shape and reform politics. Policymaking precedes the advent of the concept of policy feedback and includes policy learning. Policy learning indicates that current policies impact the ways that political actors view potential policy alternatives (Béland et al., 2022).

Policies that build on existing legislation can promote more informative continuing care practices for better management of SCD. This theory has been applied in previous ways to identify laws, legislation, and the role of government in public health programs. Lerman and McCabe (2017) examined whether the influence of personal experience on public attitudes is conditional on partisanship and political knowledge. Lerman and McCabe (2017) examined experiences and consequences of public health insurance programs on support for two distinct policies that sustain or increase the government's role in the health insurance market. This includes Medicare and the Affordable Care Act. The findings indicated that personal experience exerts a powerful causal influence on public attitudes toward both programs.

In addition, the results suggest two ways in which policy feedback is distinct from the standard two-stage model of reception and acceptance. The findings of the study help to combine two important streams of scholarship, research on opinion formation, and change and studies of policy feedback. The policy feedback theory offers diverse ways in which policies can shape policymaking. Public policies can implement changes in the political landscape by shaping the resources, incentives, and capacities, of social groups (Lerman & McCabe, 2017). Contributing policies enacted through legislation and governance can construct new constituencies to defend programs for impacted populations and particular groups.

The policy feedback theory was chosen for this research study because it relates to how existing policies can form the basis for the implementation of new policies. The Sickle Cell Disease Control Act was passed by Congress in 1972 to support research, treatment, surveillance, and prevention (Manley, 1984). Current literature and studies have not identified public policy efforts and regulations for transition of care guidelines from childhood to adulthood, for patients with chronic conditions. The policy feedback theory can offer insight into the reformation of new policies to promote better health outcomes, prepare for the transition of care, and decrease mortality rates among specific groups. Transition from childhood to adulthood is a critical period that has been long associated with increased mortality and morbidity among patients with long-term diseases (Durieux et al., 2018).

Legislative Treatment of Sickle Cell Disease

Between (1972 and 1982), there was a flow of activities developed in all areas about SCD, research, treatment, teaching and educational materials, public awareness campaigns, and community participation (Manley, 2018). In 2018, the S. 2465 – The Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act was passed by Congress and signed into law. The bill embodied a unified commitment by the government to continue research for Sickle Cell Disease (Sickle Cell Disease Association of America, 2021). This law was developed to increase the understanding of predominance, distribution, healthcare outcomes, and therapies for SCD. It also reauthorized prevention and treatment grants provided by the Health Resources and Service Administration. In addition, the enactment of this bill permitted the Centers for Disease Control and Prevention to award surveillance grants for Sickle Cell Disease to states, academic institutions, and non-profit organizations (Sickle

Cell Disease Association of America, 2021).

The National Sickle Cell Disease Control Act

According to Manley (1984), The United States Congress enacted the National SCD Control Act in 1972 to authorize and establish education, screening, testing, counseling, research, and treatment programs. The comprehensive sickle cell research and treatment centers were established under the National Institutes of Health (Manley, 1984). During the following decade between 1972-1982, The Health Services Administration created screening for sickle cell screening and educational health clinics were established (Manley, 1984).

H.R.6216/S.3389 Sickle Cell Disease Comprehensive Care Act

U.S. Senators Cory Booker (D-NJ) and Tim Scott (R-SC) introduced the Sickle Cell Disease Comprehensive Care Act (Booker Senate.Gov, 2021). This legislation obligates the Centers for Medicare and Medicaid Services to implement a Medicaid demonstration program, to promote access to comprehensive, quality-based outpatient care, including clinical and support services for people living with SCD (Booker Senate. Gov, 2021). In accordance with the Centers for Medicare and Medicaid Services, the objective is to develop a program in up to ten states to enhance access to distinctive and comprehensive outpatient care for people with SCD (S.3389 - 117th Congress, 2021-2022). As part of this legislation, it seeks to implement grants that improve accessibility to outpatient care for individuals living with SCD. A high priority would be provided to states that have a high prevalence of people with SCD, in addition to states that partake in the Centers for Disease Control and Prevention, and the sickle cell data collection program (Congress.gov, 2021). According to the American Society of Hematology, this bill offers coordination and access to necessary healthcare services. This includes clinical, mental health, and other support services to address the social, mental, and physical needs of this population. It also fosters a commitment to service and connects individuals with SCD to the necessary providers (American Society of Hematology, n.d).

H.R. 7177, The Sickle Cell Care Expansion Act

The Sickle Cell Care Expansion Act was enacted by the Senate and House of Representatives of the United States to amend the Public Health Service Act. This act permits scholarship and a loan repayment program, to create an incentive for physicians to work in the field of SCD and promote research and treatment (S.4425 - 117th Congress, 2021-2022). The bill seeks to promote learning and knowledge about SCD and enhance the supply of physicians for the adult population. According to Congress.gov (2022), under the provisions of this law, it fosters an expansion for the National Health Service Corps to assist with scholarships and loan repayment opportunities. It also offers competitive grants to increase awareness about SCD in addition to, expanding the resources offered including comprehensive sickle cell care, mental health, and support services for young adults 18-29 transitioning from pediatric to adult care. In addition, these grants may be used to provide more programs dedicated to training more sickle cell care specialists about the needs of the young adult population (Congress.gov, 2022).

Sickle Cell Disease Treatment Centers Act of 2022

According to Van Hollen Senate.Gov (2022), this legislation was passed to provide the establishment of a national network of medical and community-based centers to advance efforts and health care services, to meet the needs of people living with SCD. The law seeks to address comprehensive care gaps and ensure people with SCD have access to current and future medical treatments (S.4866 - 117th Congress, 2021-2022).

According to the U.S. Food and Drug Administration (2023), two groundbreaking treatments were approved for SCD. This includes Casgevy and Lyfgenia, the first cell-based gene therapies for patients 12 years and older living with SCD. In addition, according to the U.S. Department of Health & Human Services (2024), the Biden-Harris Administration recently declared that SCD will be the primary focus of the cell and gene therapy (CGT) access model, which is, “designed to improve health outcomes, increase access to cell and gene therapies, and lower health care costs for some of the nation’s most vulnerable populations” (p. 1). Under the direction of the Centers for Medicare and Medicaid Services, the access model will test outcomes-based agreements for cell and gene therapy. These agreements will promote ground-breaking access to life-changing treatment for individuals with SCD (U.S. Department of Health & Human Services, 2024).

Literature Review

A study conducted by Clayton-Jones et al. (2021), suggested eight themes due to healthcare transitions related to social and psychological health. Some of these include accessible support, spiritual distress, priorities for goal setting and support, the need for collaboration, and appreciation for healthcare providers. Results of this study offered insight into improving the transition of healthcare experiences via support from community networks, peers, and family members. These are all fundamental factors that should be considered in the assessment and planning stages. Future research and studies to understand the social and psychological conditions regarding general and internal stigma are essential, to understand the influence of familial factors and health care providers. Interventions to foster more awareness of the impact of stigmas including techniques to support coping with this condition and for adults living with SCD, are essential (Clayton-Jones et al., 2021).

Perry Caldwell and Killingsworth (2021) examined health literacy disparity among young adults with SCA. It is estimated that there are 100,000 individuals living with SCD in the United States. The demographics of this population can lead to significant healthcare barriers to treatment. In addition, the transition of care from childhood to adulthood can increase the vulnerability of this population and morbidity and mortality rates. There is a significant correlation between health literacy and grade level in young adults with SCA. The study conducted provided insight for nurses and healthcare providers seeking to implement or evaluate health promotion and patient education (Perry Caldwell & Killingsworth, 2021). Likewise, research from the study can be utilized as a tool to inform public policy guidelines for lawmakers and establish a criterion for education materials.

Literature has examined the efficacy of a protocolized transition navigator intervention in adolescents and young adults with SCD (Manwani et al., 2022). The transition navigator intervention was utilized to assess transition readiness, examine barriers to transition, establish clear goals, and provide disease and pain management education (Manwani et al., 2022). The transition navigator intervention was found to be an acceptable protocol for young adults with SCA and easy to implement within an urban academic medical center addressing barriers to the transition of care (Manwani et al., 2022). Cushman et al., (2021) considers biopsychosocial factors pertaining to transition of care among young adults with SCD.

Many national organizations (e.g., American Academy of Pediatrics) have emphasized developmental factors increasing the young AA adult population's vulnerability (e.g., higher health risk behaviors) and encouraged increased support for transition to adulthood care (Cushman et al., 2021). Biopsychosocial factors related to enhanced transition of care outcomes in this population included: older AYA age, severity of the disease, neurocognitive functioning, pain, and coping skills. Cultural considerations and communication with providers also played a major factor. Approximately ten studies were conducted analyzing the efficacy of specific transition interventions, and 80% indicated improvements (Cushman et al., 2021). Retention in programs remained low, as well as gaps in knowledge and skills. Early assessments for transition readiness and barriers to culturally tailored interventions, can improve transition outcomes among young adults (Cushman et al., 2021).

Chakravorty et al., (2019) conducted a study to identify barriers and unplanned hospital care during adult care transition services. The study highlighted the improvements needed and education for staff on SCD-specific care, compassionate care, and communication skills (Chakravorty, 2019). Results indicated significant problems in the care received in adult care hospitals and basic healthcare needs which were not met, such as pain management. Transition skills of self-management and self-advocacy are important for young adults with SCD, in addition to education for the staff regarding this condition and when providing services (Chakravorty, 2019). Ayers et al., (2017) focused on utilizing community-based participatory research (CBPR) to evaluate cultural competency training and improve culturally appropriate care among Marshallese and Hispanic communities. The study found that participants at 25 organizations reported higher levels of knowledge after completing cultural competency training (Ayers et al., 2017). The conclusions of this study can help providers foster cultural competency training to improve culturally appropriate care.

In a study conducted by Crosby et al. (2021) the researchers focused on factors that activate patients' knowledge, motivation, self-efficacy, and social support to self-manage SCD by using Sickle Cell Thrive (SCThrive) a mixed in-person and online technology-enhanced mobile app for self-management. The researchers found that Sickle Cell Thrive was highly feasible and helped participants with SCD manage their condition (Crosby et al., 2021). The results of this study offered interventions for disease management via technology, which can be useful in educating the younger adult population. Davies et al. (2019) examined the healthcare experiences of individuals with chronic conditions like cancer and asthma in New Zealand. The research found that chronic illnesses disrupted the trajectory of one's life and indicated that healthcare professionals require effective cultural competence training (Davies et al., 2019). The study provided insight into how young people with chronic conditions experience the health system and actively include them in the decision-making process to meet their diverse needs.

Hamilton et al. (2016) conducted a qualitative study to describe the perceptions of young adults between the ages of 18-35 with SCD. The researchers found that young adults faced many challenges living with this disease including (a) struggles to maintain or achieve a good quality of life, (b) struggles to maintain self-care, (c) interruptions to maintain or achieve a good quality of life, and (d) difficulties accessing healthcare (Hamilton et al., 2016). The study provided information regarding appropriate interventions to improve health education for minority populations. Britto et al. (2017) evaluated the feasibility of self-management interventions with the Stanford chronic disease self-management program (CDSMP) for adolescents and young adults with SCD. The study found significant improvements in self-efficacy following the intervention (Britto et al., 2017). These interventions can be helpful by providing informative guidelines for young adults with SCD, during the transition of care.

Andemariam et al. (2017) focused on a study to explore the meaning of transition to self-management in SCD. The researchers discovered that the meaning of transition to self-management was found in lived time, space, body, and human relationships. The results also emphasized the cultural meaning of transition to self-management for SCD and integrating transcultural perspectives into nursing practice. The results of this study can promote knowledge and understanding of cultural perspectives in promoting better self-management practices for people with SCD. Shapiro et al. (2017) focused on interventions utilized to help with the transitioning of care for young adults with chronic illnesses. The researchers found that changing the system of care for young adults and adolescents with chronic diseases can help navigate the challenges of transition in care. A transition coordinator can help with adult clinics and peer support groups to ensure the well-being of individuals with chronic conditions. This study offered intervention strategies utilized for adolescents transitioning to adult care and how establishing self-management programs and clinics can prepare them for better management of a chronic condition.

