Walden University

College of Health Sciences and Public Policy

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Evelyn Carol Ellis-Washington

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Abstract

Factors Influencing Transitional Care Seeking Behaviors of African Americans Living with Sickle Cell

by

Evelyn Carol Ellis-Washington

MS, Delta State University, 2001

BS, Delta State University, 2000

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Public Health

Walden University

August 2023

Abstract

Sickle cell (SC) is an inherited blood disorder that affects millions globally and approximately 100,000 people in the United States. SC causes excruciating pain and organ damage. This qualitative study was conducted to examine the factors influencing the decision-making process of African American diagnosed with SC regarding maintaining continuity of care. This qualitative study was conducted to understand how perceived susceptibility and severity, perceived benefits versus barriers, sense of threats, cues of action, and self-efficacy influence the transitional care-seeking behaviors of African Americans diagnosed with SC in the rural Mississippi Delta. The health belief model was the theoretical framework used to underpin this study with a phenomenological research design. Data were collected through semi structured interviews with 15 participants, who were between ages 18 and 61, diagnosed with SC, and who resided in the rural Mississippi Delta. Spreadsheet was used as the coding technique to code and analyze the data collected. The themes emerged from the data were the majority of the participants kept all medical appointment, traveled long distance to receive specialty healthcare, missed appointments, and etc. Microsoft Excell The study findings confirm that additional research is needed to understand better the lived experiences of African American adults with SC, the need for specialty healthcare providers to meet the unmet medical needs of this population. The findings from this study have potential implications for positive social change that include helping the medical community better understand the barriers associated with this phenomenon, which may help improve the quality of life for this population.

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Dedication

This dissertation is dedicated to God for giving me a vision and a desire to make a difference in the lives of children and adults living with sickle cell, and to DaMarius DeUndra Washington, whom God placed in my life and changed our family forever. However, due to the uncertainty of his illness, I am grateful to my mother, Earline Ellis, and my siblings for caring for my daughters, Denetara and Rhonda. Furthermore, I am thankful our mother envisioned a life for our family beyond a plantation in the rural Mississippi Delta. Not to mention how our mother led by example by working at the Mid-State Sports Wear Jacket Factory, attending GED classes at night, graduating from Coahoma Community College with me, serving as an election commissioner in Tallahatchie County, and ensuring that each of us attained education beyond high school. Additionally, I am thankful to my father, Roy Williams, a janitor, who only had a third-grade education, and my stepmother, Rosia Williams, an educator, who reiterated the importance of education.

Finally, I want to give a special thanks to all the adults who shared their lived experiences with sickle cell to add to the body of knowledge and enhance the quality of life of adults living with the disease.

Acknowledgments

Once again, I thank God for putting people in my life when I needed them and for making this day a reality. I thank Dr. W. Sumner (Bill) Davis, my committee chair, for mentoring me in my dissertation journey. I thank Dr. Davis for telling me never to be afraid to ask a question whenever I was unsure about anything I did not understand. Additionally, after reading Dr. Davis's introduction in the Class Café, I was even more inspired to successfully complete my dissertation journey. I would also like to thank Dr. David Anderson, methodologist, for serving as my guide and believing that if I remained persistent, I would make it across the finish line. Having a committee knowledgeable about the rural Mississippi Delta and its many health disparities was an honor.

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Chapter 1: Introduction to the Study

Introduction

The growth of the adult population with a sickle cell disorder (SC) has rapidly increased and the disease is prevalent among African Americans in the United States (Centers for Disease Control and Prevention [CDC], 2022). Historically, SC was perceived to be a fatal childhood disease but due to the improvement in supportive and preventive healthcare (newborn screening, penicillin prophylaxis, and transcranial doppler [TCD] screening), life expectancy has increased into adulthood (Meier, 2017; Thein et al., 2017). Although the survival rate of children living with SC has increased, the mortality rate remains high among the adult population in the United States (Maitra et al., 2017; McGann et al., 2013; Onimoe & Rotz 2020; Payne et al., 2020). Yanni et al. (2009) found that the mortality rate among children with SC decreased from 1999–2002 by 42%, but the mortality rate among older SC patients did not decrease, suggesting additional research is needed to better understand why African Americans diagnosed with SC are failing to seek transitional services as they become adults (Cerns et al., 2013; Keller et al., 2017). However, little research is available about adults and their experiences living with SC (Matthie et al., 2016; Thein, et al., 2017).

This chapter includes the study's background, problem statement, purpose of the study, research questions, theoretical framework, and nature of the study. Additionally, definitions of key concepts or constructs are provided to clarify the meaning of adult experiences living with SC. The scope, delimitations, and detailed aspects of the study to address any biases, population boundaries, transferability, strengths, and weaknesses are

identified. Finally, a summary is focused on the significance of the study's contributions to individuals, the community, society, and public health.

Background

SC is a complex inherited disorder that affects over 100,000 people in the United States (Adams-Graves & Bronte-Jordan, 2020; Ara & Brown, 2021; CDC, 2020). Adults living with SC face many debilitating health conditions, such as chronic anemia, severe pain, and chronic organ damage (Chakravorty & Williams, 2015; Onimoe & Rotz, 2020). Thus, continuous medical treatment and preventative health care have increased patients' lifespans over the past decades. Despite this, most patients diagnosed with SC who live beyond the age of 18 are faced with significant healthcare barriers and challenges (Bemrich-Stolz et al., 2015). Some of the barriers identified, such as stigmatized (drug seeker, behavior), discrimination, lack of specialty health care providers, and the fear of leaving their pediatric healthcare providers (HCPs), can interfere with the ability of adults living with SC to comfortably transition from child-centered healthcare to adult-centered healthcare (Clayton-Jones et al., 2019).

According to Jenerette et al. (2014), 88% of adult patients diagnosed with SC attempt to manage their pain and other health-related issues at home to avoid negative experiences in the healthcare system. Given this reality, further research is needed to better ascertain adults' quality of life (QOL) beyond the transitional stage (McClish et al., 2017). Thein et al. (2017) found that in the United States, individuals living with SC face many health inequities compared to patients living with cystic fibrosis and other genetic conditions (Thein et al., 2017). Even though significant strides in healthcare and

diagnostics have been made over the past decades to understand the needs of adolescent SC patients, a gap in the literature exists regarding addressing the needs of adults living with SC as they transition to adult HCPs, which should be expanded.

Little is known about the barriers that African American adults experience or why African Americans living with SC delay seeking medical treatment, and limited research has been published addressing the factors impacting care-seeking behaviors among adults living with SC (Jenerette et al., 2015). Therefore, further research is required to explore why African American adults living with SC fail to maintain care continuity.

Problem Statement

SC is an inherited blood disorder that affects millions globally (CDC, 2021; National Heart Lung and Blood Institute [NHLBI], 2022). SC is prevalent in descendants of Sub-Saharan Africa, Spanish-speaking regions in the Western Hemisphere (South America, the Caribbean, Central America), Saudi Arabia, India, and Mediterranean countries, including Turkey, Greece, and Italy (CDC, 2021). SC affects approximately 100,000 people in the United States (CDC, 2021), African Americans (Calhoun et al., 2018).

In 2019, the Mississippi Department of Health (MSDH) and the American College of Genetics identified over 600 hemoglobin diseases, 13 of which were identified in Mississippi. SC was considered the most prevalent form of anemia in the Mississippi Delta (see Table 1 and Table 2). The decision to focus on the Mississippi Delta for this research was based on the prevalence of SC in this geographical area (MSDH, 2019). According to Mennito et al. (2014), two thirds of adolescents living with SC have yet to

talk with an HCP about transitioning. There is a need for further research to understand better why adults living with chronic diseases opt not to seek out healthcare services from adult HCPs (Abdallah et al., 2020). Additionally, these adults tend to be from a lower socioeconomic status (SES; McCarty et al., 2020). With clinical support, people diagnosed with SC can have a better QOL, so there is a need for increased understanding of why African Americans diagnosed with SC who reside in the Mississippi Delta do not maintain continuity of care.

Table 1

Mississippi Hemoglobinopathy (Sickle Cell) Registry 13 Identified in Mississippi

***Hemoglobin sickle cell anemia	Hemoglobin C/Beta O thalassemia
***Hemoglobin sickle cell disease	Hemoglobin Beta + thalassemia
***Hemoglobin S/Beta + thalassemia	Hemoglobin sickle cell disease + Barts
***Hemoglobin C/Beta + thalassemia	Hemoglobin beta thalassemia intermedia
Hemoglobin C disease	Hemoglobin E disease
Hemoglobin S/Beta O thalassemia	Hemoglobin E disease + Barts
Hemoglobin sickle cell anemia + Barts	

Note. *** = most severe. *Source*: MSDH, 2021 (American College of Genetics).

Table 2

Most Frequently Confirmed Hemoglobin Traits in Mississippi

Hemoglobin S trait	Occurs when a normal Hemoglobin A gene is inherited from one parent and a Hemoglobin S gene is inherited from another parent
Hemoglobin C trait	Occurs when a normal Hemoglobin A gene is inherited from one parent and a Hemoglobin C gene is inherited from another parent
Hemoglobin D trait	Occurs when a normal Hemoglobin A gene is inherited from one parent and a Hemoglobin D gene is inherited from another parent
Hemoglobin O Arab trait	Occurs when a normal Hemoglobin A gene is inherited from one parent and a Hemoglobin O Arab gene is inherited from another parent

Source: MSDH, 2021

Purpose of the Study

This qualitative study was conducted to examine the factors influencing the decision-making process of African American adults diagnosed with SC from maintaining continuity care as they transition from adolescence to adulthood. This study has a geographical focus exclusive to the Mississippi Delta as many Delta residents must travel long distances to access specialized care (Cronin et al., 2018; Rural Health Information Hub [RHIhub], 2021). Additionally, this study may increase the limited body of research regarding African Americans living with SC.

Research Questions

RQ1: Do the perceived susceptibility and severity of African American adults diagnosed with SC in the rural Mississippi Delta influence transitional care-seeking behaviors?

RQ2: Do the perceived benefits versus barriers, sensed threats, cues to action, and self-efficacy influence transitional care-seeking behaviors of African American adults diagnosed with SC in the rural Mississippi Delta?

Theoretical Framework

The theoretical framework used to guide this study was the health belief model (HBM) devised by Hochbaum, Rosenstock, and Kegels in 1952 while conducting research for the U.S. Health Service. According to Hayden (2019), the HBM is a psychological health behavior change model developed to explain and predict health-related behaviors. More precisely, the model proposes people's beliefs about health problems, perceived benefits of actions and barriers to action, and self-efficacy to explain

engagement (or lack of engagement) in health-promoting behavior. The HBM model comprises six constructs: (a) perceived susceptibility, (b) severity, (c) benefits, (d) barriers, (e) cues to action, and (f) self-efficacy. The HBM was used to understand the limitations of people's understanding better and to overcome the transitional barriers and perceptions that African American adults living with SC experience. Previous studies have suggested that when SC patients transition from pediatric to adult care providers, they face many challenges (Matthie et al., 2016; Speller-Brown et al., 2015). According to Matthie et al. (2016), limited studies have been conducted to assess adults' perceptions of living with SC.

