MORE THAN A CURE: A QUALITATIVE EXPLORATION OF SELF-IDENTITY IN BLACK ADULTS FOLLOWING STEM CELL TRANSPLANT FOR SICKLE CELL DISEASE

by

JASMINE MCGHEE AKOMA

(Under the Direction of Linda Campbell)

ABSTRACT

This study, using interpretive phenomenological analysis, explored the self-identity of Black adults who underwent a hematopoietic stem cell transplant as a curative treatment for sickle cell disease (SCD). This study explores an area of study that has a gap in the literature for identifying the various psychosocial implications and self-identity factors that impact the experience of Black adults who undergo stem cell transplant. Illness identity, which overlays the context from which Black adults' self-identity is impacted by living with a chronic illness. A critical race theory lens critically examines the role of healthcare systems on the medical experiences of Black adults and their self-identity. Five areas highlight the impact of stem cell transplant on Black adults' self-identity: 1) impact of SCD on identity, 2) navigating medical trauma, 3) adjustment in the first year after transplant, 4) navigating survivorship, and 5) self-identity after transplant. This study's themes and implications for psychologists working with or interfacing with the medical system, as well as those with a history of sickle cell disease, are discussed.

INDEX WORDS: sickle cell disease, chronic illness, chronic pain, mental health, self-identity, illness identity, medical mistrust, stem cell transplant, hematopoietic stem cell transplant, curative treatment

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DEDICATION

It’s only because of God I’m here. I sincerely thank my husband, my best friend and rock from day one. Thank you for lifting me up. I love you.

Mama and Dad—the two people who have spoken life into me, helped guide me to be the woman I am today, and love me unconditionally. My aunt, like a second mother, has taught me that character and attitude are the most beautiful qualities.

And to my family and friends, I thank you for always loving me unconditionally, praying for me fervently, and supporting me every step along this journey.

To my Beanie—I hope this inspires you to never give up even when it’s hard,
To trust God above all else,
And to trust in who you were created to be.
Your gift will make room for you.
Thank you for inspiring me more than you realize.

..

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CHAPTER 1

INTRODUCTION

“*Our transplant team was sought out by a patient to be considered for a stem cell transplant to cure him of sickle cell disease. He had a successful career as a lawyer, but the disease [SCD] had taken its toll on his body as he got older. He could no longer practice law. He felt defeated. His health was declining due to the severe complications, and he was spending most of his days in the hospital for pain crises or getting blood transfusions instead of doing the work he loved so much.*

After the transplant was successful and he completed the course of treatment, he asked the transplant team, ‘*What do I do now? What life do I go back to?*’. *As a team, we were surprised by these questions and asked him to explain. He described how the disease had taken the best part of him. He had reluctantly disentangled himself from his work and the idea of continuing with life as he knew it. He accepted that [this] was going to be his life—one where he no longer had a career and must dedicate the rest of his life to managing the symptoms of this disease. However, when he discovered a cure was available, he felt a glimmer of hope.*

Now, he was at a crossroads, grappling with whether he should return to the life he knew or try to start his life over. He had been living his life as a person with a chronic illness for so long—going to the hospital, going to treatments, and back again. Though grateful for the transplant, he was unsure what his life would be like without sickle cell disease.”

This story is from my mentor, the hematologist who conducted the stem cell transplant with this patient. He noted that this was the oldest patient [50 years old] he had transplanted in his career. He explained that this story is not an anomaly but one of many stories of patients he has transplanted who find themselves experiencing a sense of disillusionment after the transplant and difficulty transitioning from life with sickle cell disease to a life without it.

Seven years ago, this physician introduced me to his patients living with sickle cell disease and educated me on the impacts of the disease, drawing me into his world as a hematologist and the world of the patients he served. I learned about the unique challenges of this community and how they were contending with a disease that was not only physically debilitating but also impacting multiple areas of their lives—family, relationships, career, social life, and much more. As a hematologist who spent a great deal of time with this community, he observed how the physical and emotional stressors were taking a toll on his patients.