Jacobs et al. (2019) focused on age specific SCD knowledge, self-management skills of patients, and educational goals for patients and parents. Results of the study indicated that patients and parents both had adequate knowledge regarding SCD. However, adolescents and young adults lack disease knowledge to transition from parent to independent care. The study offered insight into the barriers that adolescents and young adults face when transitioning to more independent care, self-management, and the strategies needed to foster a better quality of life. Hardy et al. (2021) focused on chatbots to support SCD management, improve self-efficacy, and reduce disease severity. The researchers evaluate patients' perceived usefulness of information provided by the system. Hardy et al. (2021) found that chatbots could be utilized to promote recommended health behaviors and self-care practices. This information can be valuable to understanding how digital chatbots may be used to help educate young adults on self-management techniques.

Baer et al. (2019) focused on assessing the value of an electronic teaching module to educate adult patients with SCD. The researchers discovered that the electronic teaching module was associated with increased knowledge in patients with SCD. Technology can be a central component used with the young, sickle cell adult population to promote better self-management for vaso-occlusive pain crises. O’Connor and Mintrom (2020) focused on how the narrative policy framework played a key role in effective responses related to Covid-19.

The researchers found that policymakers everywhere should establish a routine to integrate narrative development in advising practices. The narrative policy framework can also be used to inform policies and practices for self-management guidelines, which can be beneficial for individuals with SCD. Lerman and McCabe (2017) focused on personal experiences and political knowledge. Findings indicated that individuals must receive, accept new information and have their own experience with public policy to be attentive towards political messages (Lerman & McCabe, 2017). This provides understanding of the application of policy feedback theory and the role it can play in establishing continuing public policy initiatives for young adults with this condition.

Summary

Due to the existing gaps, there was an opportunity to understand the connection between the narrative policy framework and policy feedback theory and examine current legislations for SCD, to increase policy learning and reformation. Considering the minimal research available regarding the reformation of public policies for the transition of care and from the perspectives of young adults with SCD, the study contributed to a better understanding of the questions in this study. Chapter 3 provides a comprehensive methodology and generic qualitive approach as the foundation for this research, role of the researcher in conducting this study, a review of the alignment of method instrumentation, and a solid description of the theoretical framework.

Chapter 3: Research Method

The purpose of this qualitative study was to explore the experiences of young AA adults ages 18 and 25 with SCD to understand what education is necessary for policymakers to reform legislation, public policies, and health promotion to streamline transition of care guidelines and enhance quality of life. Chapter 3 provides an overview of the research design, rationale, role of the researcher, and methodology used. This chapter provides the research question that was used to guide the study. Details regarding the site selection, participant selection criteria, instruments used, and data collection are also provided in this chapter. Issues regarding trustworthiness in research, efforts to mitigate challenges, and efforts to ensure validity and credibility are discussed. Ethical issues are examined in accordance with Walden IRB and efforts to protect human participants. A concise summary concludes the chapter.

Research Design and Rationale

To address the research question in this study, the research design was a generic qualitative design with thematic analysis. The research question was the following: What are personal factors, for young adults living with SCD, that public health policymakers should know so that legislators are better able to reform policy, update care guidelines, and promote disease management? The generic qualitative inquiry approach included in-depth interviewing of participants to answer the research question. The goal was to gather as much data as possible without framing the inquiry within an explicit theoretical, philosophical, epistemological, or ontological tradition (see Patton, 2015). Researchers use this type of inquiry with descriptive methodology to understand how individuals create meaning regarding a particular phenomenon or situation, and to determine what works best in finding answers to the questions asked.

Generic qualitative approaches leverage the strengths of one or more qualitative approaches to draw out participants' ideas about things that are outside themselves instead of focusing on their feelings. The purpose of qualitative research is to understand a phenomenon, process, or the perceptions of the participants (Bellamy et al., 2016). The current study provided an understanding of the perspective of individuals with SCD and their experiences with the transition of care from childhood to adulthood.

Kahlke (2014) viewed generic studies as studies that refuse to claim full allegiance to any one established methodology. Researchers have the option to draw on a single established methodology but deviate from its intent, rules, and guidelines in a way that is advantageous to the study (Kahlke, 2014). According to Lim (2011), the inclination toward more flexible methodological approaches is natural and inevitable for individuals conducting research on a topic or area that few theories or empirical studies have addressed (Kahlke, 2014). Researchers also find merit in the generic qualitative inquiry even when significant research or theories are available (Kahlke, 2014). The generic qualitative design includes thematic analysis as a primary tool for analyzing data.

This provides a flexible analytic method for obtaining central themes from verbal data obtained from the participants. A researcher can use thematic analysis to extract key ideas from participants that include theme statements for categories of codes (Capella University, 2022). The current study included inductive thematic analysis in which data were interpreted inductively without any preselected theoretical categories. Theoretical thematic analysis can offer insight into how the participants' words are interpreted according to categories or constructs from the current literature (Capella University, 2022). Thematic analysis was used to understand how young adults with SCD perceive their experiences. A generic qualitative inquiry approach with thematic analysis was suitable for a topic that had few studies related to the enaction of public policy, legislative efforts, and health outcomes.

Role of the Researcher

My role as the researcher was to ensure integrity in research practices during the process and performing interviews with participants, collecting data, analyzing data, and transcribing the recordings. In addition, I was required to have specialized skills for explaining the study without potential bias to participants, conducting the interviews appropriately with respect to the design, conducting appropriate field observations, selecting appropriate artifacts, and collecting and transcribing data using appropriate software (see Capella University, 2022). As the researcher conducting a generic qualitative inquiry, I was the primary instrument for the study to interview and observe participants. Interviews were conducted with each participant and transcribed by me. The role of the researcher includes serving as the instrument for the study and analyzing the descriptive data and emerging themes.

When conducting a study, researchers must be mindful of credibility and bias. Bias in research may occur intentionally or unintentionally and result in false conclusions that can be misleading in the study. It is an unethical practice to conduct biased research. In addition, researchers should be mindful of all possible sources of bias and undergo all actions to reduce or minimize deviating from the facts (Simundić, 2013). To ensure the study was objective and to avoid bias, I used triangulation to promote validity. This included using multiple sources of data or data analysis approaches to enhance the credibility of my study.

Decisions that the researcher makes should be guided by consideration of research ethics, recruitment of participants, storing of data, and analyzing and disseminating the information (Burkholder et al., 2020). Researchers should comply with standards set forth by the IRB and should provide an informed consent process. The researcher should be aware of conducting research with vulnerable populations, seek every opportunity to maintain privacy, and apply the principle of beneficence (Burkholder et al., 2020). In addition, researchers must incorporate the code of ethics within the respective discipline and abide by regulations for the protection of research participants. It is imperative for the researcher to assess the cost-benefit ratio or risk-benefit ratio associated with the study performed. This includes articulating the ethical safeguards in place to protect participants from risks associated with the research study. Prior to collecting any data, I submitted the proposal and obtained approval from the Walden IRB and as identified by approval number 04-19-23-0665298 (Walden University, 2024).

Methodology

The research methodology was a generic qualitative inquiry. Participants were asked open-ended questions and engaged in the in-depth interviewing process. This approach was useful in gathering data, observing matters of interest in real-world settings to solve problems, and improving programs or developing new policies (see Patton, 2015). I used a semistructured interview guide to conduct interviews and obtain data from participants. The participants had a wealth of knowledge concerning SCD from firsthand experience and provided accounts of their transition of care from childhood to adulthood. Thematic analysis was used to analyze the data and highlight commonalities and differences with respect to participants' experiences. To eliminate unconscious bias and prevent personal preferences, knowledge, and experience from the information shared, I used bracketing. According to Burkholder et al. (2020), bracketing is a method used in qualitative research to mitigate the harmful effects of preconceptions that may impact the research process.

Participant Selection Logic

To be eligible, the participant had to meet the inclusion criteria for the study. Inclusion and exclusion criteria include factors such as age, gender, race, ethnicity, type and stage of disease, treatment history, and presence or absence of other medical, psychosocial, or emotional conditions (Yale University, 2024). Exclusion criteria are characteristics that would disqualify prospective subjects from partaking in the study. To partake in the current study, the participants had to have SCD and live in Pennsylvania. The participants consisted of AA men and women between the ages of 18 and 25 who experienced or were in the process of transitioning from childhood to adulthood hematology care for SCD. Participants who did not fall within the age group, race, or demographic population or have sickle cell (trait) were excluded. A homogeneity sampling strategy was used to identify groups of young adults with SCD who could share relatable experiences with this condition. Participants were recruited using community support groups, networking, and social media outlets including LinkedIn, Twitter, Facebook, and Instagram.

A formal invitation to participate letter was provided to interested participants, which contained information about the study. Interested participants received additional information regarding informed consent along with the form to review, sign and return. The participants were also informed that the study was voluntary, and the young adults were free to discontinue their participation at any time. The research complied with the Walden IRB guidelines and regulations for conducting research with human subjects. U.S. federal regulations mandate that colleges, universities, government entities, and research institutions that receive funds for scientific research involving human participants, have IRB protocols in place (Burkholder et al, 2020). Ethical compliance in research studies is essential to identify harm or risk to participants (Burkholder et al., 2020).

Instrumentation

In the field of social sciences, Glaser, and Strauss (1967) introduced the technique of qualitative interviews as a research methodology (Roberts, 2020). The research instruments consisted solely of interviews including a semistructured, open-ended, and researcher-developed guide which contained questions for the study. The interview questions must be detailed to convince evaluators that no harm will happen to research participants and be open enough to allow unanticipated material to emerge during the interview (Roberts, 2020). According to Jamshed (2014), semistructured interviews are in-depth interviews, in which the participants respond to open-ended questions and are widely utilized by different healthcare professionals in their research. Semistructured, in-depth interviews are utilized extensively as an interviewing format, with an individual or sometimes even with a group.

The list of interview questions is included in Chapter 4. Follow-up questions were utilized as needed to achieve goals and develop responsive interviewing strategies. An interview guide was crafted by the researcher with open-ended questions that enabled participants to fully explain their answers. All interview questions are aligned with the purpose of the study and research question (Roberts, 2020). Before the main interviews were conducted for data collection, practice interviews were performed with professionals and relatives. In addition, the questions were selected based on the criteria of the study and key terminology referenced in my research study. The instrument for the interviews was developed using key themes from the literature review including self-management of care, relationships with providers and the healthcare team during the transition of care, and education regarding how to manage their condition long-term.

In-depth interviewing enables the researcher to examine complex and contradictory matters. The amount of researcher engagement in qualitative interviewing and the personification of the distinctive researcher as the instrument for qualitative data collection has been widely recognized (Miller-Day, 2012). The goal was to conduct in-depth qualitative interviews to explore in detail the experiences, motives, and perceptions of this population (Rubin & Rubin, 2012). The interviews were virtual and set at a convenient time for the participants. Sessions were conducted virtually through Zoom/phone, recorded, or taken via notes, and stored for five years, in accordance with the IRB requirements. The researcher engaged in the appropriate process for transcribing the data after the interviews were completed. Recording of conversations is governed by IRB protocols and participants had to provide consent to record interview sessions or consent for the researcher to conduct notetaking. The qualitative interviewing process focused on exact research questions to obtain rich, in-depth details (Rubin & Rubin, 2012).

Procedures for Recruitment, Participation, and Data Collection

Recruitment of participants consisted of a non-probability, snowball sampling method, to enlist other potential subjects. Snowball sampling was developed by Coleman (1958–1959) and Goodman (1961) as a process for examining the structure of social networks. Many years after Coleman's and Goodman's formation of snowball sampling, the terminology emerged as a nonprobability approach to sampling design and inference in hard-to-reach populations (Heckathorn, 2011). According to Charles and Kirchherr (2018), snowball sampling is a frequent technique applied in qualitative research.

It has also been utilized in medical science and other social sciences, including sociology, political science, anthropology, and human geography. This sampling method gave an opportunity for the interviewee to provide the researcher with the name of at least one additional potential interviewee. That interviewee, in return, offers the name of at least one more potential interviewee and creates a domino effect. The sample continues to grow as a rolling snowball if more than one referral per interviewee is provided (Charles & Kirchherr, 2018).