The HBM has been widely used in multiple studies. The HBM focuses on how people's thoughts, actions, and decision-making processes about health-related issues or concerns they are experiencing lead to action (Herrmann et al., 2018). For example, if adults living with SC believe that scheduling a medical appointment with adult healthcare providers may help them maintain a better QOL or if they believe the recommended medical treatment (action) may extend their life beyond adulthood, and if the recommended medical treatment may not increase their QOL (Herrmann et al., 2018).

After several decades of application, HBM was further defined by Janz and Becker (1984) to understand the resistance to beneficial change. Hochbaum (1958) worked collaboratively with the National Tuberculosis Association, the Tuberculosis Program, the Public Health Education Services, and the U.S. Department of Health Education and Welfare. This model helped provide a better understanding of why adolescents do not maintain continuity of care as they transition from adolescent to adult-

centered care. Plus, to facilitate and generalize the findings in this study, as noted several decades (57 years) that assumptions could not be used in this study (Hochbaum, 1958; Hochbaum et al., 1952). Based on the tuberculosis study conducted by Hochbaum and his colleagues (Rosenstock & Kegels, 1952), the HBM helped identify factors that determine the identified population decision-making process about how the transition from child-centered health care to an adult-centered program would benefit them. When the cues of actions would occur, specific concerns arose about how the population would react regarding their ability to accept the responsibility for making necessary healthcare decisions (Hochbaum, 1958; Hochbaum et al., 1952).

While some studies have recognized that multiple problems exist in the transitional stages of adults living with SC, there is currently limited information available to address the issues related to SC patients transitioning from pediatric to adult HCPs. Some variables that may influence the theory are demographics (age, ethnicity, gender), SES being a common concern identified, finding HCPs, and receiving adequate medical treatment. The HBM constructs were used in this study to guide and make sense of factors influencing the transitional care-seeking behavior of African Americans diagnosed with SC residing in the rural Mississippi Delta through their lived experiences. The HBM is explored more in depth in Chapter 2.

Nature of the Study

In this study, I employed a phenomenological design. A phenomenological design is used to describe people's views, beliefs, and interpretations on an individual and personal level concerning lived experiences (Neubauer et al., 2019). More specifically,

this design is used to describe what individuals have in common as they experience a phenomenon (i.e., a need to move to transitional care when diagnosed with SC; see Neubauer et al., 2019).

Furthermore, the aim of this study was to reduce individual experiences with a phenomenon to a description of the universal essence. I drew from the lived experiences of African Americans diagnosed with SC in the rural Mississippi Delta and identified influencing factors impacting their transitional care-seeking behaviors. Such a study goal aligns well with the purpose of phenomenological research design. The key concepts are the beliefs and perceptions of African American adults who reside in the rural Mississippi Delta. The data were collected from in-depth face-to-face interviews to understand better African American adults living with SC in the Mississippi Delta.

Definitions

Healthcare transition: is defined as the purposeful, planned movement of adolescents and adults with special healthcare needs from child-centered to adult-centered healthcare (Machado et al., 2016).

Phenomenology: An approach to research that seeks to describe the nature of a problem by exploring it from the perspective of those living it (Neubauer et al., 2019).

Sickle cell anemia (SCA): One of the most frequently reoccurring genetic disorders that affect the red blood cells and can be referred to as *SCD, SS,* or *SC* (Chakravorty & Williams, 2014; MSDH, 2021).

Sickle cell disease (SCD): A term used to classify all the hemoglobin disease genotypes (MSDH, 2021).

Sickle cell trait (SCT): An inherited gene that a child receives from only one parent (MSDH, 2021).

Special healthcare needs: A population (children and youth ages birth to 21) of individuals living with chronic illnesses, disabilities, hospice patients, elderly, low-income, inner-city, and rural populations (Agency of Healthcare Research and Quality [AHRQ], 2021). Children and youth with chronic illness healthcare needs require various specialized HCPs (MSDH, 2021).

Stigma: A form of labeling leading to negative consequences (Bulgin et al., 2018). Those living with specific diseases or health conditions experience multiple forms of healthcare stigma in health facilities while seeking medical treatment when they are vulnerable. Some of the forms of healthcare stigma are denial of proper medical treatment, suboptimal healthcare that interferes with patients' QOL, patients being viewed as drug seekers, verbal abuse, and waiting longer before receiving medical treatment. Stigma also impacts the QOL of patients with chronic illness in the workforce by concealing their health status or seeking medical treatment (Nyblade et al., 2019).

Assumptions

In this study, I assumed the participants would respond honestly to the questions according to their lived experiences. I assumed that a physician diagnosed the participants and that they adhered to the correct medication regimen and treatment plan.

Scope and Delimitations

This study's goal was to explore factors that influence the decision-making process of African Americans diagnosed with SC from maintaining continuity of care as

they transition from pediatric HCPs to adult HCPs. I chose this population because individuals diagnosed with SC are living longer, the mortality rate is rapidly increasing, and they are facing many unmet healthcare challenges. The scope of this study only included African Americans (male or female) ages 18–61, diagnosed with SC by an HCP, who lived in the rural Mississippi Delta. Participants had to be English speaking and able to read and write on at least a sixth-grade level. All participants signed an informed consent and were required to not have any cognitive disabilities that would interfere with their level of comprehension. Therefore, individuals who were not African American, did not speak English, or were not diagnosed with SC were excluded from the study. Additionally, this study has a geographical focus and participants were recruited from 22 counties in the rural Mississippi Delta.

This study could also be instrumental in affording African Americans living with SC a better QOL. In addition, findings could provide HCPs with additional education to meet the unmet healthcare needs of this population, decreasing the high emergency department use and mortality rate, and increasing funding sources to develop quality healthcare options for this population. Even though portions of the study may not be transferrable because of the specific population and sample size, the findings may be beneficial for future research.

This study may serve as a catalyst for future research to provide a better understanding of the healthcare needs of African Americans living with SC and may close the communication gap between African Americans and HCPs, researchers, social workers, and policymakers regarding hemoglobinopathies. This research could be

instrumental for future researchers to expand by continuing to apply this study to a larger population to explore other healthcare disparities and medical treatments and devise a comprehensive healthcare transitional plan to enhance the QOL of African Americans living with SC and the educational, financial burden, and housing issues of this population.

Limitations

The study was limited in that it was focused on African Americans living with SC in the rural Mississippi Delta. Another limitation was the sample size and the method in which information was gathered from participants. Also, a limitation was the number of specialized healthcare professionals available in rural Mississippi to provide adequate medical treatment to adult patients compared to the number of available pediatric HCPs. Participants in this study consisted only of volunteers located in specified counties in Mississippi who were between ages 18 and 61.

Significance

This study may shed light on African Americans' transitional care needs with SC as they move into adulthood. This research relied on study participants' lived experiences to help determine the factors that may inhibit continuity of care received by this population. As a result, this study could catalyze social change and help the medical community better understand the barriers associated with this phenomenon, which may help improve the QOL for this population. More specifically, identifying barriers that adversely impact the transitional care of African Americans diagnosed with SC in the Mississippi Delta could serve society's best interest by improving the community's

health status. As the medical community gains a deeper understanding of the factors influencing this population's care-seeking behaviors, it may stimulate change in current practice. Providers may better understand how to overcome the barriers preventing African American adults' transitional care from childhood to adulthood. The results from this study could lay the foundation for future research into psychosocial factors adversely affecting the care-seeking behavior of African Americans with SC as they enter their adult lives. Furthermore, as the body of research grows, the findings could spur more innovation in practice, which may help overcome barriers to transitional care-seeking behaviors and improve the health status of this population.

Summary and Transition

While significant progress has been made in providing a better understanding of what SC is and how it impacts the lives of adults in the rural Mississippi Delta, more research is needed to understand the factors that influence the care-seeking behaviors of African Americans. This chapter was focused on the research problem and the study's background. By applying the HBM to a phenomenology framework, a more in-depth understanding of African American adults living with SC in the rural Mississippi Delta region may be gained. The existing literature has identified various barriers and the importance of becoming knowledgeable about SC's effects when transitioning to adulthood. A more in-depth review of the literature is explored in Chapter 2.

Chapter 2: Literature Review

Introduction

SC is an inherited blood disorder that affects millions globally (CDC, 2021; NHLBI, 2021). SC is prevalent in descendants of sub-Saharan Africa, Spanish-speaking regions in the Western Hemisphere (South America, the Caribbean, Central America), Saudi Arabia, India, and Mediterranean countries, including Turkey, Greece, and Italy (CDC, 2021). SC affects millions worldwide and approximately 100,000 people in the United States (CDC, 2021), and most are African American descendants (Mayo-Gamble, 2014).

In 2019, the MSDH and the American College of Genetics identified over 600 hemoglobin diseases, 13 of which were identified in Mississippi. SC was considered the most prevalent form of anemia in the Mississippi Delta. The decision to focus on the Mississippi Delta for this research was based on the prevalence of SC in the geographical area (MSDH, 2019). According to Mennito et al. (2014), two thirds of adolescents living with SC have not talked with an HCP about transitioning. There is a need for further research to understand better why African Americans living with chronic diseases opt not to seek out healthcare services from adult HCPs (Abdallah et al., 2020). In addition, these African Americans tend to be from lower SES (McCarty et al., 2020). With clinical support, persons diagnosed with SC can have a better QOL, so an increased understanding is needed for why African Americans diagnosed with SC who reside in the Mississippi Delta are not maintaining continuity of care.

This qualitative study was conducted to examine the factors that influence the decision-making process of African American adults diagnosed with SC regarding lack of continuity care as they transition from adolescence to adulthood. This study had a geographical focus exclusive to the Mississippi Delta as many Delta residents must travel long distances to access specialized care (Cronin et al., 2018; RHIhub, 2021). Additionally, this study may increase the limited body of research regarding African American adults living with SC.

While significant progress has been made in providing a better understanding of what SC is and how it impacts the lives of African Americans in the rural Mississippi Delta, more research is needed to understand factors that influence the care-seeking behaviors of African Americans. This literature review includes studies on factors influencing the care-seeking behaviors of African Americans living with SC, the research problem, the study's background, transitional barriers of SC, the HBM to a phenomenology framework, the QOL of adults living with SC, socioeconomic factors, continuity of care, and hospital utilization. Meier and Rampersad (2017) stated that more than 95% of children born with SC live into adulthood. Even though the survival rate of children has increased, African Americans living with SC still experience barriers, such as access to subspecialty care and sociodemographic factors (Meier & Rampersad, 2017). Additionally, Cronin et al. (2018) noted that the literature on medical barriers is focused on children, and little is known about healthcare barriers among adults.

Literature Search Strategy

The literature review consisted of peer-reviewed articles. The following Health Science databases were used: CINAHL, MEDLINE with Full Text/ PubMed, Science Direct, Academic Source, Sage Research, APA PsycINFO, EBSCOhost, Embase, MSDH, CDC, NHLBI, National Institutes of Health, and World Health Organization. Older literature was included for foundational purposes only; most of the literature obtained was published from 2016–2021 and was accessed through Walden University's online library and other databases. The following terms were used to identify literature to support the need for the proposed study: *sickle cell, sickle cell anemia, sickle cell disease, transition, pediatric and adult care, chronic disease, youth with special health care needs, adults, sickle cell transition, the health belief model, mortality, morbidity, vulnerable population, decision making, sickle cell gaps, income socioeconomic status, low income and poverty, transitional care, continuity of care, care-seeking behavior, health-seeking behavior, patient acceptance of healthcare, African Americans, Blacks, anemia, sickle cell disease management, psychosocial determinants of health care utilization in SCA patients, Mississippi Delta, quality of life,* and *sickle cell transition.* The search included qualitative peer-reviewed sources as they related to SC. SC is a chronic illness, with limited research focused on factors influencing transitional care behaviors of African Americans living with SC. However, researchers have indicated or suggested the need for additional research to address the medical needs of this population.