Learning that a curative treatment is available for sickle cell disease, a hematopoietic stem cell transplant, gave me a sense of joy, and I felt relief for this community. This treatment was growing in utilization and showed promising results. However, to my surprise, this was only part of the story. In its simplest terms, this course of treatment would remove the significant physical/biological barrier that this community was living with for so long—sickle cell disease. However, like the account from above about the patient who underwent a stem cell transplant, there could be some difficulties associated with the transition to a proverbial "new normal." With a life shaped by a chronic disease since birth, something can be said about how one's self-identity evolves after receiving a curative treatment.

Background and Context

History of Sickle Cell Disease

Sickle cell disease (SCD), also known as sickle cell anemia, is a genetically inherited blood disorder. Individuals with the disease inherit one copy of the genetic trait from each parent. Specific hemoglobin disorder types organize SCD, (1) homozygous for HbS, or (2) heterozygous for HbS with another abnormal allele such as C, β-thalassemia (either HbSβ+ or HbSβ0) (Adegbola et al., 2012). The most severe types are HbSS (SS) and HbSβ0 thalassemia, with the others being less severe (SC and HbSβ+).

Sickle cell disease was first discovered in 1910 by Dr. James B. Herrick after observing a blood smear from a 20-year-old dental student from Grenada (National Institutes of Health, 2010). He described the blood as "very irregular…with a large number of thin, elongated, sickle-shaped and crescent-shaped forms" (National Institutes of Health, 2010). His observation was the first account in Western medicine of this unique blood cell shape. In 1933, over 2,500 African Americans in Memphis, TN, were tested, and it was then that scientists found that there was a difference in sickle cell trait and sickle cell disease (ASH, 2008). This observation meant that individuals who carry the trait do not have the disease; therefore, they only take one copy of the genetic trait. However, this trait can be passed to their children.

Sickle cell is a genetic evolution to protect against malaria, which relates to its prevalence in descendants of countries with a history of malaria (Serjeant, 2013). Sickle cell affects people of different races and ethnic backgrounds (Campbell et al., 2020; American Society of Hematology, 2023). The disease is most common among African Americans, with 1 in every 365 births and sickle cell trait prevalence in 1 in every 13 African American births (CDC, 2023c; NIH, 2010). Among Hispanic Americans, the second-largest population affected by sickle cell disease, a prevalence rate of 1 in every 16,300 births (CDC, 2023c; NIH, 2010; Valle et al. et al., 2022). The disease is prevalent globally among indigenous individuals (adults and children) in Sub-Saharan Africa, the Middle East, South East Asia, and Latin American and Caribbean countries (Campbell et al., 2020). Due to difficulty accurately tracking the affected individuals' rate, an estimated 7.74 million people live with the disease (Grosse et al., 2011; Global Burden of Disease, 2023; Osei & McGann, 2023).

The trajectory of sickle cell disease holds a high mortality rate amongst adults and children, with the mortality rate dropping 48 percent since the 1930's. Memphis, TN, had the highest infant mortality rate in the country due to the lack of available and viable screening for sickle cell disease (National Institutes of Health, 2010). These infants would succumb to more well-known diseases like pneumonia or tuberculosis as a complication of SCD. People with sickle cell in America were underserved due to a lack of research, funding, and education about the disease. In 1972, during the civil rights movement, the poor treatment of this community was addressed and recognized as an example of racial inequality in the healthcare system (National Institutes of Health, 2010). Former President Richard Nixon increased the budget for research into this disease after the Sickle Cell Disease Association of America proposed the National Sickle Cell Anemia Control Act to implement newborn screening, counseling, education, research, and treatment programs for this community (National Institutes of Health, 2010). These measures have had a valuable impact on the SCD community, with over 94 % of children surviving to adulthood with a median life expectancy of 42-47 years old in adulthood (ASH, 2008; CDC, 2023b).