The snowball sampling strategy was used in this study to recruit young adults with SCD and provide interviewees with the opportunity to recruit similar participants. Likewise, the age group, characteristics of the participants, and virtual channels for conducting the research, influenced the decision to utilize a snowball strategy approach. A study conducted by Sun et al., (2019) found the beneficial and practical implications for the individual participants of online environmental communities. Forming groups in the virtual world to exchange experiences and encourage each other can optimize social influence and promote continuous engagement. All of which is vital for the success of online social wellbeing. In addition, a snowball effect plays an essential role in attracting more individuals to online environments and communities (Sun et al., 2019).

As a researcher, it was critical to provide a trustworthy space for interviewees to share their experiences and recognize the value that each participant had. This included understanding the connection that the young adults have with similar groups, who have experienced the same chronic condition. A snowball sampling strategy created a meaningful opportunity to encourage and reach other young adults SCD. The recruitment strategy consisted of an in-depth application of all requirements in accordance with the Walden IRB. Before the study was conducted, it was approved by IRB before engaging in the recruitment strategies. The research study was conducted in a manner consistent with IRB guidelines. According to Iowa State University Institutional Review Board (2022), ethical considerations included respecting the privacy of all participants, ensuring the participants know that their involvement in the research is voluntary and that the young adults reserved the right to forgo participation at any time. Research participants were provided with an accurate and clear review of the study. This includes a full review of the aligned research plan, correlation to participants' involvement and commitment, eligibility criteria, and consent protocols. Information should be unbiased in the presentation of the study and free of misleading emphasis (Iowa State University Institutional Review Board, 2022).

To recruit and invite potential human subjects to participate, a formal invitation to participate letter was shared. Interested participants were provided with an informed consent form and were required to review and sign. Lastly, the researcher-developed interview guide which included the semistructured interview questions was utilized. Recruiting participants was conducted via the snowball sampling strategy. This also included recruiting via online platforms, social media networks, distributed to support, advocacy, and community service groups, dedicated to the population of young adults with SCD.

To ensure integrity throughout the research process and remain unbiased, referrals may be provided in which the researcher asks a colleague to provide study information to potential participants (Iowa State University Institutional Review Board, 2022). Effective research begins with recruiting participants that meet the study's goals and in qualitative research it is common to recruit participants with experiences in relation to the topic being explored. Accounting for biases in reference to the sampling strategies is essential (Noble & Smith, 2014). According to Doku et al. (2003), the two primary focuses of the recruitment process include recruiting a sample sufficiently representing the target population. In addition, the researcher must recruit adequate participants to meet the sample size and requirements of the study. Once participants expressed interest in the study, the researcher provided them with the consent form. The objective was to recruit between 10-20 AA adults, with SCD and engage in meaningful semistructured interviews.

Population and Sample

The population of individuals that were included in my study consisted of AA adults with SCD, between the ages of 18 and 25. It included participants that are on social media, part of SCD support groups, council advisory boards, or other activities and community involvement. Participants have experienced or were in the process of completing a transition of care for the management of this condition. All participants had some form of SCD which may include hemoglobin SS disease, hemoglobin SC disease, hemoglobin SB+ (beta) thalassemia, hemoglobin SB 0 (beta-zero) thalassemia. hemoglobin SD, hemoglobin SE, and hemoglobin SO. The population did not include young AA adults, with sickle cell trait.

Sampling Technique

Nonprobability sampling also referred to as nonrandom sampling, is the strategy that would be used for this study (Burkholder et al., 2020). This sampling strategy is dependent upon subjective judgment instead of random sampling. Each member of the direct population has an equal chance of being chosen as a participant in the research. Non-probability sampling is a feasible and cost-effective technique used in qualitative research. The researcher performed snowball sampling. Snowball sampling was beneficial to use with a specific and relatively small population, that was difficult to identify or reach. Due to its non-probability nature, it is one of the best data collection techniques for exploratory or qualitative research.

According to Ghaljaie et al. (2017) in snowball sampling, the population is selected in a social context and through a multi-stage process. I recruited participants via networking platforms, social media, SCD support groups and community events. After gaining access to the preliminary participants, via snowball sampling, the young adults introduced other individuals to the study to take part in the research. This process continued in a semi-automatic and chain-like manner until data saturation was obtained. The researcher's study also embodied a purposive sampling strategy. In this technique the researcher selected participants, based on the criteria set. This sampling strategy is best when the researcher is certain about the population with respect to the whole target population. Purposive sampling solely refers to selecting a sample that is based on a specific purpose and meets the expectations of the study (Burkholder et al., 2020). In addition, this sampling method is utilized when an interest exists regarding a specific characteristic. This study focused solely on the young, AA adult population with SCD.

Sample Size

For this research study, the sample size of participants was 10 or until data saturation is reached. The concept of saturation was created by Glaser and Strauss (1967) as theoretical saturation and inclusive of the influential grounded theory approach to qualitative research. According to Hennink and Kaiser (2022), as part of this approach, theoretical saturation indicates the point at which collecting additional data about a theoretical construct provides no new properties or supplementary theoretical insights about the developing grounded theory. Most qualitative research does not follow a grounded theory approach.

In addition, the concept of saturation is commonly used in other approaches to qualitative research, where it is referred to as data saturation or thematic saturation (Hennink & Kaiser, 2022). According to Baker et al. (2012), the saturation level is dependent on the depth and range achieved by understanding the research purpose. Qualitative research can be time-consuming, and the researcher should capture in-depth, meaningful data from a smaller group of participants (Mason, 2010; Rudestum & Newton, 2015). The sample size included 10 participants, (men and women) and data saturation was assessed and reached.

In the beginning stages of the study, when the design is developed and approved by IRB, a targeted sample size may be specified (Patton, 2015). This sample size was a beginning point or minimum, however, not reflective of the final sample size in the study. Depending upon size and composition, the sample may be adjusted depending on the knowledge gained through fieldwork and as the research goes in-depth with inquiry (Patton, 2015). In qualitative inquiry, the sample may increase or if data saturation is achieved sooner, the sample size may be decreased. I determined saturation when there was not enough information to replicate the study, when the ability to obtain additional or new information had been achieved, and when further coding is no longer feasible (Fusch & Ness, 2015). Purposeful strategies applied in this study and allowed the sample size to be open which defines the evolving nature of qualitative inquiry (Patton, 2015).

The literature review contributed to the interview questions by examining the transition of care factors physically, socially, and psychologically and participants' understanding of public policies or health promotion education. In addition, the literature focused on interventions as well as strategies for success during the transition of care for individuals with chronic conditions. Shapiro et al. (2017) examined the transition of care programs and having a supportive provider and peer network. The interview questions were to understand their experiences and common themes in connection to the literature review or other emerging findings. In addition, Britto et al. (2017) considered the feasibility of self-management interventions with the Stanford chronic disease self-management program.

The questions concentrated on providing an opportunity to evaluate self-management practices that may be helpful during this process, in connection with how lawmakers can foster effective programs within public policy. The questions focused on providing content validity, by analyzing how much measure covers the range of meanings included within a concept (Babbie, 2017). According to Abbaszadeh (2015), it is addressed in three common forms and is determined as its three common forms including content, construct, and criterion-related validity. Content validity addressed the degree to which items of an instrument sufficiently represents the content domain (Abbaszadeh, 2015). In addition, it provided answers to questions seeking to understand, to what extent the selected sample in an instrument or instrument items is a comprehensive sample of the content. Content validity provides preliminary evidence on the construct validity of an instrument used (Abbaszadeh, 2015).

Data Collection

Data collection processes are not linear (Carl & Ravitch, 2021). In addition, data collection processes are iterative and inductive processes that form a foundation on and influence upon each other theoretically and empirically (Carl & Ravitch, 2021). The process of collecting data incorporates organizing the information, coding elements, presenting the results obtained and identifying consistent themes. The researcher served as a central instrument in qualitative data and structures the data that is being collected. There are four prominent ways to engage in reflexivity during this process. This included composing memos, tracking information in a journal, dialogic engagement and performing research interviews (Carl & Ravitch, 2021).

Memos include information about the observations during the study, reflections, collection instruments and perceptions of how the researcher may influence the data. According to Rogers (2018) reflective commentary another term for "analytic memos" can promote the credibility of a study. Researchers or doctoral students can utilize analytic memos as a beneficial way of recording the research process. In this study, data were collected via semistructured interviews and observational field notes. Data were analyzed and coded using the appropriate qualitative data analysis tool. Interviews were conducted virtually via Zoom/phone, recorded, taken via notes, and stored as per the Walden IRB data retention procedures of five years.

Participants completed the consent form process prior to beginning the interview session. According to Douglas et al. (2021) online interviews are cost-effective compared to face-to-face interviewing due to eliminating travel time and offers an expansion for recruitment protocols. Virtual interviews were widely used during the global Coronavirus pandemic because face-to-face interviewing was not always feasible. This option was especially important within disability research. People with disabilities are disproportionately affected by public health risks due to the pandemic and are at increased risk of contracting the virus (Douglas et al., 2021). Conducting the research online would include the safety of young adults with SCD, mitigate any challenges in considerations with the uncertainty or continuous post-pandemic spikes and concerns, and allow flexibility in participants' desired schedule of conducting the interview. To ensure the privacy of online interviews with participants, the researcher created a safe virtual environment in a confidential space and instructed the participants to do the same at a timeframe convenient for them to answer questions.

Interview sessions with participants were recorded, taken via notes, and conducted via Zoom/phone (as preferred by the participant) and stored in a safe location. After completing the recruitment process and consent procedures, participants were contacted by phone or received an invite with information to join the private Zoom session. According to Lyons et al. (2021), the researcher should conduct practice sessions before interviewing participants to ensure familiarity with logistics and storing the data. I conducted practice sessions before interviewing participants for my research study. Commercial video chat platforms host or store files on the servers, so it is essential to ensure that any commercial video chat platform used for research, meets both the Health Insurance Portability and Accountability Act and institutional standards for secure data or cloud storage (Lyons et al., 2021).

Data Sources

In this research study, sources for data included semistructured interviews with young AA adults with SCD. Semistructured interviews are a core of in-depth qualitative interviewing (Rubin & Rubin, 2012). During the interviews, the researcher is focused on a specific topic, gathering information and intends to ask participants follow up questions. Participants served as a primary source for data collection. Primary sources for data collection for generic qualitative inquiry include recorded, structured, and unstructured interviews, open-ended qualitative surveys, participant observations, and field notes (Burkholder et al., 2020).

In addition, with primary data analysis, the researcher designs, collects and analyzes the information received to answer the overarching research question (Benedictine University, 2024). The researcher can collect the specific elements to not only answer the question, however, control the data collection process to guarantee data quality and assess the reliability of the instruments (Benedictine University, 2024). Observational field notes were taken during the interview to obtain additional insight regarding their personal experiences. Secondary sources for collecting data during the research study are through textbooks, documents, scholarly articles, dissertations, and journals. I utilized these sources to triangulate my data and ensure validity in the research study.

Data Analysis Plan

The purpose of this qualitative study was to explore the experiences of young, AA adults with SCD, to provide policy makers with insight and an understanding of what education is required and necessary for policymakers to reform legislation, public policies, and health promotion, to streamline transition of care guidelines and enhance quality of life. Qualitative data analysis (QDA) software was used for data management and analysis. QDA will be a valuable tool to enable researchers to build connections and promote more complex insights (Patton, 2015). The analysis process incorporated creativity and analytical rigor. Qualitative research has profited from a wide scope of software tools to simplify qualitative methodological techniques, including those with multimedia digital data (John Hopkins Sheridan Libraries, 2021). Reviews of QDA software and web-based programs pertaining to theoretical or practical issues in qualitative assessment, can help the researcher decide which method would be best to use (Patton, 2015).

The type of qualitative software that was used for this study included NVivo transcription to transcribe the audio recordings and Delve: Qualitative data analysis software for coding and thematic analysis. Qualitative data software provides researchers with the ability to analyze content, and connect information from interview documentation, surveys, or other data. Researchers can use this to interpret, code, evaluate themes and draw meaningful conclusions. QDA miner is an additional qualitative data analysis tool, which could be utilized to annotate, code, and evaluate collections of documents and images (UCI Libraries, 2024). It is used to review interview or focus group transcripts, visual files, legal records, articles, and speeches (UCI Libraries, 2024).