Theoretical Framework

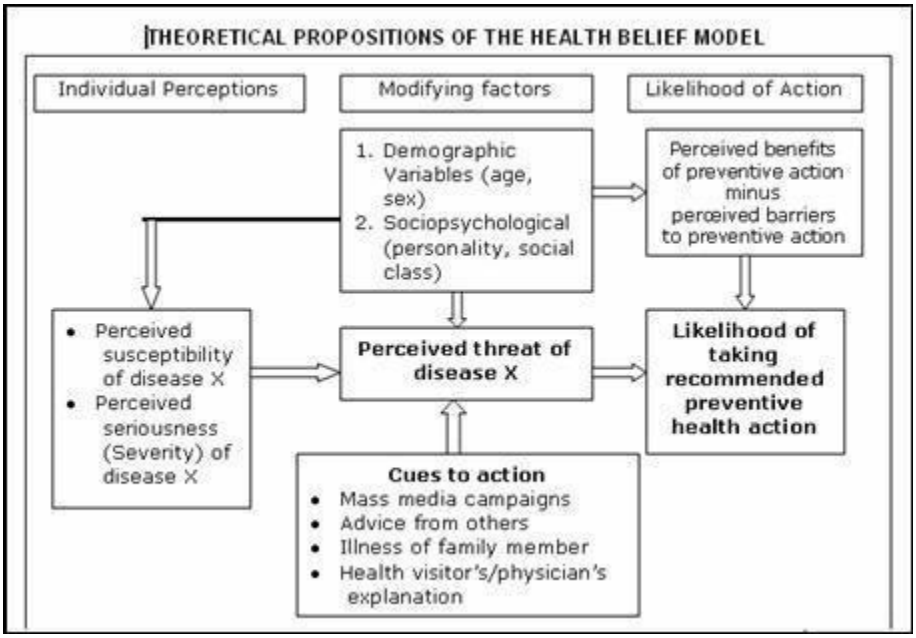
The theoretical framework used to guide this study was the HBM devised by Hochbaum, Rosenstock, and Kegels in 1952 while conducting research for the U.S. Public Health Service. According to Hayden (2019), the HBM is a psychological health behavior change model developed to explain and predict health-related behaviors. More precisely, the model proposes that people's beliefs about health problems, perceived benefits of actions, barriers to action, and self-efficacy explain engagement (or lack of engagement) in health-promoting behavior (see Figure 1 and Table 3). The HBM model comprises six constructs: (a) perceived susceptibility, (b) severity, (c) benefits, (d) barriers, (e) cues to action, and (f) self-efficacy. The HBM was used better to understand the limitations of people's understanding of SC and overcome the transitional barriers and perceptions that African American adults living with SC experience.

Previous researchers (Matthie et al., 2016; Speller-Brown et al., 2015) have suggested that when SC patients transition from pediatric to adult HCPs, they face many challenges. According to Matthie et al. (2016), limited studies have been conducted to assess adults' perceptions of living with SC. The HBM has been used in multiple studies (Glanz et al., 2010). The HBM focuses on people's thoughts, actions, and decision-making processes about health-related issues or concerns they are experiencing, leading to action (Herrmann et al., 2018). The premise of the HBM is that African Americans living with SC may take action if they believe that seeking medical treatment from adult HCPs would afford them a better QOL. Additionally, if African Americans living with

SC believe that medical recommendations extend their life beyond adulthood, they may take action (Herrmann et al., 2018).

Figure 1

Theoretical Propositions of the Health Belief Model



Source: Odeoemelam, C.C. & Ebeze, U. V. (2015). Patterns of Exposure to Communication Interventions on Obstetric Fistula among Men in Ebonyi State, Nigeria. *New Media and Mass Communication, 33*, 49–60.

Table 3

Constructs of the Health Belief Model

Construct	Definition	Context for this study
Perceived susceptibility	The point at which a person feels they are at risk of a health problem	The point at which an African American adult living with sickle cell anemia believes they are at risk of experiencing problems after transitioning to adult healthcare providers
Perceived severity	The point at which a person believes the consequences of the health problem could be severe	The degree to which an adult believes the consequences of non-adherence, poor knowledge, could be severe and death
Perceived benefits	The point at which a person believes that adhering could benefit	The point at which an adult believes that adherence and increase in knowledge could benefit
Perceived barriers	The point at which a person believes a negative outcome would result from the action	The point at which a patient believes they would obtain a negative reaction based on the action they take
Cues to action	The point at which an external event motivates a person to act	The point at which a patient decides to make an informed decision to obtain better quality of life
Self-efficacy	The point at which a person believes in their ability to take action	The point at which a person develops the knowledge to deal with their own medical care

The HBM, as defined by Janz and Becker (1984) after several decades of application, helps to understand resistance to change. Hochbaum (1958) worked collaboratively with the National Tuberculosis Association, the Tuberculosis Program, the Public Health Education Services, and the U.S. Department of Health Education and Welfare to develop the HBM. This model provides a better understanding of why adolescents do not maintain continuity of care as they transition from adolescent to adult-centered care. HBM helped to facilitate and generalize the findings in this study; as noted several decades (57 years) that assumptions cannot be used in this study (Hochbaum,

1958; Hochbaum et al., 1952). Moreover, while some studies have recognized that multiple problems exist in the transitional stages of adults living with SC, there is currently limited information available to address the issues related to SC patients transitioning from pediatric to adult HCPs. Some variables that may influence the theory are demographics (age, ethnicity, gender), SES being a common concern identified, and finding HCPs and receiving adequate medical treatment. The HBM constructs were used to guide and make sense of the factors influencing the transitional care-seeking behavior of African Americans diagnosed with SC residing in the rural Mississippi Delta through their lived experiences.

Perceived Severity

This construct was designed to address individuals' perceptions of the severity of contracting SC and seeking or not seeking medical treatment. The perceived severity, perception, and an individual's feelings vary from person to person because of their perceptions of how SC would affect them if diagnosed or if they could be diagnosed with the disease. Dempster et al. (2017) found that when patients become noncompliant, significant medical problems can occur and lead to increased morbidity, mortality, decreased QOL, and excessive medical expenditures. While studies have been conducted to understand adherence to medical treatment, only select components of the model have been applied to the pediatric population (Dempster et al., 2017).

Perceived Benefits

During the perceived benefit stage, a person may accept that they are vulnerable to being diagnosed with SC, but this does not determine what plan of action is used by

the individual to seek medical treatment. Individual beliefs and perceptions on how SC could impact their lives (negatively or positively) determine if they would accept the medical recommendation from the HCP (Dempster et al., 2017). Furthermore, a person living with a chronic illnesses must determine if the information provided by the HCP will decrease the number of other health related medical complications and enhance their QOL (Herrmann et al., 2018)

Perceived Barriers

This component or construct focuses on whether an individual feels the medical recommendation would enhance their QOL etc. If they ignore medical recommendation, the outcome would be the same. According to Dempster et al. (2017), people react if they feel the disease could become worse or interfere with their QOL in some form or capacity; additionally, if an individual feels the health behavior would be beneficial compared to the treatment barrier.

Cues to Action

Cues of action are the techniques used to aid individuals in becoming knowledgeable of what SC is and how it can impact people's lives through mass media (TV, internet, brochures, pamphlets), group sessions, healthcare providers, and families. According to Rosenstock (1974), external and internal forces, such as phone reminders (text messages or phone calls), are used to remind patients to take their medication or keep a medical appointment and serve as a cue to engage in a specific behavior. Even though an individual knows a disease is life-threatening, if the alternative measure is not

perceived as helpful or seems to be at great risk, the individual is less likely to adhere to the recommended medical treatment (Dempster et al., 2017).

Self-Efficacy

This component or construct focuses on an individual's ability to face difficult times, make informed decisions, and formulate a plan of action to obtain a positive outcome. Therefore, individuals who accept responsibility for their own health outcomes are most likely to implement a behavior change and would enhance their self-efficacy. Self-efficacy is viewed as a mediating factor between perceptions of benefits vs barriers and the act of patient actively engaging in the decision-making process of their health (Tshuma et al., 2017).

Literature Review

According to Rendo et al. (2019), adult SC patients experience lengthy delays in receiving medical treatment at emergency rooms (ERs), which causes them to delay seeking medical treatment and presents other medical barriers (Rendo et al., 2019). Some of the barriers identified by patients are feeling out of place; distrust in medical providers; lack of specialty HCPs; abandonment; lack of insurance; and medical staff lack of knowledge, openness, or willingness to listen to the patient, making going to the ER the last resort as compared to children receiving health care in the pediatric ward. Therefore, these barriers compromise this population's healthcare needs (Machado et al., 2016; Rendo et al., 2019; Travis et al., 2020).

Children living with SC had life expectancies of 14 in the 1970s, but today, they are living into their 40s and 50s—although they face many healthcare challenges. Among

children living with SC, 93% survive into adulthood and lack disease knowledge to successfully transition and become independent or responsible in making informed decisions about their medical needs (Saulsberry et al., 2019; Speller-Brown et al., 2019). During the transitional phase, adolescents and adults experience an increased number of hospitalizations, morbidity, and mortality, causing the life expectancy to decrease to 20 years lower than an adult living without SC (Calhoun et al., 2018; Travis et al., 2021). Suboptimal transitional care available for the identified population leads to poor health outcomes, disease progression, and health deterioration (Viola et al., 2021). Programs were implemented for children living with cystic fibrosis in 2015 to address the medical needs of this population to ensure a better QOL (Speller-Brown et al., 2019).

According to Sergeant (2010), four cases of SC were identified in the early 1900s. In 1910, Dr. Herrick documented the first known case of SC, and the first documented case was a 21-year-old man from the Caribbean Island of Grenada. The man was hospitalized, and his diagnosis today would be acute chest syndrome, which is one of the most serious complications a patient diagnosed with SC can encounter. This complication causes chest pain and fever due to lung infections caused by sickling blood cells that block the blood flow in the lungs (Mayo Clinic, 2020). The term *sickle cell anemia* (SCA) was coined in 1922, and because of the medical documentation, the disease was indicated as African in origin—a misconception. The erroneous error led medical providers to perceive that the disease only affected this populace.

Thirty years after the first cases were identified, after extensive research, Dr. Diggs (1933), a medical provider and researcher in Memphis, Tennessee, proposed two

forms of SCA, active and latent. The active form of SCA was identified in individuals encountering multiple systems and continuous pain, whereas the latent form of SC remains hidden or laid dormant. In 1949, Beet, a colonial medical officer, and Neel, a geneticist, confirmed that SCA is an inherited heterozygous and homozygous disease (Serjeant, 2010).

In this chapter, I examine transitional factors to understand better the care-seeking behaviors of African American adults diagnosed with SCA in the rural Mississippi Delta. Also, I examine how socioeconomic factors influence the transitional care-seeking behaviors of African American adults and further explore how knowledge and personal factors influence the transition care-seeking behaviors of African American adults diagnosed with SC in the rural Mississippi Delta.