With a disease highlighted by pervasive and severe pain episodes, the relationship with the healthcare community is one that serves to treat and diagnose. Yet, the relationship is complicated by physicians and medical staff harboring negative attitudes toward patients. One study found that over 50% of physicians and 20% of nursing staff surveyed believed that more than 20% of adults with sickle cell disease could be diagnosed with an opioid use disorder (Shapiro et al., 1997). Equally, over 30% of nurses feel uncomfortable giving the recommended medication dosage to treat these crises (Pack-Mabien et al., 2001). The negative beliefs that SCD patients are drug-seeking and the implicit bias from providers occur as patients who endorse severe and chronic pain episodes request medication to manage their pain (Sinha, Bakshi, Krishnamurti, 2019; Pack-Mabien, Labbe, Herbert, et al., 2001). These beliefs are a paradox as the medical community has determined that the standard course of treatment for managing pain crises is oral and intravenous delivery of opiates (Field, 2017). This complex issue and relationship between patients and providers result in the under-treatment of pain and poor health outcomes for people with sickle cell disease (Pack-Mabien, Labbe, Herbert, et al., 2001; Zempsky, 2010; DeBaun; 2018), with a disproportionate effect on Black adults (Bulgin, Tanabe, & Jenerette, 2018; Sinha, Bakshi, Krishnamurti, 2019; Berghs, Horn, Yates, et al., 2022).

Hematopoietic Stem Cell Transplant Use for Sickle Cell Disease

As a remediation, and currently, one of the most promising curative treatments for sickle cell disease, hematopoietic stem cell transplant is an available option to child and adult patients showing some of the most severe complications of sickle cell disease (Krishnamurti, 2007). The first successful transplant occurred in 1984, and with substantial research to improve the transplant regimen, reduce toxicity, and improve success rates, hematopoietic stem cell transplant has become a viable and successful curative option for more than 2,000 patients with sickle cell disease (Leonard & Tisdale, 2018; Kate, Piel, Reid, 2018). In a study conducted in 2021, overall rates of disease-free survival were between 85-93% (Alzahrani et al., 2021). A rate of 9 out of 10 patients who undergo hematopoietic stem cell transplants are considered cured of sickle cell disease (Leonard & Tisdale, 2018; Hsieh et al., 2014).

Despite its promising success rates, a recent study found increased depression and suicidal ideation among 43% of patients who underwent transplants for sickle cell disease (2022). Though this case study was exploratory, it connects with additional literature referencing persisting negative mental health symptoms before and after transplant (Dovern et al., 2023; Amonoo, Massey, Freedman, et al., 2019).

Problem Statement

Over 2,000 patients with sickle cell disease have undergone stem cell transplants as a curative treatment (Leonard & Tisdale, 2018; Kate, Piel, Reid, 2018). However, there remains limited research on the psychosocial impact of this treatment on sickle cell patients (Dovern et al., 2023). Findings for improvement after stem cell transplant include the complete resolution of vaso-occlusive pain episodes, improvement in physical functioning, and opportunities for improved quality of life (Bruce, Guilcher, Desai et al., 2022; Bhatia, Kolva, Cimini, et al., 2014). Inversely, there are subsequent findings in the research of an increase in depressive symptoms, anxiety, post-traumatic stress symptoms, suicidal ideation, isolation, persisting complications from having sickle cell disease (e.g., necrosis, organ damage), and challenges negotiating a new sense of “normalcy” living without sickle cell disease remain prevalent among this community–specifically in the first-year post-transplant (Dovern et al., 2023; Hamayel et al., 2021; Padova, Grassi, Vagheggini et al., 2021; Bhatia et al., 2014; Mishkin, Cheung, Hoffman, et al., 2022).

This curative treatment is generally considered a positive among the medical community, “leaving the patient, by medical standards, in a better condition than before treatment” (Orfali & Anderson-Shaw, 2005, p. 283). So, with much interest, there remains curiosity about the significant mental and emotional health issues that persist in some of their post-transplant patients even after successful transplantation (Dovern et al., 2023; Amonoo, Massey, Freedman et al., 2019; Mishkin et al. et al., 2022). Some researchers have conceptualized hematopoietic stem cell transplant as a form of trauma due to the intense and highly physically and mentally stressful treatment regimen (Fenech, Benschoten, Jagielo, 2021; Griffith, Fenech, Nelson, 2020), but also to the significant disruption of a sense of identity that comes with being born with a chronic illness and living with it for decades (Oris et al., 2018; Charmaz, 1987; Charmaz, 1995; Orfali & Anderson-Shaw, 2005).