Coding is an essential component of the qualitative data analysis strategy, which provides a descriptive label that allows the researcher to distinguish related content across the data. Once all information was gathered and data transcribed, the researcher engaged in cycles of coding. Descriptive coding was used in this qualitative study to capture, "who, what, where, and when of the data" (Burkholder et al., 2020, p. 101). Qualitative analysis requires examining the codes across the data and developing diagrams and matrices to integrate findings. The study accounted for all discrepancies in data in the findings section. Discrepancies may be due to potential bias, analysis of methods, study design and misalignment between the datasets. According to Mbotwa et al. (2017), it is essential to understand the implications of the discrepancies between the analysis method and study design. Understanding discrepancies can be avoided and is of great importance for principled research practice.

Issues of Trustworthiness

Trustworthiness in research is a qualitative terminology referred to the degree to which the researcher has confidence in the sources and methods used to collect the sources (Burkholder et al., 2020). Trustworthiness is a primary way for researchers to persuade themselves and readers that the research findings are worthy of attention (Lincoln & Guba, 1985). Lincoln and Guba (1985) improved the perception of trustworthiness by establishing the criteria of credibility, transferability, dependability, and confirmability to correspond to quantitative evaluations of validity and reliability (Nowell et al., 2017). The steps conducted in the early stages of research involving the purpose and design can enable the researcher to decide the appropriate methods to ensure trustworthy data for the research questions (Burkholder et al., 2020). Field notes, interviews, observations, recording, and archived records provide both pros and cons. Applying a combination of these data collection strategies to this study provided the researcher with the ability to evaluate multiple data sources.

According to Connelly (2016) trustworthiness and the rigor of the study refers to confidence in data, interpretation, and methods applied to promote the quality of a study. During the study, researchers should create the protocols and procedures respective for the study to be considered worthy of regard by readers. Debates in research have been waged in the literature in terms of what constitutes trustworthiness, although many researchers see trustworthiness as necessary (Connelly, 2016). Evaluation of multiple data sources can highlight the inconsistencies in themes and the need to establish further inquiry. The trustworthiness of emerging themes in data can be reviewed during the data collection process via observer effects, employing multiple researchers and member checks (Burkholder et al., 2020).

Strategies to mitigate issues of trustworthiness included triangulation and member checks. According to Motulsky (2021), member checking is the process of asking for feedback from participants about one’s data and interpretations. It has become so commonly and consistently recommended as a validity check and a mandate for rigorous qualitative research. Walden IRB, dissertation advisors, peer reviewers, and researchers may presume that threats to validity are not sufficiently addressed, unless member checking is included in the research design. In addition, triangulation has been used as a qualitative research strategy to test validity through the conjunction of information from various sources. Denzin (1978) and Patton (1999) recognized four main types of triangulations. This includes (a) method triangulation, (b) investigator triangulation, (c) theory triangulation, and (d) data source triangulation (Blythe et al., 2014). The important aspect of triangulation is to ensure that researchers understand the need to seek multiple perspectives in efforts to answer core research questions (Carl & Ravitch, 2021).

Credibility

To ensure validity and credibility, peer debriefing may be utilized to promote engagement with a qualified colleague who is not involved in the study (Burkholder et al., 2020). The objective of including a peer is to ask questions that may help with clarifying conclusions and removing researcher bias. The concept of validity is reflective of an idea that results of the research indicate a true phenomenon, mechanism, or attitudes under the study (Burkholder et al., 2020).

To promote credibility in this research study, it is imperative to be accurate and transparent in the process of analysis. Participants had to be knowledgeable about the topic and have personal experiences. A major foundation of qualitative interviewing is providing highly credible results (Rubin & Rubin, 2012). The researcher should engage with experts and inform them about any concerns. To ensure credibility in research and transparency of data, interview notes, and recordings were protected and stored, should anyone decide to reference the data. A log of the transcripts with participants was tracked and findings are available in a clear report. Transparency during the reporting of results enables readers to assess how thorough the design is, the reliability and biases of the researcher (Rubin & Rubin, 2012).

Transferability

According to Burkholder et al. (2020), transferability refers to the degree to which a set of findings can be transferred to another specific situation. The difficulty encountered in transferability is explaining the setting of the study to provide enough transparency, for readers to make their own judgements on what may or may not be applied in other scenarios (Burkholder et al., 2020). Researchers can apply transferability in multiple ways. This includes utilizing the same data collection methods with diverse groups or populations, providing a range of experiences for readers to understand what may be applicable to another field of practice, and offering good descriptions of the population being studied in a particular geographical area (Queens University of Charlotte, 2024).

Dependability

Dependability in qualitative research indicates that there is evidence of consistency in data collection protocols, analysis, and reporting (Burkholder et al., 2020). Strategies to establish dependability in research include involving peers in the interview process, offering detailed descriptions of the research method, and providing a precise repetition of the study to find similarities in the results or enhance the findings (Queens University of Charlotte, 2024). Methodological rigor is imperative in research and establishing trustworthiness. Lincoln and Guba developed strict criteria in qualitative research, known as credibility, dependability, confirmability, and transferability (Aboagye-Sarfo et al., 2018). To maintain consistency, in collecting data, documenting changes and revisions to the research protocol should be maintained, and a trackable record of how changes were implemented (Aboagye-Sarfo et al., 2018).

Confirmability

The steps that the researcher takes to ensure that the findings are not due to participant or researcher bias are referred to as confirmability (North Central University, 2024). In qualitative data, confirmability is certain when data is constantly checked throughout collection and analysis, to confirm the results would be repeated by others. Lincoln and Guba indicate that credibility of a research study is important to evaluating its worth. Credibility establishes truth to the findings and results (Robert Wood Johnson Foundation, 2008). Guba and Lincoln suggest a confirmability audit as the sole means for ensuring confirmability (Burkholder et al., 2020).

Ethical Procedures

The research study was performed in accordance with the protocols and standards of Walden IRB for doctoral research and to ensure the protection of human participants. The study was defended at the IRB to obtain approval for data collection and recruitment. All decisions made by the researcher should be guided by ethical considerations involving participant recruitment, instruments utilized, storing data, and disseminating information (Burkholder et al., 2020). Human subjects were protected, and measures taken to ensure that the participants were not identified throughout the research process and were properly informed. Participation was voluntary, confidentiality was maintained, and the informed consent was provided to all participants in the study. All data collected from participants during the study (raw and final copies), were secured and stored via a one drive folder for the IRB record retention protocol of five years. A log was also kept and includes the date of participant recruitment or data collection tasks including the invitations provided, consent forms, interviews conducted, and dataset access. I utilized recruitment and data collection logs or resources that are readily available on the IRB website as needed (Walden University, 2022).

The ethical principle of respect for persons was in place to respect autonomy and personal choices (Burkholder et al., 2020). Once the IRB approved conducting the study, the recruitment process and procedures began. Researchers must follow the professional code of ethics in their discipline when conducting research. During the research-planning stage, risks and benefits should be assessed (Burkholder et al., 2020). A thorough informed consent protocol was established for the study and protection of internet-based and virtual research. Privacy in online research poses many challenges. Researchers must consider how to protect stored information that may detect participants' identities.

As part of the study, an in-depth informed consent process was incorporated. The 2018 U.S. federal regulations requirements have incorporated changes to the informed consent process. Researchers should ensure compliance with the updated guidelines and federal mandates, U.S. DHHS, 2018 – 45 CFR 46.116 (Burkholder et al., 2020). The consent to the research process incorporated concise information and key details about the study, the purpose, expectations, and duration (Burkholder et al., 2020). This included the study's procedure, an in-depth review of what the participant was engaged in, any experimental procedures, risks, and benefits of participating in the study and incentives (if any).

Participants should be made aware that being involved in the study is at their sole discretion, voluntary and individuals may discontinue the study at any time (Burkholder et al., 2020). The young adults were made aware of this in the research study. Likewise, participants were informed whether the study was conducted online and virtual or in person. Strategies that the researcher may apply include emailing participants information or a link with debriefing content, including this information in the body of a message, and directing them to a debriefing webpage upon completion of the study (Burkholder et al., 2020). Safeguarding research conducted in person, holds the same importance as conducting research online.

The researcher must identify ways to reduce potential threats to privacy and safeguard all information (Burkholder et al., 2020). Ethical considerations were in place to protect participants during the recruitment process and gathering information as part of the interview process. Participants were informed of their rights to withdraw from participation in the study at any time. Consent in qualitative research consists of different situations in which the researcher seeks to (a) access particular settings and groups, (b) collect data or documents that cannot be retrieved publicly, (c) eliciting information or data from participants, through interviews, focus groups, observations, and documentation (Carl & Ravitch, 2021). According to Carl and Ravitch (2021), consent to participate is informed and voluntary. Confidentiality was maintained all throughout the study and the information gathered during the interview process was safeguarded. Participants’ identities were protected and masked throughout the research study.

Summary

In conclusion, Chapter 3 elaborates on the research method utilized to conduct the study. A generic qualitative inquiry and research design was used to address the purpose of this research. Purposive sampling was used to recruit 10-20 young adults and gather data via semistructured interviews virtually. The population included young AA adults with SCD between the ages of 18 and 25. The study was to explore the experiences of young, AA adults with SCD, to understand what education is necessary for policymakers to reform legislation, public policies, and health promotion, to streamline the transition of care guidelines, and enhance quality of life.

The research question provided insight into the meaning of young adults with SCD during the transition of care from childhood to adulthood. The role of the researcher was essential during the study to observe, interview, collect, transcribe data, remain free from bias, and ensure integrity in research and as per the IRB protocols. Purposive sampling was used to select well-informed individuals on the research topic. A snowball strategy was also included to provide an opportunity for interviewees to refer other eligible participants to the research study.

The interview instruments created included the interview protocols, invitation to participate letter, informed consent and procedures and the researcher-developed guide for the semistructured interviews. The population included young AA adults between the ages of 18 and 25. Purposive sampling was used to recruit 10-20 adults and gather data via semistructured interviews virtually. Chapter 3 examines vital components to consider when conducting research. This includes trustworthiness, validity and reliability, transferability, credibility, dependability, conformability, and ethical procedures followed. Chapter 4 provides an in-depth review of the results and findings of the study. Chapter 5 discusses the interpretation of the findings, limitations of the study, specific recommendations, and implications of the study.

Chapter 4: Results

The purpose of this qualitative study was to explore the experiences of young AA adults with SCD between the ages of 18 and 25 in Pennsylvania, and to provide policymakers with an understanding of what education is required to reform legislation, public policies, and health promotion to enhance the quality of life. The study's research question was the following: What are personal factors and the experience with education on SCD from existing legislation for young adults living with SCD, that public health policymakers should know so that legislators are better able to reform policy, update care guidelines, and promote disease management?

The researcher-developed interview guide was used to conduct semistructured interviews to examine perceptions of young AA adults on their transition of care from childhood to adulthood via a generic qualitative inquiry. These findings may be used to inform policymakers on what is necessary in public policy and health promotion efforts to impact reform and legislation. In this chapter, the results of the study are discussed. The demographics, data collection, and analysis are also provided.

Setting

The research study and protocols were approved by the Walden University IRB on April 19, 2023. The study took place virtually via Zoom/phone at the discretion and convenience of each participant. I conducted the study in a quiet and confidential environment and ensured flexibility with participants' schedules, which allowed participants to complete their interviews one-on-one during the most convenient time. I took reasonable steps to protect the identity of each participant. This included referring to the individual by their unique identifier during the study, having participants mask their identities and video settings prior to beginning any recordings, and taking notes with participants who provided consent. I reviewed the interview process, procedures, and informed consent with each participant prior to starting the interviews. Participants who wanted to opt out of audio recording were provided with an approved IRB consent form for notetaking. All of the young adults were satisfied with the way interviews were conducted with respect to the purpose of the study and processes in place to ensure confidentiality as voluntary participants.