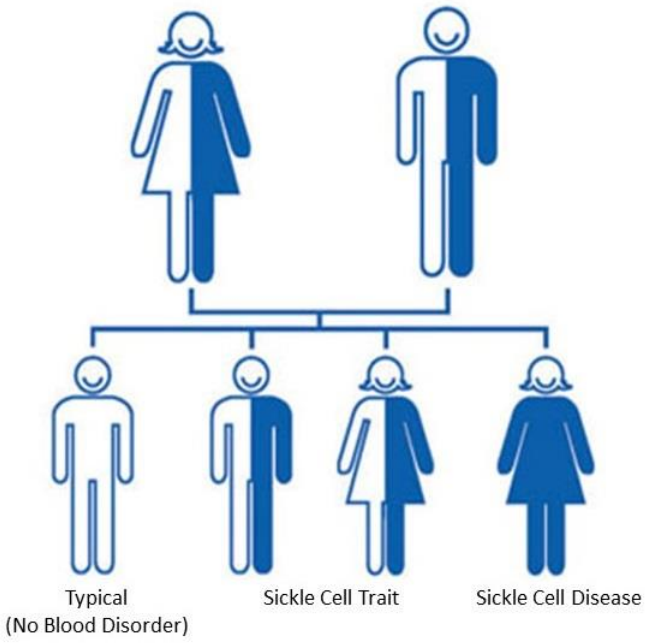
Etiology of Sickle Cell

SC is an inherited genetic disease of African descent and affects more than 100,000 people in the United States (Lanzkron et al., 2019). Lanzkron et al. (2018) stated that 60%-70% of people live with the most severe form of the disease (sickle cell anemia or Hemoglobin SS (HBSS). SC has been declared a world health problem, and the African American population is affected in the United States (Shet & Thein, 2019). This genetic disease is a group of inherited red blood cell disorders that affects hemoglobin (NHLBI, 2020). According to NHLBI (2020), hemoglobin is the protein that carries oxygen throughout the body. When these cells become crescent or sickled shape, the cells begin to develop a blockage in the veins preventing the blood from flowing throughout the body, which causes individuals living with SC to have serious medical complications

(strokes, vision impediments, infections, necrosis, excruciating pain, organ damage, and are at a greater risk of contracting COVID-19) (NHLBI, 2020; Mayo Clinic, 2021). There is a scarcity of information on the natural history of SC in areas with a high prevalence. However, the natural history of SC in the United States can be found in several institutions that conduct neonatal screenings (Kato et al., 2018). According to Kato et al. (2018), over the past twenty years, 40,000 of the 76,000 babies born have been diagnosed with SC. In the United States, 1.1 million babies are born with the SC trait (Kato et al., 2018). According to CDC (2020), SCT is inherited when an infant receives a normal gene (A) and a sickle defected gene (S) from each parent. When both parents have the SCT gene, a child has a 50% (1 in 2) chance of a child inheriting SCT and not experiencing any symptoms of SC, but the child or children can pass the SCT gene to their children. When both parents have the SCT gene, the child has 25% (1 in 4) chances of any child having the disease and 25% (1 in 4) chance of the child not having SC or SCT (CDC, 2020; NHLBI, 2020) (See Figure 2).

Figure 2

Sickle Cell Trait



Source: National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention. (2020) Retrieved from https://www.cdc.gov/ncbddd/sicklecell/traits.html

Kato et al. (2018) stated that the occurrence of SC varies from state to state because of race and ethnicity, and 1 in 360 African American newborn babies are diagnosed with SC. By 2050, the demographic projection of SC babies is estimated to exceed 400,000 per year worldwide (Kato et al., 2018). According to Cesar et al. (2019), SC migrated into the American continent between 1492 and 1870 through the slave trade. Approximately 11,000,000 Saharan Africans transitioned to America as enslaved people.

The presence of the heterozygotes SC mutation of 2% has risen among blacks to 6-10% in Brazil, estimating that 700-1,000 birth annually, even though Brazil has a high degree of different ethnic backgrounds (European, African, and Amerindian (American Indians) as compared to other regions of Brazil. There is a higher prevalence of HbSS heterozygotes in the north and northeast regions and 2-3% in Brazil's south and southeast regions (Cesar et al., 2019; Kato et al., 2018). SC is a mutation in the hemoglobin beta (Hβ) gene, and to be diagnosed with this severe form of HbSS (sickle cell anemia), a person must inherit the βS gene from both parents (Ware et al., 2017). In Africa, SC is viewed as a life-threatening hematological disorder. In many tribal cultures, it is identified by many names (chwechweechwe, ahututuo, nuidudui, kibeka, malaria ya mifupa ina paska), which reflect patients' pains and cries (Ware et al., 2017).

The purpose of hemoglobin is to transport oxygen from the lungs to other body parts. Normal red blood cells' hemoglobin A is round and smooth. When the blood becomes abnormal and begins to sickle, the hemoglobin S molecules occur, forming long rod-like structures that stick together, which causes the cells to pile up and block the blood flow from traveling up or down vital organs and tissue (lung tissue damage causes acute chest syndrome, pain episodes, strokes, and priapism (prolonged, painful erections). SC also causes damage to the spleen, kidneys, and liver (NHLBI, 2020). According to the MSDH (2019), SC affects one in every 500 African American births in the United States. Every baby born in Mississippi is screened for SCT and the disease, and babies diagnosed with the disease are referred to a medical specialist to develop a medical plan (MSDH, 2019). SC is a lifelong disease, and BMT and SCT is currently the only cure for

SC. These medical treatments are only provided to patients with severe SC and little organ damage (CDC, 2020; NHLBI, 2020; Ware et al., 2017).

According to the NHLBI (2020), SC prevalence is high among the African American population, and one in 12 are SCT. SCT carriers do not have the disease, and the disease is caused by mutation. The mother and father must be a carrier of the SC gene for a child to have the defective gene, and if a child receives the SC gene from one parent, the child is only a SCT carrier. People with one normal hemoglobin gene and one defective form of the gene can make both normal hemoglobin and SC hemoglobin. Even though their blood contains some SCs, they normally do not experience any symptoms. However, these carriers can pass the gene to their children (NHLBI, 2020).

Challenges to Sickle Cell Transition

The Association of Pediatric Hematology/Oncology Nurses (APHON) and the American Society of Pediatric Hematology/Oncology (ASPHO), in a study conducted by Travis et al. (2021), further noted that despite the medical improvements this identified population experienced other health-related barriers such as neurocognitive deficiencies and increased morbidity and mortality (Travis et al., 2021). The transitional period is viewed as a critical time frame for SC patients with poorer health outcomes because of the medical complexities of the disease, like pain, pulmonary disease, infection, and high emergency department dependence (Travis et al., 2021).

Due to the vast improvements in health care over the past three decades, children diagnosed with SC now survive into adulthood; and the disease has evolved into a chronic and debilitating disorder as patients age (Compas et al., 2017; Howard & Thien,

2019; Thien et al., 2017; Treadwell et al., 2020). According to DiMartino et al. (2018), 60% of individuals living with SCD in the United States are adults. Researchers noted that individuals feel treated differently compared to other patients living with a chronic illness. Additionally, patients believed that HCPs' knowledge level was limited, they did receive medical treatment in a timely manner, transportation barriers (not owning a vehicle, transportation cost, access to public transportation), insurance criteria (such as limited choices of health care providers, location, and services (DiMartino et al., 2018; Oyedeji & Strouse, 2020; Renedo et al., 2019; Treadwell et al., 2020). Therefore, managing adult patients during the transition from pediatric care is crucial for older adults to decrease the lifetime impact of SC. In some ways, SC can be considered an accelerated aging process (Howard & Thein, 2019). For example, renal end-organ damage (e.g., end-stage renal failure (ESRF), neurological impairment, and chronic cardiorespiratory disease) are illnesses that manifest in SC patient's decades or so earlier compared to people without SC. The transition from pediatric to adult care is a vulnerable time, and patients are at a greater risk of not maintaining continuity of care (Hoegy et al., 2020). Patients subsequently experience a higher ratio of morbidity and mortality because they are learning how to manage their personal and medical experiences. Furthermore, patients living with SC face multiple challenges that result in poor health outcomes (Hoegy et al., 2020). These gaps increase disease burden and higher healthcare expenditures (DiMartino et al., 2018).

Pediatric Health Care

Porter et al. (2017) stated that child-centered healthcare settings differ from adults. African Americans described the pediatric setting as caring, nurturing, and a place where the healthcare provides baby patients and ensures their medicine is received. Whereas adult-centered services are limited, patients wait until the last resort to seek medical treatment. Some of the negative experiences SC patients encounter are having to wait long periods of time to receive medical treatment, basic care not being met, non-specialist HCPs may lack knowledge about SC, and patients may feel like they are not being heard (Renedo et al., 2019).

Additionally, SC patients may feel lost in the adult healthcare system (Zhou et al., 2016) and endure many life disruptions (Machado et al., 2016). All SC patients do not have insurance and are not knowledgeable of the available services provided by insurance companies. Finally, the negative experiences patients may encounter include stigmatization and being viewed as drug seekers (Matthie et al., 2018), which causes poor health outcomes and other health-related problems (Matthie et al., 2018; Zhou et al., 2016). According to Lanzkron et al. (2018), there is a need to develop an adult-specialized healthcare delivery system to address the growing population of adults living with severe, chronic childhood-onset health conditions. Even though medical milestones have occurred, gaps still exist in healthcare of individuals living with SC and other chronic illnesses compared to their peers (Lanzkron. Et al., 2018). SC affects every aspect of people's daily life. Compas et al. (2017) stated that over four million children in

the United States suffer from chronic health conditions (cancer, sickle cell disease, and diabetes).

Educational Barriers

SC affects every child or person differently because of various factors (changes in temperature, oxygen levels, stress, infections, and medication). Based on SC's complexities, some individuals must take medication and may have neurocognitive deficits and frequent hospitalizations, medical appointments, and miss excessive days out of school. As a result, this population's academic performance is affected by adults living with SC experience educational barriers which impede their ability to obtain gainful employment (Olatunya et al., 2018; Harris et al., 2019). Harris et al. (2019) further noted that 11% of children diagnosed with SC experience an overt stroke by the age of 20, causing neurological damage, and almost 40% experience a silent stroke by age 18. Silent strokes have no physical findings correlating with brain lesion(s). However, silent strokes result in significant cognitive deficits and are thus particularly relevant to academic outcomes for youth living with SC (Estcourt et al., 2020). Even though the effects of silent strokes are not readily apparent upon examination, the deficits of silent strokes are not visible to teachers or peers. Therefore, SC is viewed as an invisible disability that reduces this populace's academic achievement and ability to gain and maintain gainful employment (Harris et al., 2019; Mennito et al., 2014).

Quality of Life of Adults Living With Sickle Cell

SC is a chronic condition with debilitating effects and disproportionately impacts the QOL of adolescents and adults, particularly those in or near poverty. This

population's demographic, educational, and community understanding must correlate with the disease to develop effective interventions for adult living with SC (Harris et al., 2019). Porter et al. (2017) described adult SC treatment as cutthroat, a place with more rules to follow, and the HCPs were not performing handholding compared to pediatric care. Only some adult providers are available with expertise and interest in SC management. There needs to be more literature examining interventions that teach transition skills; most research has focused on assessing disease knowledge and perceptions of skills and self-efficacy (Porter et al., 2017). Future research is needed to assess skill attainment, such as scheduling an appointment or refilling a prescription (Porter et al., 2017).