Sickle cell impacts people of various racial and ethnic backgrounds. Systematically and socially stigmatized as a “Black illness,” there are negative implications for less comprehensive care than other genetic disorders (Grosse et al., 2009). Sickle cell disease affects individuals of African, Caribbean, Hispanic, Middle Eastern, Mediterranean, and Asian descent (Campbell et al., 2020; American Society of Hematology, 2023). However, there is a disproportionate impact on Black or African descendant communities, particularly Black adults (CDC, 2023c; Bulgin, Tanabe, & Jenerette, 2018; Sinha, Bakshi, Krishnamurti, 2019; Berghs, Horn, Yates, et al., 2022). This distinction is essential as the unique experiences of this particular community have little to no literature exploring the evolution of their identity after stem cell transplant. One case study examined the impact of a cure on identity and included one case exploring this impact on a Black woman with sickle cell disease (Orfali & Anderon-Shaw, 2005). A systematic review found 27 studies on stigma in this community demonstrating the negative impact on the health and well-being of individuals with sickle cell disease (Bulgin, Tanabe, Jenerette, 2018). The various sources and effects of health-related stigma (e.g., racial health disparities, racial bias, healthcare injustice, etc.) have lasting effects on this community and varying consequences on the ways this community may navigate the world, perceive themselves, and make decisions about their healthcare (Bulgin, Tanabe, Jenerette, 2018).

Purpose of The Current Study

This study aims to utilize an intersectional approach and qualitative research methodology to gain an in-depth understanding of the lived experiences and identity negotiation of Black adults who have undergone hematopoietic stem cell transplant as a curative treatment for sickle cell disease. It is essential to the aims of this study to understand how the embodiment of being a Black person living with a chronic illness and the process of negotiating a new health status impact Black adults' sense of self after undergoing curative treatment. These viewpoints on self-identity will help illuminate the mental and emotional undertaking that occurs after transplant and how they make sense of this experience. The proposed study will employ a qualitative methodology and theoretical framework to understand and inform the interpretation of the data. This framework will center the concept of illness identity, overlaid with a critical lens that contextualizes how the historical and contemporary issues involving racial health disparities in the medical system interplay with the meaning-making process for these individuals post-transplant.

The lack of understanding about identity negotiation, combined with the psychological and emotional symptoms that persist in this community following transplantation, is essential to explore as interest in stem cell transplant as a curative option for this community grows. A comprehensive exploration is vital for this community to articulate, in their words, their unique lived experience. The goal is to better inform the medical community about how to support this community while also fostering dialogue among sickle cell patients regarding the transition experience after undergoing a stem cell transplant.

Research Questions

The following questions will be addressed in this study:

1. How do Black adults describe their adjustment one-year post-transplant?
2. How do Black adults describe the evolution of their identity after stem cell transplant?
3. How do Black adults navigate the experience of living with their new health status?
4. What is the experience of Black adult's post-transplant, as it relates to navigating medical settings?

Definition of Terms

***Sickle cell disease* -** Sickle cell disease (SCD) is a chronic multisystem disorder characterized by blood cells that are long sickle-shaped cells that often block blood vessels. These abnormal cells are hemoglobin S, and due to their shape, they can lead to severe pain and organ damage (ASH, 2008).

***Hematopoietic allogenic stem cell transplant* -** May also be abbreviated to 'stem cell transplant' or 'transplant' – Refers to a medical procedure to infuse stem cells (collected from a donor) after chemotherapy as a preparative regimen to suppress the immune system. Stem cell transplants are used to treat various cancers and conditions (Bazinet & Poradi, 2019). The primary goal is to cure hematologic disorders and malignancies (Bazinet & Poradi, 2019).

Curative treatment - refers to a course of therapies designed to completely resolve an illness or disease. The goal is to restore the patient's health to its pre-illness status, or as close to it as possible. This approach also aims to improve or eliminate symptoms and promote recovery from the illness or disease (Telen, 2020; Fuller. 2022).

Health Status **–** How people measure or perceive their overall health. These ratings can range from excellent to poor, denoting a person's well-being (CDC, 2023).

Self-Identity **–** Holds multiple definitions. Broadly, self-identity refers to the stable and prominent perceptions one holds of oneself. From the field of psychology, the definition of identity comes from a psychodynamic perspective, referring to self-identity as self-schemas that are unconscious generalizations. Through self-representations, the unconscious generalizations about oneself are made conscious and expressed using “words, images, or bodily tensions” (Horowitz, 2012). Self-identity will also be shortened and referenced as ‘identity’ throughout the study.