Demographics

The demographic population included young AA adults with SCD. A total of 10 participants agreed to take part in the study. Participants included women and men ages 18–25 who had a form of SCD. I interviewed participants over the course of several weeks and asked open-ended interview questions. The Zoom/phone interviews were conducted and recorded, or notes were taken with consent from each participant. The data was stored in a secured location, per the Walden IRB retention protocol, of five years. Figure 1 provides the data on gender participation (men vs. women). Figure 2 offers insight regarding their education level or occupation. The sample consisted of 10 participants.

Figure 1

Gender

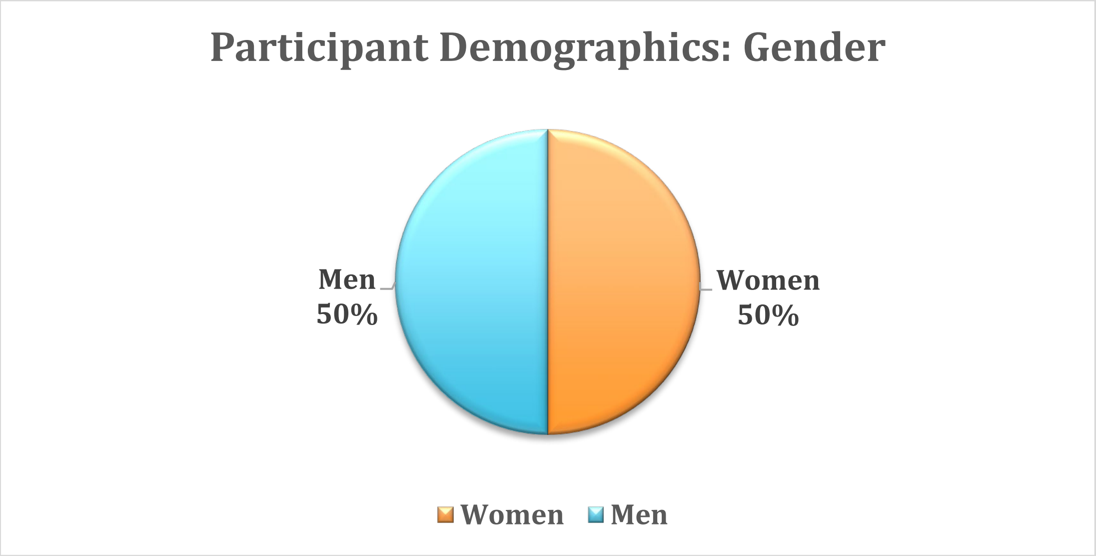
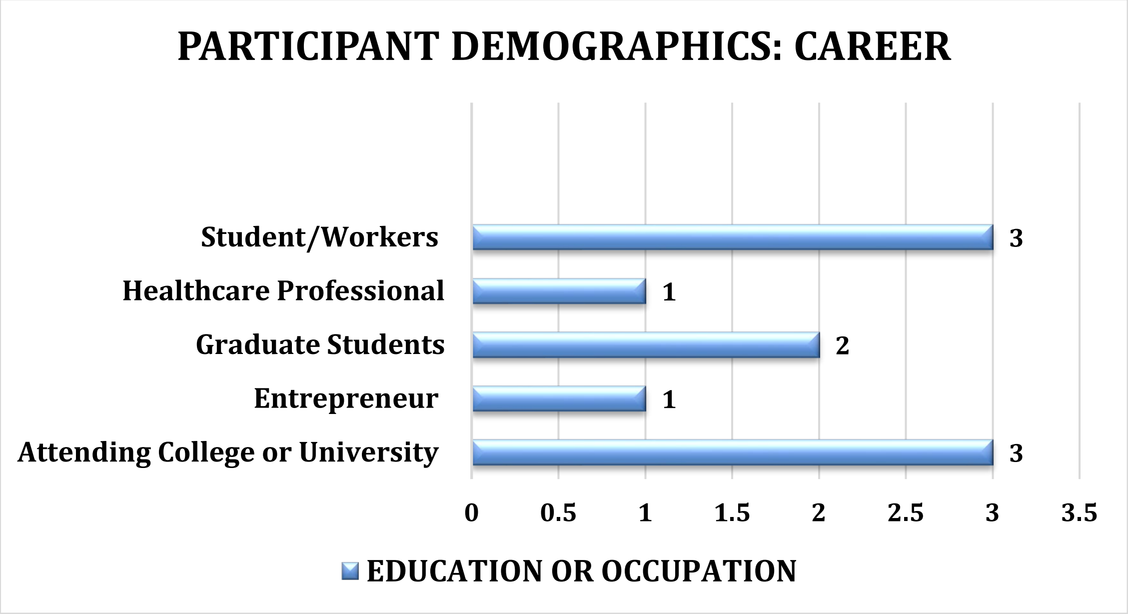


Figure 2

Career



Data Collection

The study was approved by Walden's IRB prior to data collection with participants. Upon approval by the IRB, I posted a flyer online via social media and shared it with the SCD community and support groups. The flyer included information about the study, the purpose, criteria for the study, and contact information for me. Individuals were welcome to voluntarily participate. This included young AA adults with SCD between the ages of 18 and 25. The study was conducted virtually by Zoom or phone in a quiet space and at the convenience of each participant.

Interested candidates were provided with the protocols of the study and the informed consent form to review and sign before beginning the interview. I reviewed the consent form with each participant, inquired if there were any questions, and provided them with a signed copy of the form. Participating young AA adults who joined agreed with the protocols of the study, and I ensured privacy and confidentiality of their identities. Notetaking was conducted with participants who wanted to join but opted out of being audio recorded. Participants reached out to me via social media and by email to join the study. The young adults also reached out via SCD support groups, community events, and through snowball sampling. The participants were provided with an opportunity to introduce themselves and answer a few personal questions as desired. The participants were asked six main questions forming the foundation of the study, to understand their personal experiences with the transition of care from childhood to adulthood and the education received.

Interview Questions

Q1: What is your experience with managing sickle cell disease throughout your childhood?

Q2: Drawing on your personal experience, in what ways have you received education to effectively manage this chronic condition?

Q3: What is your experience with continuing care practices, health promotion education, and the knowledge received to adequately manage sickle cell disease from childhood to adulthood?

Q4: Tell me about your transition of care experience and the guidance that was provided to you. What were some benefits or challenges experienced?

Q5: Please describe in what ways that you believe the transition of care from childhood to adulthood impacted you physically, socially, or psychologically and your experience with adjusting to the change?

Q6: What has been your overall experience since the transition of care from childhood to adulthood and in what ways has it affected you?

I also mentioned the following: Before we conclude, do you have any insights to share or recommendations on how the transition of care from childhood to adulthood can be improved for people with sickle cell disease? Are you satisfied with the way this interview was conducted with respect to the purpose of the study and processes in place to protect you as a voluntary participant? Yes, or No? Is there an individual that you feel would be a suitable candidate for participation in the study that you would like to refer?

The six main questions were developed to understand the lived experiences of individuals with SCD from childhood to adulthood. Participants agreed and consented for their preference of audio-recording or notetaking, with their identity fully protected and information stored for five years, in accordance with the Walden IRB requirements. The interviews were recorded using a computer recording software, or via notetaking, transcribed, and stored in a safe location. Notetaking was conducted with participants who wanted to join but opted out of being audio recorded. The interview records were reviewed, analyzed, and stored in a secure location. This device was only accessed by the researcher and used solely for the purpose of the study with utmost protection of personal experiences shared. The researcher reviewed the responses provided by each participant through member checking, to ensure accuracy of the information captured.

Data Analysis

The data collection was reviewed and analyzed from the transcriptions and notes were taken. I used NVivo transcription to transcribe all interview recordings. NVivo transcription is a powerful automatic software used to optimize qualitative and mixed method data analysis (Lumivero, 2023). It serves as a transcription assistant and provides a dual feature to listen to the recording in addition to, reviewing the automatic transcription for accuracy. NVivo transcription provides verbatim transcription and 90% accuracy from quality audio and video recordings (Lumivero, 2023).

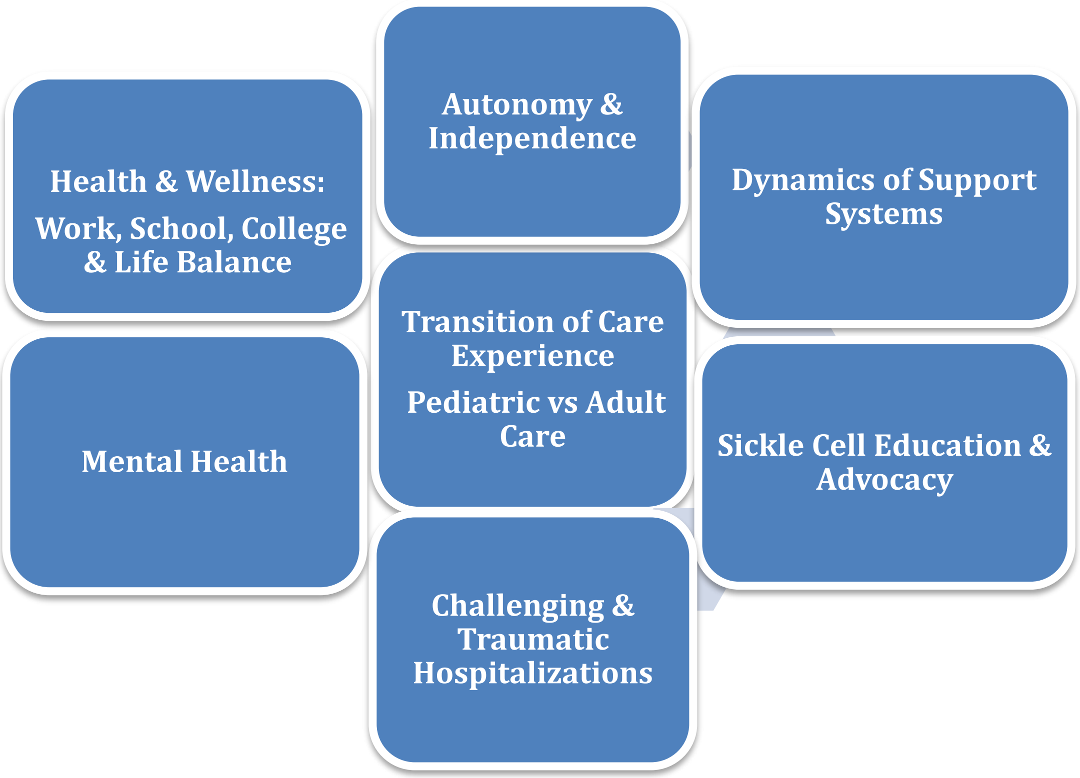
The editorial feature provides for flexibility to quickly make changes, identify speakers, and provide proper formatting (Lumivero, 2023). In addition, the data is securely stored to ensure and protect the privacy of each participant according to HIPAA standards and general data protection regulation compliance (Lumivero, 2023). Upon completion, each recording and transcription was reviewed to ensure the accuracy of the transcription reports. The transcriptions were exported into a Microsoft word file to save. The notes taken from participants as desired were also reviewed, exported into a Microsoft word file, analyzed, and stored in a safe location. All participants were de-identified during the entire process to ensure their confidentiality.

The Delve: qualitative data analysis software was then used for cycles of coding the data and thematic analysis. Delve is a cost-effective qualitative data analysis software tool that is simple to use, provides frequency insights with coding and is a collaborative online qualitative analysis tool that allows researchers to find rigorous, human insights quickly (Delve Tool, n.d.). In addition, it allows a grounded method for categorizing and grouping important themes, sub-themes, and frequencies within the coding respectively (Delve Tool, n.d.). The features provide flexibility to use this tool for analyzing qualitative data from various methodologies including grounded theory analysis, thematic analysis, and narrative analysis (Delve Tool, n.d.).

The questions asked during the interviews were utilized to develop themes for the overall perspectives of the participants' transition of care experience from childhood to adulthood and the education provided was obtained from their responses to each question. The data collection period continued until data saturation and the participant goal was achieved. At the end of the study, participants had the opportunity to engage in the snowball sampling strategy and refer other young, AA adults with SCD, between the ages of 18 and 25 to participate. Figure 3 provides the main themes which emerged during the research study and data analysis.