Leger et al. (2018) stated that SC interferes with the daily QOL of individuals with this disease. Patients experience multiple issues due to the invisibility of SC; SC affects their personal relationships, access to healthcare services, and self-efficacy. Leger et al. (2018) noted that adults living with SC experience poorer health related QOL than adults living with other chronic illnesses. Adults living with SC experience poor QOL, inadequate coping skills, and poor self-management skills and continue to foster sporadic care, which leads to poor health consequences. Leger et al. (2018) explained that health disparities exist when early detection of organ damage is not identified, and childhood disabling conditions can lead to cognitive impediments. These health disparities persist in low or middle-income countries where they do not have access to quality health care (Leger et al., 2018). Patients tend to delay seeking medical attention until the pain is unbearable because of past negative medical experiences (Kanter et al., 2020; Rendo et

al., 2019). Patients are often viewed as drug seekers, addicts, frequent flyers, deprived of access to proper dosage of pain medication because of frequent ER visits, therefore, interfering with the patient receiving correct triage and pain management (Elahi et al., 2017; Estcourt et al., 2020; Evensen et al., 2016). When patients do not receive proper medical treatment, it causes them to be readmitted to the hospital and increases the disease burden (Leger et al., 2018). Approximately 60,000 patients diagnosed with SC are hospitalized annually, and 90% are admitted for acute chest pain treatment (Cronin et al., 2019).

According to Leger et al. (2018), stigma among adults living with SC has a wide range of behavioral effects, such as psychological stress, depression, fear, delay in diagnosis, and suboptimal treatment alignment compared to other adults living with a chronic disease. Additionally, these stigmas interfere with health behavior and medical outcomes is one of the negative experiences individuals encounter when seeking medical treatment at the ER, which limits their independence and increases isolation. Leger et al. (2018) identified other healthcare disparities, such as cultural differences, socioeconomic status, education, environmental exposure, stigma, social marginalization, discrimination, and stress (Leger et al., 2018; Olatunya et al., 2018). Olatunya et al. (2018) further noted that 88% of the children diagnosed with SC experienced high pain intensity and delayed pain medication compared to children with long-bone fractures.

Sub-Saharan Africa has the most significant burden, and 75% (300,000) of babies diagnosed with SC 50-80% globally die before adulthood. The researchers further noted that the highest burden of SC in the world was in Nigeria, and the disease had a bearing

on the QOL of this populace (Olatunya et al. 2018). Little is known about the outcomes of older adults living with SC (Howard & Thein, 2019). According to Slightam et al. (2018), in the United States, one in four Americans dominate the primary care practices and approximately 70 % live with multiple chronic conditions (MCCs) are Medicare recipients and require special healthcare needs. Slightam et al. (2018) explained that when patients and HCPs disagree with medical treatment, it interferes with the patient's compliance. Patients in this qualitative study identified that pain impacted their lives because it impeded their ability to do things they wanted or needed, such as mobility, maintaining gainful employment, and daily QOL activities (Slightam et al., 2018). In the article by Leger et al. (2018), *stigma* is defined by Goffman (1963) as a mark of shame, disgrace, disease, or abnormality.

Socioeconomic Factors

According to the National Unemployment Rate (2002-2010), many adults living with SC struggle with obtaining and maintaining gainful employment compared to individuals not living with SC. The unemployment rate of adults living with SC ranges from 28-52%. Medical complications impact the livelihood of people living with SC, interfere with their ability to work, and add to the economic burden of managing their lifelong illness. adults who had four or more vaso-occlusive episodes (VOES) in a twelve-month period decreased work attendance and performance. These patients experience other negative impacts, such as social functioning, sleep, and pain.

Continuity of Care and Racial Bias

According to Hoegy et al. (2020), globally, during the pediatric and adult transition, patients live beyond age 18 and fail to maintain continuity of care (keeping medical appointments and adhering to medication). Therefore, patients tend to seek medical care in the ER and endure multiple hospitalization admissions, which causes them to receive suboptimal healthcare and increases the morbidity and mortality rate among this populace (Crosby et al., 2015; Hoegy et al., 2020; Hsu et al., 2016).

Hospital Utilization

Meier and Rampersad (2016) stated that the transitional period for adolescents and adults is a fragmented and abrupt time for SC patients, and there is increased usage of the ER, hospital admissions, readmissions, and mortality despite the medical enhancements (Meier & Rampersad, 2016; Porter et al., 2017). Adult SC patients experience more hospital admissions and readmissions during the transition from pediatric to adult healthcare providers than any other timeframe of their lifespan (Cronin et al., 2019). Approximately two thirds of the SC populations on Medicaid have a higher hospitalization rate than patients with private insurance. Additionally, patients in low socioeconomic communities experience a higher rate of hospital readmissions because of other health-related medical comorbidities, including asthma, pain, and other SC complications (Cronin et al., 2019).

Summary

Today, there is an emerging group of adolescents living with special healthcare needs transitioning to adulthood. Despite the major medical achievements, SC is still a

global burden and inadequately addressed. The life span for adults living with SC has not improved beyond the fifth decade (Ware et al., 2017). There needs to be more information regarding transition outcomes, partly due to a lack of communication between pediatric and adult HCPs of patients living with SC (Travis et al., 2021). There appears to be a paucity of literature examining interventions that teach transition skills; most research has focused on assessing disease knowledge and perceptions of skills and self-efficacy. Future research should develop interventions to assess skill attainments, such as scheduling appointments or refilling prescriptions (Porter et al., 2017).

Given that SC is a disease that affects people of specific races, implicit bias may play a role in the QOL of this population (Clayton-Jones et al., 2021). People living with SC should not receive, nor should they expect to receive, a lower standard of care than the general population for any reason, including but not limited to their race, age, or gender. However, implicit associations—whether unconscious or conscious—can influence treatment decisions, resulting in implicit bias (Clayton-Jones et al., 2021).

African Americans, as well as other racial and ethnic minorities, are known to receive poorer healthcare and are less likely to receive routine medical care as compared to White Americans and others living with special healthcare needs (Lee et al., 2019). In the United States, patients that are diagnosed with cystic fibrosis and hemophilia are fewer in number when compared with SC patients. cystic fibrosis and hemophilia patients have access to more than 130 comprehensive treatment centers nationwide. These multidisciplinary healthcare teams are dedicated to improving health outcomes, providing quality care, and reducing costs and healthcare disparities (Lee et al., 2019). Therefore,

increasing healthcare disparity is due to the increased survival of patients with severe childhood-onset diseases. More studies of effective transition practices are essential as the survival rate increases among individuals diagnosed with severe childhood diseases (Connolly et al., 2019).

Chapter 3: Research Method

Introduction

This qualitative study was conducted to examine the factors that influence the decision-making process of African American adults diagnosed with SC regarding maintaining continuity care as they transition from adolescence to adulthood. This study has a geographical focus exclusive to the Mississippi Delta as many Delta residents must travel long distances to access specialized care (Cronin et al., 2018; RHIhub, 2021). This chapter includes the research design and rationale, research questions, role of the researcher, methodology, participant criteria, recruitment strategy, and data collection instrument. The findings of this study may increase the limited body of research regarding African Americans living with SC.

Research Design and Rationale

This study used a qualitative methodology to explore the lived experiences of African Americans who transitioned from pediatrics to adult care. The participants were from rural Mississippi Delta counties. I used the phenomenological approach to understand better the lived experiences of adults living with SC. According to Alase (2017), the interpretative phenomenological analysis approach can allow a researcher to bond a relationship with participants (interviewees) and allow them to express their thoughts and lived experiences freely. According to Alase (2017), qualitative researchers aim to explore participants' lived experiences. Alase (2017) and Smith et al. (2009) stated that interpretative phenomenological analysis has a dual position role. The role of the researcher makes them appear like a participant. The researcher is human, just like the

participant drawing on everyday resources to better understand the world. Second, the researcher is not the participant; they only have access to the participant's experience through what the participant shares about their experience and is also seeing this through the researcher's experimental lens (Alase, 2017).

The rationale for using the phenomenological approach was that the qualitative method would allow me to conduct my study in its natural environment and collect data specific to each participant. Additionally, the phenomenological approach allows researchers to inquire about and interpret the daily ethical concerns of people with disabilities (Alase, 2017; Poku et al., 2021). Vasileiou et al. (2018) contended that qualitative researchers conducting structured and semi-structured interviews in the health sciences are able to justify the sample size because it provides relevant information about a specific phenomenon being explored. Finally, the qualitative research method allowed me to answer the who, what, and why of the lived experiences of adults living with SC (see Busetto et al., 2020).

Role of the Researcher

According to Knox and Burkard (2009), qualitative research studies enable researchers to gather information regarding the phenomenon being explored. Additionally, qualitative research allows researchers to access participants' thoughts and feelings about their lived experiences. Qualitative research provides opportunities for a researcher and participant to build trustworthy relationships and feel comfortable sharing their experiences (Raheim et al., 2016). According to Raheim et al. (2016), the role of a researcher is to conduct a relevant literature review of articles and books published within

the last 5 years and other foundation material related to the study. Additionally, my role as a researcher was to ensure that each participant received due diligence (no harm) during an interview process (see Raheim et al., 2016). Finally, I had a personal and professional relationship with a participant in the study. However, as a researcher, I must ensure that ethical procedures are met for each participant to alleviate research bias (see Raheim et al., 2016).

Research Questions

RQ1: Do the perceived susceptibility and severity of African American adults diagnosed with SC in the rural Mississippi Delta influence transitional care-seeking behaviors?

RQ2: Do the perceived benefits versus barriers, sensed threats, cues to action, and self-efficacy influence transitional care-seeking behaviors of African American adults diagnosed with SC in the rural Mississippi Delta?

Methodology

The identified population for this study was African Americans living in the rural Mississippi Delta between ages 18 and 61. Clark and Braum (as cited in Vasileiou et al., 2018), stated that in prior studies, 12 is the medium recommended number to conduct a qualitative study. Lincoln and Guba (as cited in Vasileiou et al., 2018) suggested that the criterion of informational redundancy guides sample size determination. Informational redundancy is reached when no new information can be obtained from participants (Vasileiou et al., 2018). Malterud et al. (2016) introduced the concept of *information power* as a pragmatic guiding principle that suggests that the more information power the

sample provides, the smaller the sample size needs to be, and vice versa. For this study, I recruited 20 participants to ensure I could obtain the information needed to answer the questions for this study.

Participant Criteria

Participants must have met the following criteria to participate in this study. The participant must be an African American male or female diagnosed with SC by an healthcare professional, must be age 18–61, must live in the rural Mississippi Delta, must be able to read or write at least on a sixth-grade level, must not have a cognitive disability that would interfere with their comprehension, must be English speaking, and must comprehend and sign an informed consent.