Black **-** It is essential to acknowledge that the Black identity is not homogenous and cannot be solely understood by phenotypical traits or as a biological conception of race (Helms et al., 2005). Instead, it exists as a wide range of diverse ethnic and cultural identities. For the purposes of this study, the term “Black” refers to individuals who self-identify as persons of African descent, connecting their cultural experiences and historical roots. However, the power of the Black identity is in one’s ability to self-name (Petillo, 2020). Therefore, participants will be individually referred to in the results by the term or self-identifier of their choosing (e.g., Black, African American, Nigerian, Afro-Caribbean, etc.).

CHAPTER 2

REVIEW OF LITERATURE

Introduction

The following chapter will explore previous and current research related to sickle cell disease, its clinical features and disease trajectory, psychosocial impacts of stem cell transplant, identity, and chronic illness, and the interplay of cultural mistrust and racial health inequalities, specifically on research that includes Black participants with sickle cell disease.

Sickle Cell Disease

Sickle cell disease (SCD) is the most common inherited chronic blood disorder. SCD is a global health issue, with over 300,000 babies born with it each year (Piel, Hay, Gupta et al., 2013). SCD is common in ethnic groups, including people of African descent, Hispanic descent (from Central and South America), and Middle Eastern, Mediterranean, and Indian descent (Campbell et al., 2020; American Society of Hematology, 2023). In the United States, approximately 100,000 Americans have sickle cell disease (CDC, 2023c; 2023b). However, the rate of incidence for SCD disproportionately affects Black persons (Brennan-Cook et al., 2018), with 1 in every 365 births (CDC, 2023c; 2023b).

Even with the advances in the screening and comprehensive care of sickle cell disease, the severe complications among those with sickle cell disease are still pervasive and a precursor to premature mortality and morbidity, with the median age of death being between 40 to 43 years old in men and women, respectively (Platt et al., 1994; Payne et al., 2020; Paulukonis et al., 2016).

Clinical Features

Pain and Disease Complications

The first signs of SCD are present within the first year of life, or around five months of age, with symptoms and complications ranging from mild to severe for each person (CDC, 2023a). SCD is often associated with chronic, acute, and fluctuating pain attacks known as vaso-occlusive pain episodes (Aisiku et al., 2009). A sickle cell epidemiology study found that half of the sickle cell patients report experiencing pain more than three days per week, and 30% report daily pain (Smith, Penberthy, Bovbjerg et al., 2008). These episodes contribute to significant disability among patients, leaving them with severe joint, hip, and chest pain (Swanson, Grosse, & Kulkarni, 2011). The episodic and variable nature of this pain can be acute (occurring suddenly), chronic (with known or unknown etiologies), or a combination of both types simultaneously, also known as mixed pain (Ballas, 2011). Chronic persistent pain is the hallmark of sickle cell disease-related complications and occurs in more than a third of adults with SCD. Opioid analgesics are the primary treatment for managing acute and chronic pain (Ehrentraut et al., 2014; Sinha, Bakshi, & Krishnamurti, 2019). SCD pain can be related to acute disease complications such as organ and tissue death (necrosis), stroke, anemia, blood clots, infection, kidney problems, priapism (uncontrollable penile erections), insomnia, vision loss, etc. that can lead to substantial morbidity, impaired health-related quality of life, increased health care costs, and a high risk of premature death (Platt el al., 1994; CDC, 2022). These pain episodes and crises can vary with triggers from cold weather to stress and dehydration, contributing considerably to the disease's deleterious effects and compounding the patients' mental, emotional, and social distress (Adegbola et al., 2013).

Mental Health Implications

Mental health issues are often a risk factor for chronic pain (Hasan, Hashimi, Alhassen, et al., 2003). An estimated 35 - 45% of individuals living with a chronic illness report experiencing depression (American Psychiatric Association, 2020), with another study noting a prevalence rate as high as 85% (Bair, Robinson, Katon, et al., 2003). Chronic pain and mental health issues are associated with chronic pain, serving as an exacerbator of heightened stress states, with implications of poor sleep quality and low mood (American Psychiatric Association, 2020; Bair, Robinson, Katon, et al., 2003).