Figure 3

Themes That Emerged From Coding Analysis



Theme 1: Young Adults' Responsibility for Their Overall Health and Well-Being

Based on the interview responses shared and data analysis, the young adults recognized the level of responsibility and commitment required to manage their health and overall wellness independently, from childhood and during the transition into adulthood. This included ensuring adequate personal care, exercise, nutrition, avoiding triggers for a pain crisis, medical adherence to treatments and medications.

Theme 2: Young Adults' Perception of SCD Education from Their Health Care Teams

There was an emphasis placed by participants on the views of SCD education from childhood versus adulthood and preparation for life-long disease management by their healthcare teams. Specifically, the young adults shared the levels of variation and educational perceptions from pediatric providers vs. adult primary care providers. The participants shared common views that more education and awareness is required for SCD and the misconceptions and biases which exist, among healthcare teams and society.

Theme 3: Challenges With SCD and Experiences with Frequent Hospitalizations

The young adults expressed many challenges faced with SCD and the impact of recurring hospitalizations socially, physically, and psychologically. The participants also shared the social impact of the disease as it relates to their daily lives whether it is school, college, work, and relationships. In addition, the young adults shared common views as it relates to the toll SCD takes on the body, physically, and the impact psychologically.

Theme 4: Impact of SCD on the Mental Health of Young Adults

The participants shared the ways in which SCD has impacted them throughout their lives, specifically their mental health, and the support systems which played an integral role. Mental health was expressed in conjunction to ways that the young adults were able to cope and find happiness in hobbies such as SCD advocacy, support groups, their careers, or other extracurricular activities.

Theme 5: Dynamics of Supportive Systems and Networks Throughout Life and the Transition of Care Experience

The young adults described the dynamics of multiple supportive networks via family relationships, friends, the SCD community, nurses, and hematologists, and how it positively impacted their lives and the overall transition of care experience. This also included education that was provided directly or through caregivers during the young adults' childhood and the ways that support was provided. The young adults expressed a sense of fulfillment in their lives, despite their battles with SCD.

Evidence of Trustworthiness

Trustworthiness was ensured during the research study through data collection and verbatim journaling of participant responses. The audio recording and notetaking strategies enabled the researcher to review the responses again. In addition, during the data collection and analysis process, member checks were utilized after each interview to ensure the truthfulness of the information provided by the participants. Member checking entails sharing findings with members of participant groups to ensure accuracy and obtain adequate feedback (Burkholder et al., 2020). The protocol involved in member checking is to take back the preliminary analysis to participants and obtain insight on whether the researcher's interpretation 'rings true' (Burkholder et al., 2020).

Credibility

Credibility entails that the findings of a particular study are believable given the data presented. This was ensured during this research study through engaging in the member checking step to review the responses from each participant and ensure accuracy of data collected (see Burkholder et al., 2020). The member checking or respondent validation step and technique was important to establish credibility. The data collected, interpretations, and conclusions were shared with each participant. The participants were provided with an opportunity to clarify what their intentions were, elaborate on responses, correct errors, and provide additional information if needed. This type of respondent validation is to solicit feedback about the data as well as conclusions drawn directly from the individuals being studied (Burkholder et al., 2020).

Transferability

To ensure transferability in this study, the participants provided detailed and thick descriptions of their experiences. In addition, the thick descriptions and direct quotes captured in this study resulted from verbatim transcriptions from the interviews. The transferability of the study is significant because the results of the interviews examined themes that should be considered with respect to various settings of transitions from childhood care to adulthood. Transferability examines the degree to which a set of findings from a study may transfer or correlate to another situation (Burkholder et al., 2020). This includes areas that should be evaluated or considered by policymakers when forming or re-forming new policies or legislation for individuals with SCD. Transferability of the results to other young adults with SCD may apply, based on the criteria of the study, to those from different geographical areas and diverse groups.

The study specifically focused on young, AA adults with SCD between the ages of 18 and 25. However, due to the topic and focus of the study, it can easily be transferred to a study in a different location. The criteria for recruitment allows for transferability within different geographical areas for young adults with various forms of SCD and could be considered for different ethnic backgrounds or cultural groups, in addition to other criteria and based on the designated interest area.

Dependability

The interviews with the young adults were recorded and conducted via notetaking with their respective consent for data collection. Member checking was also conducted, and the researcher reviewed each interview to ensure accuracy. NVivo transcription software was used to transcribe the recordings along with the Delve: qualitative data analysis tool for reviewing the interviews, coding, and analyzing themes. The data will be safely secured for five years and destroyed after this timeframe in accordance with Walden's IRB research protocols.

Confirmability

The results from the study were reviewed, transcribed, analyzed, coded and themes were captured. This ensured the data itself remained unbiased and focused solely on the results from the participants themselves. In addition, direct quotations from each participant were utilized to ensure the information was captured accurately and in their own words.

Results

In conclusion, a total of 10 AA adults with SCD between the ages of 18 and 25, voluntarily joined the study and agreed to the respective consent protocols via audio-recording or notetaking. This included six main interview questions which were designed and posed to the participants to address the phenomenon of study and overarching research question: What are personal factors and the experience with education on SCD from existing legislation for young adults living with SCD, that public health policymakers should know so that legislators are better able to reform policy, update care guidelines, and promote disease management?

Dependability refers to the evidence of consistency in data collection, analysis, and reporting (Burkholder et al., 2020). This is achieved through the incorporation of audit trials and records of how qualitative studies are conducted. The audit trail process in this research study included field notes and member checking. The study included an introduction and six interview questions. Data was audio recorded or taken via notes. The interviews were reviewed, transcribed, taken via notes and the data went through cycles of coding, and themes were analyzed. The key words coded included: independence, education, challenges with SCD and hospitalizations, mental health, and support systems.

Five main themes developed based on the interviews and questions asked to the young adults, regarding their SCD transition of care experience from childhood to adulthood. Participants expressed positive and negative experiences in the preparation for the transition with suggestions for future planning of transition of care for young adults with SCD.

Theme 1: Independence and Maintaining Health

Young adults expressed a sense of responsibility for their overall health and well-being during the transition to adulthood. Participant A1 stated, “Physically, I would say that I had to do more for myself. I had to find resources, did more research, and became more involved in my community so that I could manage my condition better. I found diet and exercise to be helpful, and of course drinking water." Participant B2 mentioned, "I'm very independent in general…I've always been the one to schedule my appointments. contact my doctors and all of that, but I wasn't equipped." Participant D4 stated, "Translational medicine was very beneficial for me, continuously doing exercise and continuing to take vitamins in my diet. So, I think it's very helpful for me to treat this." Participant D also stated, "yoga, you know, like developing mental and health wellness… I continued to do meditation, mental and health wellness."

Participant F6 mentioned, "Drinking water is probably one of the most important things. Using heat to remedy your crisis is definitely, another very important thing. It helps mediate it. But what I noticed may have helped me personally is trying to have a physically strong enough body to handle the day-to-day life occurrences…like the little things that may cause crises." Participant F6 elaborated further, "I pay attention to those little things like what is causing the crises. Like maybe, think about it from a scientific cause and effect aspect rather than, oh, this is a crisis that is just happening to me…I would say…like, living at home to living on my own was the biggest transitionary thing…it's not necessarily associated with the health care part, but yeah."

Participant G7 mentioned, "At age two, that's when it was first known that I had sickle cell disease. Throughout my life, I learned more about what I am dealing with, I would write about it, had to stay hydrated and take medications like folic acid. There is an expensive medication called hydroxyurea which refreshes the cells and allows the body to produce more fetal cells. I also take folic acid with it and had to stay healthy to avoid a crisis, avoid cold or chilled drinks, stay hydrated, and keep my eyes from turning yellowish. Diclofenac has been helpful for managing my pain." Participant G7 further elaborated,

> Hydroxyurea is a good medication and helps. It's not affordable. I heard about this medication from a family member as a therapy for SCD, but it is expensive. It is important to heed to the medical advice to keep yourself right and healthy. If you follow the guidance and keep yourself right, people will not think you have SCD. You would not look like the way people perceive it. People have a misconception from Google about what individuals with SCD look like. Taking care of yourself goes a long way with taking your medications.

Participant H8 explained, " I had to do more for myself and ensure that I held on to all of the knowledge provided during my childhood." Participant H8 elaborated further, "I found that adult care was very different than childhood care, so I had to be more proactive as far as keeping up with appointments." Participant I9 stated, "I cook my own food, keep up with good nutrition, drink water to remain hydrated and I take naps." Participant I9 elaborated further, "I take care of myself and try to keep up with treatments before having to go to the hospital." Participant J10 stated, "Overall, I take care of myself, and my nutrition and regularly take my medications." Participant J10 elaborated further, "I have learned to take care of myself, do what makes me happy because I am unique and always be patient, and take my medications."

Theme 2: SCD Education

Young adults had perceptions surrounding education on sickle cell disease from their healthcare teams, providers, and self-awareness. Participant A1 described,

> I received education through my provider, hematologist, and just from my experience which has taught me more about myself, crisis, and triggers. The more I experienced it at a very young age as a child, I learned as I got much older how to continue to manage my condition. This included medical treatments, staying hydrated, and keeping up with my doctors appts.

Participant B2 stated, “ I feel like there’s not enough education, there’s not enough about sickle cell... there’s not enough doctors’ offices, even when you’re in the colleges. I like, had my share of bad experiences with hematologists who don’t know enough about sickle cell and don’t care enough…As a child... I think that they did not prepare us for the transition. I don’t think that they actually helped us enough.” Participant C3 described, “ I received education through school, some support groups, doctors, hospital, through family and friends.”

Participant E5 stated, “I didn’t receive any education to manage the condition…just the change from my doctor, from a pediatrician to, regular nurse/provider for adults…they really don’t talk about it like much…there wasn’t like any kind of conversation.” Participant F6 mentioned,

> I’ve had primary care physicians tell me about drinking water, avoiding strenuous activities…I would say all of my experiences with the health care system, that’s pretty much the same amount of information given. All the education and stuff I know about my sickle cell crisis, I feel like I went out and searched proactively for multiple years.

Participant G7 mentioned, “I learned a lot from the hospital. Sickle cell groups on Instagram, people joined together sharing their experiences via live sessions. During the live sessions, I can ask questions and advice from other fellows. We connect to learn more about therapies, and treatments and gain more educational insight.” Participant H8 stated,

> I mostly received education from my doctors and nurses. When I was younger a lot of the education went to my parents who took care of me. However, I also learned a lot from my experiences and education on what was needed to stay healthy as a child growing up with this disease.

Participant H8 elaborated further,

> I would say that I had enough knowledge from my childhood to continue taking care of myself throughout adulthood. I think continuing care practices for the most part was the same as far as treatment, pain management, and adequate hydration. However, I felt a gap during my transition experience as far as the lack of knowledge from the healthcare teams, especially during some of my hospitalizations in adulthood but also not fully informed of what the dynamics of my care would look like.

Participant I9 stated, “I have received education through my mom, family, and my nurses to manage my condition.”

Theme 3: Challenges With SCD and Hospitalizations

The participants expressed the challenges with SCD and traumatic experiences with recurring hospitalizations for sickle cell disease throughout their lives. Participant A1 stated,

> I would say now, my transition is better because I'm more established with my care management team/hematologist, before it was difficult to separate from my previous team. I just learned how important it is to be independent and stay on top of my health.

Participant A1 elaborated further,

> My experience with continuing care practices has been positive in terms of managing my health and staying healthy. I felt like my pediatric team and hematologist were more hands on and involved with my care. As I got older, I noticed the difference with adult care and the need to be even more proactive with my health and advocate for myself.

Participant B2 described,

> Into adulthood, it just got worse and worse and worse and worse to the point where it's like….when you're having a sickle cell crisis, you ask the question about, should I stay home and like take care of myself by myself? Or should I possibly be traumatized in the hospital and still be in pain? Right. And they don't talk to us about that. Soon as you turn 18, they leave us alone. They don't follow up and ask like, oh, do you need extra support?

Participant G7 mentioned, “The pain is terrible, I have to take medications and follow the education.” Participant H8 stated,

> Managing SCD has been very hard. The condition is very painful and causes pain crisis all over my body, especially in my joints. During my childhood, I experienced a lot of pain crisis even up until adulthood. I still have difficulties with managing my SCD, but I’ve learned more now to help me manage it better.