Recruitment Strategy

Participants were recruited from local HCPs and the Hematology Clinics in Jackson and Southaven, Mississippi, with the assistance of healthcare provider or staff to ensure that the participant has a documented diagnosis. The suggested number of participants should be 12-15, according to Clark and Braun (2013), Fugard and Potts (2014), and Guest et al. (2006). The study's goal was to recruit 20 participants, but if anyone chooses not to participate for any unforeseen reason, 15 participants would be sufficient. In the article by Vasileiou et al. (2018), twelve is the basic number needed to obtain saturation. I proposed twenty because of the uncertainty of SC and in case a participant changes their mind or no longer wants to participate in the study (Vasileiou et al., 2018). I applied to Walden University Institutional Review Board (IRB) to obtain approval to conduct the study and work with human subjects. Upon receiving approval

from IRB, I sought permission from HCPs to post flyers with my contact number and information about the study. Additionally, I sought permission from HCPs to set up a private space in their office to recruit participants, schedule appointments, conduct interviews, and collect data for the study. Finally, when interested individuals contacted me, I scheduled an appointment to discuss the study, answer any questions or concerns, and obtain signed informed consent for participants to participate. Secondly, due to the resurgence of the Sars-CoV-2 virus that causes COVID-19, I used the telephone to answer any questions or concerns about the study and to obtain verbal consent from interested participants who may not have access to the internet. Additionally, each participant was assigned a code to protect their identity. Finally, I used free conferencing programs, including Zoom or Skype, for identified participants to gather data for this study. The above-stated methods ensured the safety of the participants and me, as well as maintaining the identity and privacy of each participant and ensuring due diligence of each participant as ethnically required by the IRB.

Data Collection Instrument

I provided each participant with an approved consent form and demographic profile form and asked them if they had any questions or concerns. The informed consent form stated the purpose and method of the study, confidentiality procedures, the risk and benefits, and the participant's right to withdraw from the study at any time. I obtained a signature and date on every consent form from each participant before beginning an interview. The interview questions were based on the two research questions. I worked

with my chair and methodologist to develop or identify interview questions pertinent to my study.

Summary

This study used a qualitative methodology with a phenomenological approach to explore the lived experiences of African Americans aged 18 and 61 who transitioned from pediatrics to adult healthcare. The participants were from 22 identified counties in Mississippi and the Hematology Clinics in Jackson, Mississippi, and Southaven, Mississippi, and local health care facilities in the rural Mississippi Delta (Attala et al.). The study explored two research questions. Upon receiving approval from IRB, I started recruiting and scheduling appointments at healthcare facilities to seek participants and begin collecting data for the study. In Chapter 4, I presented my data and findings in Chapter 5.

Chapter 4: Results

Introduction

This qualitative study was conducted to examine the factors influencing the decision-making process of African Americans diagnosed with SC in regard to maintaining continuity care as they transition from adolescence to adulthood. This study had a geographical focus exclusive to the Mississippi Delta, as many Delta residents must travel long distances to access specialized care (Cronin et al., 2018; RHIhub, 2021). The findings of this study may increase the limited body of research regarding African Americans living with SC. This study can solidify or explore participants' QOL, such as attending school, working, and their inability to gain and maintain gainful employment.

Data were collected for this study through semi-structured interviews that focused on participants' lived experiences. The subtopics included in this chapter are demographics, data collection, data analysis, education level, employment status, gender, questions, purpose, setting, SES, results, and trustworthiness of data, the process of collecting, managing data, storing and data protection through reliability, confirmability, transferability, and credibility. The chapter will conclude with a summary of findings. Finally, this chapter includes identifying, coding, and categorizing keywords and themes.

Research Questions

RQ1: Do the perceived susceptibility and severity of African American adults diagnosed with SC in the rural Mississippi Delta influence transitional care-seeking behaviors?

RQ2: Do the perceived benefits versus barriers, sense threats, cues to action, and self-efficacy influence the transitional care-seeking behaviors of African American adults diagnosed with sickle cell anemia in the rural Mississippi Delta?

Setting

After receiving approval from Walden University's IRB, I contacted participants primarily via email, phone calls, and text messages, and collected data via Zoom meetings to ensure I complied with COVID-19 guidelines. I used semi-structured interview techniques to obtain additional data from participants as needed. Due to COVID-19, the semi-structured interviews were conducted online; I was at my residence and participants were in the comfort of their home, except for participants without internet access. Before the interview, I assured participants their information would be kept private, and that any information shared would only be used for the study as discussed and indicated on the informed consent form. Participants were also informed that none of their identifiable information would be used in the study and that all data obtained would remain in a locked file cabinet in my home office for 5 years.

Based on information from the CDC and the MSDH, I conducted the semi-structured interviews according to the study guidelines and protocol in Chapter 3. For the participants that did not have access to the internet, I met them in their homes in an area the participant identified for privacy. The participant and I wore masks and sat across the room from each other, allowing us to maintain clear and precise communication. For participants who expressed an interest in the study but did not have internet access and did not wish to meet in person, I conducted telephone interviews. A code was assigned to

ensure each participant's identity and the information provided were protected. Also, to protect myself as the researcher, I guaranteed the due diligence of each participant as required by IRB. Finally, Zoom meetings were scheduled for participants with internet access, and informed consent forms and data profile sheets were emailed to participants for review. Before starting all scheduled interviews, participants were asked if they had any questions or concerns about the study.

Demographics

The participants in this study were African American adults living with SC in counties in the rural Mississippi Delta. A recruitment flier and consent form were posted on social media platforms (e.g., Facebook and LinkedIn), local businesses' bulletin boards, public facilities, medical providers' offices, and sickle cell organization Facebook groups. Also, due to COVID-19, I had to rely on participants sharing information about the study with other adults living with SC. All participants were African Americans ages 18–61 and lived with SC in counties in the rural Mississippi Delta. No vulnerable populations were included.

Data Collection

IRB reviewed and approved the study (01-21-22-0234424). Before the interviews, demographic data were captured using a demographic profile sheet completed prior to each interview. I explained to each participant the purpose of the study, including that participation was voluntary, participants have the right to confidentiality and the right to change their mind about participating at any time, and participants would not be treated any differently before expressing an interest in the study. Semi-structured interviews

were used to collect data from January 21, 2022, to January 31, 2023. Some data were collected in each participant's home via Zoom meetings. Participants who chose to participate in the study volunteered and were informed they still had the option to change their minds about participating at any time. Eight of the interviews were conducted face-to-face, three were conducted on Zoom, and four were conducted via telephone. The interviews were recorded on a phone recorder, Zoom meetings, and field notes. The 45-minute interviews were conducted in English . I observed each participant's body and verbal language during the interview and participants' verbal language and tone to determine any distress.

In an article by Vasileiou et al. (2018), Clark and Braum stated that 12 is the medium recommended number to conduct a qualitative study. Additionally, Lincoln and Guba (cited in Vasileiou et al., 2018) suggested that the criterion of information redundancy guides the sample size determination. Informational redundancy is reached when participants cannot provide new information. Data saturation occurred after the 15th participant was interviewed in this study. Therefore, I determined the study did not need additional interviews (see Vasileiou et al., 2018).

Data Analysis

Data analysis began after I completed collecting data from 15 interviews. Data were also collected via observation notes and translated transcripts of participants' lived experiences. Each interview was labeled Participant #1 through Participant #15 to ensure confidentiality during the coding process. The data collected during the face-to-face interviews and documents (informed consent and information profile forms) while in the

field were locked in a secure bag in my car. Additionally, all raw data were stored in my home office file cabinet, and no one could access the study data and codes. Finally, all data information about the study will be discarded by shredding 5 years after study completion. Each participant's responses or data were sorted before being analyzed.

After the write-up, codes were assigned according to the research questions. Codes were assigned to protect participants' privacy to the best of my ability. The participants' names and specific counties were deleted from the coding process. After the initial codes were generated, the coding process began, which involved accessing portions or segments of data from the interviews and linking them to one or more initial codes. Several cycles of coding were used in this study, which included three cycles of coding, and Microsoft Excel was used to code and analyze the data.

I sought approval from IRB to make several changes in the data collection process from my approved proposal. Those changes included seeking permission from IRB to extend the recruitment parameter from five counties to 22, having an interview conducted by the Clarksdale Press Register Newspaper, the Charleston Sun-Sentinel Newspaper, and conducting a live television interview with Woody Wilkins at WABG-Greenwood Greenville Delta News tv station. I submitted a continuing review form to IRB. My prior approved study date was scheduled to expire on January 21, 2023, but I had yet to obtain the required participants for the approved study. IRB extended my study until January 16, 2024; the IRB approval number stayed the same (01-21-22-0234424).

Evidence of Trustworthiness

Credibility

Qualitative studies provide researchers and participants with a platform to develop a relationship where an individual feels comfortable sharing their firsthand experiences with a person they do not know (Raheim et al., 2016). Qualitative researchers must remember that, for the results of their study to be meaningful, they must use a rigorous and methodical approach while collecting qualitative data and while analyzing and interpreting the themes. This approach is vital to ensure the findings of the study are credible, dependable, reliable, transferable, and trustworthy. Qualitative research allows researchers to explain patterns and processes of human behavior that are difficult to quantify (Tenny et al., 2022).

Transferability

Transferability aims to confirm that other researchers examining the same topic could conduct the same methodology and achieve accurate results. I formulated a step-by-step methodological procedure of how the participants were recruited, how the data were collected and analyzed, and the study criteria. Additionally, I described the setting and steps taken to protect the confidentiality of each participant as they shared their lived experiences.

Dependability and Confirmability

Dependability is an in-depth description of the methodology and design that allows a study to be repeated. This ensures the data are valid despite any setting or data

collection changes. Confirmability is the step to ensure the findings are not due to participant or researcher bias.

Results

Semi-structured open-ended questions were used to obtain data from 15 participants to address the following research questions:

RQ1: Do the perceived susceptibility and severity of African American adults diagnosed with SC in the rural Mississippi Delta influence transitional care-seeking behaviors?

RQ2: Do the perceived benefits verses barriers, sensed threats, cues of action, self-efficacy influence transitional care seeking behaviors of African American adults diagnosed with SC in the rural Mississippi Delta?

Eight participants stated they had a local healthcare provider to meet their medical needs. The other seven participants also needed local HCPs and had to travel to receive medical treatment. Many of the participants (1, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15) identified reasons they maintained all scheduled appointments: to ensure (a) they were able to receive prescription refills; (b) medical treatment was not delayed; (c) they would not have to seek another HCP; (d) their health was not deteriorating or they were not experiencing any other health-related issues; (e) distance traveled to receive medical treatment; (f) a better QOL; (g) intravenous (IV) infusion treatment and medication they were taking did not cause any other health-related problems; and (h) they were not experiencing any side effects due to the prescribed medication. Fourteen of the

participants stated the only reason they missed a scheduled appointment was when they were hospitalized.

Participant #2 stated he did not keep all his scheduled appointments because he did not feel good, was in the hospital, or had something else he wanted to do, and they were tired of going to the doctor. Participants 1-15 had insurance, various education levels, and employment status. Three of the participants had insurance through their employers because they worked full-time. Three participants who were gainfully employed still received Medicaid. Overall, 10 of the 15 participants received Medicaid, and two received Medicare (social security disability insurance). Finally, eight participants only completed high school; seven obtained education beyond high school; one obtained an associate of arts degree; and one obtained a master of counseling degree. All participants were single, and six participants were male, and nine participants were female. See Table 5 and Table 6.

Table 4

Demographics and Descriptive Data of Participants

Participants	Age	Gender	Education	Type of insurance	Job status
#1	27	M	Beyond high school	Medicaid	Unemployed
#2	36	M	Beyond high school	United Healthcare, SSDI	Unemployed
#3	61	F	Beyond high school	Blue Cross/Blue Shield	Employed
#4	38	F	High school	Blue Cross/Blue Shield	Employed
#5	32	M	Masters Graduate	Blue Cross/Blue Shield	Unemployed
#6	21	M	High School	Medicare, SSDI	Unemployed
#7	20	F	Beyond high school	Medicaid	Employed
#8	29	F	High school	Medicaid	Employed
#9	30	F	High school	Medicaid	Unemployed
#10	20	F	High school	Medicaid	Unemployed
#11	45	F	High school	Medicaid	Unemployed
#12	41	F	High school	Medicaid	Unemployed
#13	23	M	High school	Medicaid	Unemployed
#14	42	F	High school	Blue Cross/Blue Shield	Employed
#15	38	M	High school	Medicaid	Employed

Table 5

Gender and Age of Participants

Gender	Age
Female = 9 (57%) Male = 6 (43%)	Average Age = 33.53 (SD = 11.25)

Interview Questions

Three participants (3, 4, and 12) had a local doctor to meet their medical needs. The following participants did not have a local doctor to meet their medical needs: 1, 2,

5, 6, 7, 8, 11, and 14. These participants had to drive 3 hours round trip to seek medical treatment and specialty healthcare services. Several participants stated that due to the negative experiences, they only went to the ER as a last resort.

Participant #1 described his negative experience, especially since COVID-19, as long waiting periods, the doctors made him feel like he was being viewed as a junkie or drug seeker. The participant made going to the ER as last resort or only when the crisis had escalated beyond his/her ability to control at home. The things that caused him to refrain from going to the ER were long waiting periods, the travel distance to seek medical treatment and transportation. I feel that "my health is getting worse" because of several other health-related issues, such as my hip joint worsening since pediatrics. I am experiencing more painful episodes (crisis), difficulty breathing (asthma), and depression. Participant #1 stated that some things that make him go to the doctor are colds, dehydration, fever, nausea, prescription refills, and a severe pain crisis. Additionally, things that caused him to refrain from going to the ER were being viewed as a drug seeker by nor receiving treatment in the adequate timeframe.

Participant #2 depicted his experience in the ER as unfavorable because he had to wait long periods before receiving medical treatment. He also noted that he was viewed as a drug seeker during painful crises. Furthermore, it was frustrating that the doctor did not listen to him when he attempted to share what medical treatment worked and what did not work for the participant. Participant #2 stated he refrained from going to the ER because of his previous negative experiences with HCPs, long wait times, and fear of being hospitalized. Therefore, he maintained his health at home until the crisis became

too severe to cope with at home. Participant #2 felt that his health condition was worsening because of multiple severe infections and several surgical procedures (spleen and gallbladder removed, rotator cuff, and hip replacement). He was also wheelchair-impaired and developing iron overload due to chronic transfusions from birth to adulthood. Participant #2 stated he would go to the doctor if his fever were 101°F or higher, he was dehydrated, he needed prescription refills, and whenever the crisis was beyond his control at home.

Participant #5 also stated that he had several negative experiences at the ER. He noted that he experienced long wait times in the ER. Due to having multiple blood transfusions and IV lines, which left a lot of scars and unhealed sores, the healthcare professional stated that he looked like a person with HIV/AIDS. Additionally, the HCP refused to provide medical treatment because the HCP viewed him as a drug seeker. The participant said that after leaving the facility, the hospital called him and asked him to return to the facility for medical services. The participant stated that upon his arrival, the facility had called the police, alluding that he had threatened the HCP. He said he was fortunate the officer on call knew him and did not take him into custody. Afterward, the HCP walked out, and he was not provided with medical services.

Participant #7 stated that her only negative experience at the ER was waiting long periods before receiving medical treatment. Participant #7 rarely goes to the ER because she manages her crisis at home, and the ER is the last resort because of the long waiting period. Participant #7 feels her health is improving because she has fewer doctor visits or hospital visits. She only goes to the doctor because of chest and leg pain, temperature, or

severe headache. There is no reason the participant will not go to the ER to seek medical treatment.

Participant #10 stated that she experienced a long wait time before receiving medical treatment, being viewed as a drug seeker, and the medical staff being rude. The participant does not have an HCP; therefore, the participant does not keep all scheduled appointments. The participant will go to the ER if she can no longer maintain her treatment at home. Additionally, the participant had some negative experiences at the ER, which included long wait times, health care providers being rude, and being viewed as drug seekers. The participant feels her health is worse because of several mobility issues, strokes, and the deterioration of her joints. The participant does not go to the doctor because of a cold, low-grade temperature, mild pain, and the doctor not listening to her.

Participant #11 shared that her ER experiences were horrible and that the medical professionals made her feel she was only seeking pain medication. It made her uncomfortable because the HCPs thought she was there only for drugs or was a crackhead instead of believing she was really in a crisis.

Participant #12 stated that her ER experience was terrible because doctors did not want to see her, were rude, showed little compassion, and was viewed as a drug seeker. She stated that despite her negative ER visits, she would still go there because she had other health-related issues. Participant #12 feels her health worsens due to deteriorating joints, mobility issues, and strokes. Participant #12 does not go to the doctor for a cold, low-grade fever, and mild joint and body pain.

Participant #13 has no local HCP and is wheelchair impaired. Participant #13 keeps all scheduled appointments because he travels a long distance to receive medical treatment. The participant said his ER visits were challenging, having to wait long before receiving medical care. During the interview, I observed the participant's body language, and he appeared to be overwhelmed trying to explain his negative ER experience. I explained to the participant that we could stop if he did not want to proceed any further with the interview.

Participant #13 stated that he wanted to continue; we took a break and did not continue to talk about his ER experience. He said the only reason he would be reluctant about going to the ER would be his past ER experiences.

Participant #14 shared that her ER experience included a long wait time before seeing a doctor. After which, she stated that she was dismissed from the ER and still in pain. Participant #14 feels her medical condition is improving because she is not in and out of the hospital. She does not seek medical care for a cold, low fever, or mild pain. Additionally, this participant worked and missed very few days from work.

Participant #15 has an HCP and keeps all scheduled appointments. He stated the importance of keeping all scheduled appointments because it ensured the doctor could identify any other health-related problems early. Additionally, he shared that his experience at the ER consisted of long wait times and transportation issues to receive medical treatment. Past negative experiences at ER included being stereotyped by doctors and nurses and viewed as a drug seeker. He did not seek medical treatment at the ER if many people were in the ER and the participant felt his health was improving.

Table 6

Key Themes

Key themes	Responses
Kept appointments	To receive prescriptions refills, medical treatment in a timely manner, maintain health, other health related issues, medical adherence
Traveling distance	Limited local healthcare providers that understood SC, limited specialty healthcare providers, lived in rural Mississippi poor communities
Communication	Poor communication with healthcare providers
Missed appointments	Didn't feel good, in the hospital, had other plans, and tired of going to the doctor
Trust	Didn't feel respected or trust healthcare providers, viewed as drug seekers
Utilized ER	Because of pain, fever, could not manage pain at home, infections, dehydration, blood transfusions, long wait time at ER, frustrated

Summary

This qualitative study focuses on the lived experiences of African American adults living with SC in the rural Mississippi Delta. This qualitative study aimed to examine the factors that influence the decision-making process of African American adults diagnosed with SC from maintaining continuity of care as they transition from adolescence to adulthood. This chapter includes the study's introduction, setting, demographics, the analysis results of the data collected from the fifteen participants, the evidence of trustworthiness, results, and summary.

Furthermore, the study identified the problems that African American adults experience when transitioning from adolescent HCPs to adult HCPs, as well as their perceptions and care-seeking behaviors. Finally, Chapter 5 will include the interpretation

of the findings, limitations of the study, recommendations, implications of social change, and conclusion.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

This qualitative study was conducted to examine the factors influencing the decision-making process of African American adults diagnosed with SC in regard to maintaining continuity of care when transitioning from adolescence to adulthood. African American adults living with SC in the rural Mississippi Delta shared their experiences in semi-structured interviews. Collected social and demographic factors included age, education, gender, and SES. In Chapter 2, I identified gaps and provided a platform to explore and understand the care-seeking behavior of African American adults living with SC.

In this study, I employed a phenomenological design to help answer the research questions. According to Neubauer et al. (2019), the phenomenological design is used to describe people's views, beliefs, and interpretations of lived experiences. More specifically, this design is used to describe what individuals have in common as they experience a phenomenon, i.e., a need to move to transitional care when diagnosed with SC (see Neubauer et al., 2019). Furthermore, this study was conducted to reduce individual experiences with a phenomenon to a description of the universal essence. This study drew from the lived experiences of African Americans diagnosed with SC in the rural Mississippi Delta and identified influencing factors impacting their transitional care-seeking behaviors, which aligns with the purpose of phenomenological research design. The key concepts are the beliefs and perceptions of African American adults who reside in the rural Mississippi Delta.

The data were collected from in-depth face-to-face interviews to understand better perceptions, beliefs, cues of action, and self-efficacy related to African American adults living with SC in the Mississippi Delta. Furthermore, this study was conducted to explore participants' QOL, such as attending school and their inability to gain and maintain gainful employment in the Mississippi Delta. Finally, the study drew from the lived experiences of African American adults living with SC to identify multiple factors impeding this population's decision-making process when transitioning to adulthood. This chapter includes an introduction, interpretation of the findings, study limitations, recommendations, implications for positive social change, and a conclusion.

Interpretation of the Findings

Based on the findings in this study, the participants have encountered numerous negative experiences in the ER with HCPs. Negative experiences included long wait times at the ER, traveling long distances to seek medical specialty healthcare treatment, being viewed as a drug seeker, and seeking pain medication. Because of the negative experiences, 40% of the participants stated they delayed seeking treatment and making informed healthcare decisions.

Most participants indicated they keep all medical appointments because they fear being unable to receive medical treatment, prescription refills as needed from their HCPs or identifying another HCP because of missing medical appointments. I found additional factors that further led to the oppression of the participants in this study. For example, 14 participants (93%) were from a lower SES, even though they finished high school. Second, only four participants (26.6%) successfully obtained gainful employment, and

only one participant (6.6%) obtained financial status above the poverty level. Even though participants desire to live independently, most of the study participants could not obtain self-efficacy because of their financial status. However, most participants lived with their families and relied on family support to help meet their personal and medical needs.

Previous research confirmed that older patients with chronic pain face many barriers, such as stigma, discrimination, and increasingly denied medical treatment (Arnstein et al., 2023). These findings are consistent with the views expressed in previous research that individuals living with SC face many barriers and delay seeking medical treatment (Jenerette et al., 2022). Furthermore, Hoffman et al. (2016) stated, "because the majority of the individuals living with SC in the United States were Black and there was a myth that 'Blacks could tolerate pain.'" Jenerette et al. (2022) affirmed that stigma exists when HCPs label, profile, and stereotype individuals living with SC as drug seekers and frequent flyers, and their complaints of pain are not believed.

In this study, nine participants (16.6 %) stated that when they used the ER for medical treatment, they were viewed as drug seekers, experienced a deeper level of stigma and racism, and had to wait more extended periods before receiving medical treatment as compared to their peers living with other genetic disorders. However, the participants who encountered negative experiences at the ER stated they would still seek medical treatment because of the complexity of the disease.

This study's results are consistent with the findings of earlier research studies. Abdallah et al. (2020) studied how SC patients use hospital ERs. In that study, the

researchers identified why patients delay seeking treatment, why they choose to manage their pain at home instead of using the ER, and why they avoid being hospitalized—because they have had previous negative experiences at the ER (Abdallah et al., 2020). In that study, 67% of the participants shared that they delayed going to the ER because of being stigmatized as a drug seeker and waiting excessively to receive medical treatment (Abdallah et al., 2020). Additional research is needed to provide this population with quality healthcare in the ER and other healthcare settings (Abdallah et al., 2020).