Participant I9 mentioned, “My experience has not been easy at all. It has been very hard. I had to take medications Walking has been difficult for me.” Participant I9 further stated,

> School has been hard and work activities have been impacted also. Every time I am in school, I got sick and missed a lot. Going in and out of school impacted me a lot. I’ve had good and bad experiences.

Participant J10 stated, “I would say challenges are with my education and missing school, expressing myself and social life.”

Theme 4: Mental Health

There was a consistent reiteration among young adults as it relates to the impact of SCD on their mental health and overcoming barriers. Participant A1 stated,

> I think psychologically being in pain can take a toll on you and I’m just thankful that my family supported me because it would have been worse. But being involved in the SCD community events and making friends that have shared similar experiences has helped me a lot.

Participant B2 stated,

> My mental health like declined…I still struggle with my mental health, honestly. But it declined severely…I have better resources now into my adulthood. Going back to autonomy… I teach that and I represent that within my organization. because autonomy is so important because you have to have control over your whole story. You have to have control over your own health.

Participant B2 elaborated further,

> You have to have control over your own mental health and since I've been able to have more control over my own health journey… it's hard of course…but it's been really worth it. I've been able to understand myself better. I've been able to understand my triggers better, speak up for myself or actually, like have more control over who my practitioners are…It's a traumatizing transition, to say the least. But once you're able to actually take control of your life, it gets better in a way.
>
> Participant F6 stated,
>
> I would say benefits wise, I noticed that there was a medication for sickle cell that can lengthen our lifespan. I'd say the lifespan aspect of our average sickle cell patient really got to me sometimes. I'd also say that mental health services were brought up as options.

Participant F6 elaborated further,

> I would say like the mental health aspect of it. Like you're always alone with the disease and like dealing with the pain, but like, when you're really, really, like, alone and there's like, no one that can come help, or can come bring you this or

> bring you that or like maybe wash the dishes for you or like if you're like living with housemates…The mental health aspect as well as the financial, it just only makes the disease worse overall.

Participant G7 stated,

> It has affected me a lot and caused depression. It makes you think that you are the cause of the problem, however, some people do not realize the genetics behind it and what causes SCD, and how it all started. Sometimes, I am scared to mention SCD because I fear that I might lose friends, and it will affect my relationships due to the misconceptions. The pain is unbearable. I also regret that I do not have money for the new gene therapies.

Participant H8 stated, "Psychologically, the separation from a team that took care of me my whole life was hard as well as not knowing what to expect with a new healthcare team." Participant H8 explained, "I still experienced pain and had to manage it along with other aspects of my life like school and work. It was tough at times to miss out on fun." Participant J10 stated, "Psychologically, I would say isolation, because of the stigma associated with the disease, feeling slowed down, and physically having leg ulcers as well as the scars."

Theme 5: Support Systems and Networks

The participants shared perceptions regarding the dynamics of their support systems, community and networks throughout their lives and transition of care experience. Specifically, the influence of support systems shaped their narratives and experience with SCD throughout their lives. Participant A1 mentioned,

> Socially, I was able to meet new people and join events for SCD. It took some time for the new healthcare team to understand my needs as a patient and challenges sometimes still come. But overall, I am doing better now.

Participant B2 mentioned,

> At least I wasn't alone. At least my parents where there…Honestly, I'm still looking for resources and I feel like I can't necessarily say there were more resources when I was a child, but they will definitely take more care of me…more emphasis on my health when I was a child. I do have a good hematologist. I love my hematologist, but it took a long time for me to get this hematologist.

Participant C3 stated, "I got help from African American groups, schools, family members, family doctors." Participant D4 stated,

> My major support is my parents. Yeah, they'll continue motivating me. I was always very nervous. But after doing all the treatment, the medications, and my parents support, after all the meditation (yoga) so you know, now I am living a happy life.

Participant D4 also stated, "I attend camps…I guess it is a major benefit for me." Participant G7 described, "I learned from others, through support groups and received knowledge on staying hydrated, taking my folic acid every day." Participant H8 mentioned, "Since the transition, overall, my experience has been great. I am more involved with my care and have a great team that has been helpful throughout the change." Participant H8 explained, "My family supported me, which was great. However, it was a challenge adjusting to the change."

Additional Participant Recommendations

Participant A1 mentioned,

> I would recommend more preparation of what to expect before transitioning and more involvement in the early stages from the pediatric team working to transition patients to adult care. Like I said, it wasn't easy, but more preparation would have been beneficial.

Participant B2 stated,

> I have a lot of insight. I would encourage anyone to get in contact with the local or national or statewide organizations with sickle cell… like the support group conventions…Also like getting the pamphlets out there...pamphlets educating about childhood sickle cell, young adult sickle cell, and adult people.

Participant B2 elaborated further,

> There are many books…books that warriors or different caregivers have written about sickle cell. Hospitals need to work with other schools, organizations, local and statewide, to provide these resources. We need more funding... so the hematology departments or sickle cell organizations will be able to acquire these resources for patients.

Participant C3 stated, "I would say more care, more government relief, support groups, more representation." Participant D4 said, "My major help… elevating medicine, also translational medicine was very beneficial for me, continuously doing exercise and continue to take vitamins in my diet. So, I think it's very helpful for me to treat this."

Participant E5 mentioned,

> I just think there should be more…like you're doing now, more research studies about it, more education for it, because really no one really explains what it is like, the cause and effect…I feel like people that do have it, should be more educated on it, instead of just being told that they have it or given…pills…More information on it overall.

Participant F6 mentioned,

> Yeah, I'd say definitely being super aware of like if for example, to a parent, if you're a parent who wants to be hyper vigilant for your kid, you know, maybe realizing that the kid won't always have you there. So, like you're only hurting them by not letting them experience it, which is really hard for like a parent to fully grasp because like, that's their kid.…Like, yes, drinking water is probably one of the most important things.

Participant F6 elaborated further,

> Using heat to remedy your crisis is definitely another very important thing. It helps mediate it. But what I noticed may have helped me personally is, trying to have a physically strong enough body to handle day-to-day life occurrences like going down the stairs or getting up too fast from your bed or something. Like the little things that may cause crises and like pay attention to those little things like what are causing the crises.

Participant G7 stated, "Stay healthy, take your medications, stay hydrated, and heed to the medical advice." Participant H8 said,

> I would recommend more education on what the transition of care would look like, what to expect and more involvement with both teams, pediatric and adult care for additional support especially during the early stages. More education on the condition, more resources on support groups, where to go and how to connect with others with SCD would be helpful.

Participant I9 mentioned, “Taking medications and education.” Participant J10 stated, “I would recommend taking folic acid, drinking water, staying busy and doing what makes you happy.”

Summary

The study’s purpose was to explore the experiences of 10 young, AA adults between the ages of 18 and 25 with SCD, to understand what education is necessary for policymakers to reform legislation, public policies, and health promotion, to streamline transition of care guidelines and enhance quality of life. This chapter provides an examination of the results from the data collection and data analysis. Purposive sampling techniques were used in accordance with the research guidelines and approved recruitment strategy. Participants reached out via social media platforms, SCD support groups and SCD community events. Snowball sampling was also used which enabled participants who completed the study to refer other similar individuals to participate. Chapter 5 provides a discussion and interpretation of the research findings, limitations, implications for social change, recommendations for future research and conclusion.

Chapter 5: Discussion, Conclusions, and Recommendations

The purpose of this generic qualitative study was to explore the experiences of 10 young AA adults with SCD to provide policymakers with an understanding of what education was required for policymakers to reform legislation, public policies, and health promotion to streamline transition of care guidelines and enhance quality of life. In addition, I sought to understand the SCD transition of care experience from childhood to adulthood. The study focused on the lived experiences of young AA adults between the ages of 18 and 25. Semistructured interviews were conducted to understand the phenomenon and answer the research question: What are personal factors and the experience with education on SCD from existing legislation for young adults living with SCD, that public health policymakers should know so that legislators are better able to reform policy, update care guidelines, and promote disease management?

Five themes emerged during the data analysis process: (a) independence and maintaining health, (b) SCD education, (c) challenges with hospitalizations, (d) mental health, and (e) support systems and networks. The key findings of the study, interpretation of findings, recommendations, implications for social change, and areas for future study are discussed in Chapter 5. Participants shared the pros and cons, positive and negative experiences, and personal recommendations for the transition of care for young adults with SCD.

Key Findings

The young adults expressed ways of assuming more responsibility for their overall well-being, monitoring their health, appointments, doctor’s visits, and symptoms.

Participants shared views on self-management and how to stay healthy, including drinking water, obtaining adequate nutrition and diet, exercising, avoiding stress, and getting enough rest. Young adults had experienced a high level of involvement of caregivers, providers, and health care teams during their childhood. The transition to adulthood required more of their own responsibility to keep up with treatments, which was a new experience for the young adults. Participants had perceptions regarding the SCD education received throughout their lives among their health care team, providers, and self-awareness to manage the disease. In addition, participants expressed the misconceptions that existed regarding the disease, stigma associated with the condition, lack of education, and awareness by health care teams and society.

The results indicated that more guidance is necessary from the adult health care side for young adults to be prepared, understand the new programs, engage in new routines, treatments, and transition of care protocols. For instance, offering guidance and education to young adults on what to expect from new hospitals would be helpful. Likewise, additional guidance regarding what the SCD program would involve can offer insight into adult care early on and in preparation for the official transition. The participants also identified multiple ways of learning about SCD on their own and managing their care. Results also revealed challenges associated with repeated hospitalizations and the impact on participants' overall mental health. Participants described the impact of SCD physically, socially, and psychologically in the context of work, school, college, careers, and their relationships. Strong supportive systems and networks, internally and externally, were identified as an important factor throughout their lives and transition of care, which contributed to making their journeys better.

Interpretation of the Findings

Participants included young AA adults between the ages of 18 and 25 with a form of SCD. Interviews were conducted virtually via Zoom/phone. Participants consisted of men and women with various careers or educational experiences. The participants shared their personal experiences and views regarding their transition of care from childhood to adulthood. The following themes were discovered in the study: (a) independence and maintaining health, (b) SCD education, (c) challenges with hospitalizations, (d) mental health, and (e) support systems and networks.

Finding 1: Greater Responsibility for One's Health

Based on the responses, the young adults agreed to having a greater sense of responsibility to maintain their health during the transition from pediatric to adult care. The transition required more diligence on their part to follow through on basic medical needs, treatments, and balancing their lives with work or school. Participants also expressed more autonomy when it came to deciding on a new hematologist. The experience provided young adults with insight into managing their condition, understanding their triggers for a pain crisis, and knowledge surrounding how to stay healthy.

The young adults also expressed the challenges of being on their own with this condition despite having strong support networks. This included being in college or a university and having to manage the condition, going to the hospital on their own, and not having enough basic support in comparison to their childhood and because the young adults were now on their own by the age of 18. Participants also explained how shifting resources, unreliable finances, lack of medical support, and insufficient follow-up from health care teams after transition can pose challenges. It was up to the participants to engage in disease management and find their own ways of maintaining health and wellness.

Finding 2: SCD Education

As far as SCD education, the participants had a good foundation of knowledge regarding their condition and managing their basic needs. There were consistencies regarding a lack of education on some part by new providers or hematologists as participants transitioned. This included a lack of overall awareness of the disease by society and not adequate preparation for the transition despite an understanding of what to do to stay healthy (e.g., drinking water, avoiding stress and triggers for pain, taking medications regularly, resting, staying physically healthy, exercising, and doing yoga). However, participants described to an extent how education could be improved overall to properly prepare and inform young adults and so that health care teams would be more educated on caring for individuals with SCD. Although some participants had received the education, other young adults went searching for resources on their own, which helped them manage SCD.

Finding 3: Challenges Associated With Hospitalization

The participants shared some challenging experiences with SCD and details of frequent hospitalizations and long-term impacts. Participants described how more education is needed for providers and health care teams to understand how to manage and care for individuals with SCD. In addition, participants described medical treatments offered to them that helped with the management of their condition. These included certain therapies or medications. However, participants all agreed that more resources are necessary throughout adulthood, including financial resources. At times, the young adults also expressed, “searching on their own for resources” that may be beneficial for their health. The young adults with SCD were constantly advocating for themselves in the hospital and dealing with the biases that exist, which also impacted their treatment. The participants expressed positive and negative experiences with hospitalizations, the disease, and the physical impact of the condition.