This study consisted of 15 semi-structured interviews with African American adults living with SC in the rural Mississippi Delta. The HBM was used to understand better the factors influencing the decision-making process of African Americans living with SC regarding maintaining continuity of care when transitioning from adolescence to adulthood. The first research question in this study was the following:

RQ1: Do the perceived susceptibility and severity of African American adults diagnosed with SC in the rural Mississippi Delta influence transitional care-seeking behaviors?

Participants in this study stated they had horrendous healthcare experiences at the ER. Participants stated their negative experiences included long wait times before receiving medical treatment, being viewed as drug seekers, HCPs not listening to them, and HCPs being rude and not believing the participant was experiencing a pain crisis (Participants 1, 2, 5, 7, 10, 11, 12, 13, 14, and 15). Therefore, a secondary theme was identified as self-care. Participants tried to conduct self-care at home until the pain or

medical complications became unbearable to avoid previous negative experiences at the ER.

Age, Gender, and Decision Making

Participants face significant barriers when making informed decisions about their health and view it as an impediment to accessing quality healthcare services. The discrimination participants experienced in the ER inhibited their ability to make informed decisions about their health. The study findings correlate with existing research that individuals living with SC do not adhere to seeking medical treatment as needed when transitioning from adolescent healthcare settings to adult healthcare systems. Melita et al. (2019) stated that the transitional period is critical for adults living with SC because their health worsens while they try to identify adult HCPs to meet their medical needs. Additionally, most participants faced systemic racism, could not access quality healthcare, lived in poverty, and could not gain and maintain gainful employment due to their health. Therefore, most participants lived at home with their parents because of financial instability. Due to the identified barriers, the participants had limited access to preventive healthcare measures and higher mortality rates after leaving pediatric healthcare and entering the adult healthcare system. These identified barriers sparked a significant increase in acute care utilization and expenditures when entering the adult medical world compared to individuals living with cystic fibrosis and other health-related illnesses (Melita et al., 2019).

Education Level

Each participant in this study achieved a high school diploma, and some of the participants managed to see education beyond high school. Nevertheless, they could not complete their post-secondary studies program due to their health. Only 13% of the participants could accomplish their desired academic goals beyond high school. According to Harris et al. (2019), individuals with this chronic and debilitating condition face educational barriers that impede their ability to graduate from high school and enter the workforce. The findings in this study further confirm that this populace's academic attainment tends to be lower than their peers. Therefore, educators must understand the educational and community demographics to ensure no child is left behind. Educators and community members who access this population's academic and educational needs are more likely to implement interventions to increase the educational attainment level of this populace (Harris et al., 2019).

RQ2: Do the perceived benefits versus barriers, sense threats, cues to action, and self-efficacy influence the transitional care-seeking behaviors of African American adults diagnosed with SC in the rural Mississippi Delta?

Context of Theoretical Framework

Using the HBM, this study data analysis showed that participants missed medical appointments. Reasons included poor medical relationships with HCPs, limited finances, transportation issues, and extended wait times, so participants did not promptly adhere to or seek medical treatment. Cronin et al. (2018) also used the HBM and confirmed why participants missed medical appointments, the same reasons found in this study.

Therefore, if these barriers were eradicated African Americans living with SC would more likely comply with medical recommendations and increase their desire to seek medical treatment promptly.

Dempster et al. (2018) confirmed how the HBM model could enhance the lives of individuals living with SC and could be beneficial in identifying access to healthcare, providing a better understanding, and changing the care-seeking method of a medical regiment of individuals with chronic illness. This method is a theory of reasoning. It was developed to explain the who, what, where, and how non-adherence to medical treatment increased morbidity and mortality and decreased the QOL among individuals living with a chronic illness compared to their peers without a chronic illness.

A study conducted by Cimpeanu et al. (2021) confirmed that the unpredictability of SC is the primary reason so many individuals are unable to maintain gainful employment and are on Medicaid. Even though SC and cystic fibrosis are both severe autosomal recessive genetic disorders that cause individuals living with cystic fibrosis and SC in the United States to experience sporadic hospitalizations, significant chronic organ damage, and early deaths, the funding resources and medical treatment is limited to individuals living with SC as compared to individuals living with cystic fibrosis (Farooq et al., 2020; Badawy et al., 2021).

Limitations of the Study

Multiple limitations occurred during the study process, partially due to COVID-19. The method of recruiting participants, scheduling interviews, and collecting data were altered to ensure the safety of the participants and myself based on the guidelines

implemented by the CDC, the MSDH, and the guidelines implemented by Walden University. Second, I had to rely on participants telling other individuals living with SC about the study, expand the participant recruitment parameters from five counties to 22 counties, and expand the recruitment methods (TV and newspaper interviews) to seek volunteers to participate. Third, the communication method with potential participants consisted of phone calls, text messages, and emails which decreased the regular one-on-one in-person rapport through face-to-face interviews. Additionally, due to the geographical location of this study, small sample size, and cultural differences, this study may not fully represent the perception of every adult living with SC. Another limitation was self-reported information; more females participated in the study than males. As a mother of a SC warrior, I did not allow my personal experiences with this phenomenon to cause any bias in how I collected or analyzed my data—the method I used to capture the participants' lived experiences during the interview process. Finally, the study is non-generalizable to other studies because it only includes African Americans living in the rural Mississippi Delta. SC patients have limited specialty HCPs and medical treatments compared to individuals with cystic fibrosis and other genetic disorders.

Recommendations

Based on the lived experiences of the 15 participants, aged 18-61 (9 females) and (6 males), the insurance eligibility requirement and a strategic transition program need to be implemented for adults to decrease the mortality rate among this population because adults during the transitioning period to adult HCPs is critical for individuals living with SC to experience a higher rate of hospitalization and mortality. Some of the most

common reasons why adults living with SC miss medical appointments, delay seeking medical treatment, and do not go to the ER promptly. Therefore, this study is consistent with findings in previous literature, and the following reasons indicate the dire need for further research to better understand this populace's medical and financial instability.

In a study conducted by Brandow et al. (2020), ASH guidelines recommend that adolescents and adults who are experiencing acute pain related to SC in the ER should receive rapid care (within 1 hour of the (ER) arrival). During the assessment and administration of analgesia to optimize pain control it is recommended the HCP conduct frequent reassessments (every 30-60 minutes) due to the complexity of SC. Additionally, individuals living with SC should seek medical treatment immediately if they have a fever above 101 degrees Fahrenheit, difficulty breathing, abdominal or chest pain, headache, sudden weakness or loss of feeling, and movement, seizure, severe painful erections, persistent pain in any part of the body, or sudden vision pain (CDC, 2020).

Additionally, CDC (2020) developed an emergency guide on how to manage SC in the ER. The emergency guide includes various healthcare options that ER HCPs can use in the ER to aid them with the treatment of SC patients during triage. (See Table 8). Finally, this study can add to the body of knowledge because little is known about the lived experiences of adults living with SC.

Table 7

SC Recommendations and Guidelines

Triage	SC pain is usually severe and requires immediate treatment; evidence-based guidelines recommend administering pain medication within 60 minutes of arrival Assign an emergent priority (e.g., ESI level 2) due to: • Severe pain that cannot be managed in the waiting room. • High-risk situation that needs rapid evaluation for other serious complications increase the level of concern if the pain is not like prior episodes or new symptoms are present. Patients with ≥ 3 admissions/year for SC pain are at increased risk of death
Initiation of care should not be delayed due to space constraints	• Consider alternative spaces (such as asthma bay) if no treatment spaces are available. • Consider administering pain medications in triage (e.g., subcutaneous opioids for adults and intranasal fentanyl for children – see Treatment) • Utilize physician in waiting room, split flow model, etc. to expedite care when available.
Treat immediately	• SC pain is usually severe and requires immediate treatment. • Do not wait for lab results before starting pain medications; there are no lab values that confirm or rule out a SC pain crisis. • Requests for pain medicines/doses are most commonly due to past experiences, not drug-seeking behavior. • Opioid use was stable from 2008-2013 among individuals with SC, in contrast to the general US population. • Deaths from opioids were ≤ 10 per year in individuals with SC from 1999-2013 (representing only 0.77% of deaths in this population), significantly lower than other non-cancer conditions including low back pain, fibromyalgia, and migraine. • Evaluation and treatment should begin in alternative spaces if no treatment rooms are available. Consider administering pain medicines while in the waiting room/triage. (CDC, 2020)

Implications

This study can be instrumental in affording rural HCPs a better understanding how to provide quality healthcare services to adults living with SC. Secondly, healthcare and insurance organizations can use the findings from this study to develop a comprehensive healthcare system to ensure adults living with SC have a smooth transition from adolescent to adult healthcare systems. Thirdly, new policies could be implemented to allow individuals living with SC to live independently, enhance their SES, and, most of all, new and innovative medical treatments to meet the unmet needs of this population.

Conclusions

This study critically assesses the lived experiences of African Americans adults living with SC in the rural Mississippi Delta. The identified negative experiences in this study inhibit African American adults from seeking healthcare services promptly or making informed healthcare decisions. Therefore, due to the limited specialty HCPs in the rural Mississippi Delta, local HCPs should have opportunities to obtain educational services to meet the medical needs of this population. Also, eradicate the racial divide in medical services for African American adults compared to non-African adults living with other genetic disorders (Cystic Fibrosis and Haemophilus).

This genetic blood disorder is over ten decades old and still have limited medical treatment options compared to other genetic disorders. There are only two curative options available for individuals diagnosed with SC are HSCT and BMT. One of the significant reasons less than 15% of the individuals diagnosed with SC receive a BMT or

HSCT is because of the limited number of donors. Even though FDA has approved other treatments, Hydroxyurea is still the primary option available to SC patients (Cimpeanu et al., 2021).

Access to healthcare in the rural Mississippi Delta is still a barrier for individuals living with SC. Additionally, individuals living with SC need new and innovative policies to ensure adults transitioning from adolescent HCPs to adult HCPs will continue to have access to quality healthcare vs. suboptimal healthcare during the transitional period. The identified challenges in this study can underpin the development of medical treatment and policies to address the medical needs of African Americans in the rural Mississippi Delta. As well as alleviate the identified facets of systematic racism in the healthcare system, and ensure this population is afforded the same dignity and respect when seeking medical treatment as non-African Americans with an invisible chronic illness.

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Appendix: List of Abbreviations

African American(s)	AA(s)
African American Adults	AAAs
Adolescents and Adults	AAs
Bone Marrow Transplant	BMT
Centers for Disease Prevention and control	CDC
Coronavirus	COVID-19
Cystic Fibrosis	CF
Emergency Room	ER
Health Care	HC
Healthcare Provider	HCP
Healthcare Providers	HCPs
Health Belief Model	HBM
Healthcare Transition	HCT
Institution Review Board	IRB
Mississippi Delta	MS Delta
National Institutes of Health	NIH
National Heart Lung and Blood Institute	NHLBI
SARs	CoV-2
Sickle Cell Anemia	SCA
Sickle Cell	SC
Sickle Cell Trait	SCT
Socioeconomic Status	SES
Stem Cell Transplant	HSCT
World Health Organization	WHO