Finding 4: Impact of SCD on Mental Health and Overcoming Barriers to Finding a Purpose

The young participants described the toll that SCD takes on their mental health, stigmas associated with SCD, and rising above those challenges. Participants explained how SCD impacted them socially, physically, and psychologically. The young adults missed out on social events with friends or family or school. In addition, the young adults with SCD felt that the lack of education regarding this condition, contributed to a lack of understanding of their experiences and hardships. However, participants felt a sense of purpose from understanding how to self-manage their condition and staying healthy through yoga, meditation, support groups, or becoming an advocate for themselves and others suffering from this condition. The young adults felt that the experience made them stronger and the support of their parents or family made the journey better. In addition, participants expressed staying busy, active, and focused on doing what made them happy.

Finding 5: Strong Support Systems

Overall, the participants described having strong support systems. Their parents and family were always there and supported them throughout their lives. Although the young adults had a new level of independence when transitioning and often had caregivers and health care teams that were more engaged with them as a child, the family aspect played a huge role for the young adults. In addition, finding a good hematologist or health care provider and community support group was helpful, as well as being a part of more research and advocacy for SCD. This included community events, via social media and live educational sessions, and support groups. The participants had a sense of fulfillment and purpose whether it was through work, advocacy or school and the desire to be a part of something greater. Despite the young adults' challenges and experiences, findings indicated that the young adults had strong backbones and positivity to pursue their goals and dreams in life.

Summary of the Findings

The findings provide insight into many personal factors for young adults living with SCD and what public health policymakers should know, so that legislators can reform better public health policies, care guidelines and promote disease management. The narrative policy framework and policy feedback theory can provide additional insight into the lived experience of young adults with SCD and analyze how policy narrative learning could be a method to link policy processes to policy change. It could also evaluate current legislation and policies enacted to support the treatment of SCD for young adults and evaluate what is needed to strengthen core treatment plans and transition of care guidelines. As discussed in Chapter 2, there was a lack of information on the public policies that evaluate continuing care practices, education, and the competence of young African American (AA) adults with sickle cell disease (SCD) living in Pennsylvania. An evaluation of this framework and theory can provide additional context on the phenomenon of study and as it relates to public policy and administration.

Narrative Policy Framework

According to Jones et al. (2022), the narrative policy framework provides a valuable theoretical framework for advancing knowledge of the policy process. The narrative policy framework provides a solution to recognize, organize, and understand concepts and the relationships to other concepts within the policy process. Policy narratives provide an opportunity to understand narratives and public policy. This concept is essential to this research study because it provides context of the lived experiences of individuals with SCD. It also influences the public health policy process and the relationship between concepts that formulate fundamental advancement in research.

According to Jones et al. (2022), the narrative policy framework identifies three levels of analysis. “The micro-level focuses on the narratives of individuals. The meso-level captures group and coalition level narratives. The macro-level focuses on the broad narratives of cultures and institutions that provide ideational boundaries for micro- and meso-level narratives” (p. 179). As mentioned by Jones et al. (2022), “while often examined as discrete levels, the narrative policy framework assumes interaction between levels of analysis" (p. 179). With respect to this research study, "narrative is assumed to play a central role in how individuals process information, communicate, and reason" (p. 179). To evaluate what is necessary in SCD treatment guidelines and for policy reformation, understanding personal narratives as it relates to the topic of study provides an opportunity to explore the micro-level (narratives) of individuals and places surrounding connections on the macro-level and meso-level narratives (Jones et al., 2022).

Policy Feedback Theory

The foundational literature pertaining to policy feedback indicates that once policies are established, policies may impact future governance and shape policy alternatives selected by lawmakers (Sabatier & Weible, 2018). In addition, this can shape the type of implementations or arrangements assigned to new policies, parameters, and limits of government action (Sabatier & Weible, 2018). Recent research by scholars of the policy feedback theory has provided insight into political processes across many dimensions. Moreover, the creation of new policies is widely influenced by the existence of other policies. This approach is essential for policymakers and leaders to understand and assess existing policies with a method for promoting governance, civic engagement and fairness among groups and interests (Sabatier & Weible, 2018).

It is evident that the use of the narrative policy framework influences policy learning and helps to identify new public health policies, assess current policies, or promote reformation of existing legislation. According to Sabatier and Weible (2018), “the study of policy feedback represents an exciting and still relatively new direction in policy research, one ripe with possibilities for further inquiry” (p. 129). The narrative policy framework provides an opportunity to explore the lived experiences of young adults with SCD that may influence policy learning and provide an opportunity to assess, review and reform SCD public health policy. For example, based on the responses from participants and emerging themes, this can be used to identify additional resources that may be beneficial during the transition of care process and analyze challenges or barriers encountered. Policy narratives can be influential as it relates to policy learning. Policy narratives can also be beneficial when exploring the ways that lawmakers can promote positive social change, through policy implementation and reformation, which can improve health disparities among this population.

Limitations of the Study

The data collection focused on the criteria of the study and was limited to young African American adults with SCD. The study included women and men, ages 18 and 25, and the study was conducted virtually via Zoom/phone. Furthermore, this was a generic qualitative study with a sample size of 10 participants. The study was specific with respect to the age group, and demographics, but broad to include the perspective of men and women with different forms of SCD. Research bias existed as with any research study. However, measures were used to reduce bias which included verbatim transcription of the digital records of the interviews, notetaking and using member checking upon the completion of interviews, to ensure accuracy of the participant’s responses.

Although the study was conducted via Zoom/phone, audio-recording or notetaking, there were not many differences in terms of participants' overall views of the SCD experience from childhood to adulthood. In addition, there were no differences expressed by the young adults with SCD in relation to clinical symptoms, treatments, and perceptions of hospitalizations. However, this study was only limited to a specific group, so it is limited in understanding whether this is indicative of a whole population with consideration of the protocols set for gathering data. Future studies could provide more insight into the comfort measures among participants set by protocols within the study and sharing personal information, and whether there is a correlation between the information or insight obtained. In this study, there were no differences expressed by the young adults, other than establishing parameters for participant's personal preference for audio-recording and notetaking.

Research bias may be caused by being a known SCD advocate and connected with the cause and SCD community. However, member checking ensured that my perceptions did not influence decisions and create bias in the research study. Participants voluntarily participated in the study based on their interest in the topic and were not offered compensation. Each participant received an opportunity to partake in snowball sampling and help recruit other young adults with SCD that were interested in joining the study. Recruitment for this study was done by posting this information online via social media platforms, sharing with the SCD community and support groups. The study was limited to virtual interviews to allow for flexibility of participant's preferences for a one-to-one Zoom/phone session. Likewise, the study's focus was on understanding young AA adults' perspective with SCD and the transition of care experience from childhood to adulthood and for individuals between the ages of 18 and 25.

Recommendations

In this study a sample of 10 young AA adults, women, and men, between the ages of 18 and 25 with SCD were interviewed. The study sought to understand what education is necessary for policymakers to reform legislation, public policies, and health promotion, to streamline the transition of care guidelines and enhance quality of life. The basis of this study was due to a lack of information on public policies that evaluate continuing care practices, education, and the competence of young, AA adults with SCD. Public policy research is limited regarding SCD to understand the public health initiatives and education necessary to help these individuals manage this chronic condition throughout their lives. The study sought to examine the gap by understanding the young adults' experiences from childhood to adulthood.

The study's population focused primarily on young AA adults within a specific age range, 18 and 25, and geographical area and was conducted virtually. However, future research may consider this topic with respect to different states and geographical areas, among an older age range of young adults and ethnic groups, and from a different perspective or even comparison from counties and states. This would allow for the expansion of assessing a bigger population to examine the findings and generalizability of the study. The similarities or differences may be valuable with respect to public health policy and reformation. Moreover, focusing on one type of SCD among young adults, with additional criteria set forth by future researchers, may provide an opportunity to examine specific trends or perspectives (if any) that correlate to the individuals with a type of SCD, mild or severe form.

Future research could also entail examining this topic from a quantitative or mixed- method approach. All of these recommendations could provide insight on this topic and dive deeper into this study by examining other populations and different factors. Additionally, the study may be useful for examining public health policies, SCD legislation, or public health promotion and factors for considering continuing treatment protocols or the transition of care practices. Empowerment of young adults with SCD is essential in addition to helping them use their voices to inform action or reformation of policies that impact their transition of care experience.

The theoretical framework used for this study was appropriate for examining the perceptions of young, AA adults with SCD between the ages of 18 and 25. The study could be valuable for creating a plan or guideline by policymakers to understand what is needed in the reformation or development of new policies to improve healthcare outcomes among this population. Continuing research and study pertaining to this topic may provide more insight into the preparation and transition of care for young adults with SCD.

Implications for Social Change

The study may have implications on the public policy process, policymaking, or reformation for SCD transition of care guidelines. Recommendations of the study may also assist with examining childhood to adulthood practices for transition of care outlined, with respect to legislation and how mandates could be fostered to ensure adequate education and public health promotion for SCD. As transition of care may create benefits and challenges for young adults with SCD, this study may be useful for policy planning and ensuring that the appropriate resources are in place for the young adults. This also includes an evaluation of childhood and adulthood care practices for transition within hospitals, healthcare clinics and facilities, and to establish standards for the transition of care for young adults with SCD. The overall objective is to promote the quality of life for individuals with this condition and decrease mortality rates. It is important to provide young adults with the educational resources to succeed, and reform certain healthcare guidelines or public policies which may be beneficial.

Conclusion

In conclusion, the transition of care from childhood to adulthood can impact young adults with SCD. SCD is a chronic, inherited disorder impacting more than 100,000 mostly Black and/or African American individuals in the United States and millions worldwide (Boucher et al., 2023). Young adults face challenges associated with this chronic condition throughout their lives and require resources and treatments to promote disease management and enhance their quality of life. According to Docherty et al. (2019), there is an “substantive increase in mortality during the adolescent and young adult years, coinciding with the time of transfer from pediatric to adult care” (p. 1). In addition, recent data and research indicates a sharp increase in mortality for young adults with SCD in their early 20s in comparison with younger ages. There is a need to evaluate specific health disparities and actively reform SCD transition approaches for young adults (Boucher et al., 2023).

The purpose of this generic qualitative inquiry research study was to explore the experiences of at least 10 young AA adults between the ages of 18 and 25 with SCD. The study was to understand what education is necessary for policymakers to reform legislation, public policies, and health promotion, to streamline the transition of care guidelines, and to enhance the quality of life. Participants described several personal factors and themes that contributed to their transition of care experience. The themes were (a) the level of independence to maintain health and wellness, (b) experience with SCD education, (c) challenges with hospitalizations, (d) overcoming mental health barriers and (e) the benefits of their supportive systems and networks. Based on the findings, connecting to resources earlier on during their transition of care is the key for young adults to have accessibility to resources that can help support them. This includes fostering a supportive community, and connection with transitional healthcare teams, which is essential on both sides of the spectrum during childhood and transferring into the adult care setting.

Sickle cell education is still necessary and training for individuals caring for young adults with SCD. There is still a lack of awareness surrounding the condition especially among new providers, hematologists, and health care teams. Having autonomy and the appropriate resources to decide which care setting or adult hospital is preferred is important for young adults and to ensure their voices are heard. Many young adults described the need for more funding, resources, and community involvement to help during their lives. Perhaps having more supportive teams or individuals with SCD who already transitioned and championing this initiative may serve as an additional supportive system.

Considering this group is widely connected with their peers, perhaps an incorporation for peer-to-peer support and a transition of care team may be beneficial during their transition and after completion of the process. Policymakers can evaluate all of these factors and identify ways to evaluate or reform policies by incorporating the feedback identified in the narratives of the young adult population with SCD. Based on the research study conducted, there are opportunities to make improvements. This includes promoting resources for young adults, encouraging more SCD education, awareness, and advocacy during their transition of care. By addressing these components, policymakers, legislators, leaders, and public administrators, can make a difference in the lives of people living with SCD on a local, state, and national level.

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