The rate of depression among adults with SCD is 35% compared to 5 - 6.7% in the general adult population (WHO, 2023; Adam, Flahiff, Kamble et al., 2017; Franco, Farooq, Franco, et al., 2022) and about 18% of adults in the United States (CDC, 2023d). Chronic persistent pain occurs in about 50% of adults with SCD (Smith, Penberthy, Bovbjerg et al., 2008). These comorbidities' impact on sickle pain includes insomnia, resulting in a continuous spiral of physical and emotional stress from physical disease complications, leading to more severe mental health concerns. Mental health concerns can further exacerbate the pain, leading to more pain episodes and the need for pain medication, culminating in a negative feedback loop of symptoms that worsen each issue (Belgrave & Molock, 1991). The combination of these comorbidities and varying disease complications in individuals with SCD has a biopsychosocialspiritual impact that can lead to feelings of helplessness, fear of death, loss of purpose/impact in one’s life or circle of influence, social isolation, difficulty maintaining healthy relationships, etc. (Adegbola, 2011; Booker et al., 2006).

Healthcare Utilization and Patient Care

Hospital utilization denotes the rate at which individuals with SCD utilize the Emergency Department to manage complications and pain crises associated with sickle cell disease. SCD complications and pain episodes accounted for 71.3% of hospital admissions (Fingar, Owens, Reid et al., 2019) and an average of $1.6 billion per year from Medicaid in overall health-related costs (Kauf, 2009). It is the fifth-ranking diagnosis in the top 10 health diagnoses with the highest healthcare utilization and readmission rates (Jiang, Weiss, Barrett et al., 2015; Broousseau, Owens, Mosso, et al., 2010).

With frequent sickle cell vaso-occlusive crises or pain episodes, their treating physician uses a treatment strategy called a Pain Management Plan (Brennan-Cook, 2018; Adegbola, 2012). This treatment plan includes prescription oral narcotics (e.g., morphine) and prescription-strength anti-inflammatory medications (e.g., acetaminophen, ibuprofen) given consistently to self-manage pain episodes at home. When the home medications fail, the episode persists so intensely that the oral pain medications cannot control it. This phenomenon is known as “breakthrough pain” (Portenoy et al., 2006). As a part of this plan, patients go to a nearby hospital for more intensive pain management. This treatment strategy utilizes higher doses of intravenous narcotics (e.g., morphine, Dilaudid) to treat the pain episode more effectively (Brennan-Cook, 2018).

Individuals with SCD who have an increase or influx in pain episodes can lead to increased hospitalizations and readmissions (Smith, Penberthy, Bovbjerg et al., 2008). These patients can find themselves in the Emergency Department as often as monthly or weekly, depending on the frequency and severity of the episodes (Fingar, Owens, Reid et al., 2019). The patients, on average, have longer wait times for pain medication than other patients (mean >30 minutes) even with high pain scale ratings during initial triage (Haywood, Tanabe, Naik, et al., 2013; Linzkron, Little, Field, et al., 2020). Patients with frequent hospital visits are often labeled pejoratively as “frequent fliers” in their Emergency Medical Records (Williams, Bottle, Rogers, et al., 2005; Boatright & Abbott, 2013). These patients can often be considered as “drug seeking” or deemed to have a “substance-use disorder” due to the frequency of the ED visits, coupled with their immediate and specific request for intravenous pain medication (Brennan-Cook, 2018; Zygotsky, 2010; Shapiro, Benjamin, Payne, et al., 1997).

Race and Sickle Cell Disease

The psychological and emotional burden on sickle cell patients is contextualized by looking at the disease trajectory, psychosocial implications, and historically and culturally relevant factors prevalent amongst this population. Mental health symptoms can have multiple forms of expression, including psychological distress, emotional burden, somatic manifestations, and environmental and social exacerbators. Each of these factors can impact how a mental illness presents and is explained by a patient. Additionally, when considering all factors and intersections of a client’s identity (Hays, 2008), there can be factors such as language and idioms or culture-bound expressions that help explain their experiences and symptomology (Hall, 1976).

Between 2000 - 2016, of all SCD hospital admissions, almost 90% of the patients identified as Black (Fingar, Owens, Reid, et al., 2019). With an invisible illness like SCD (Olkin, 2017; Banks, 2017), these patients may not present like someone in acute pain. With a lifetime illness underscored by pain, some patients may not show the “normative" expressions of pain, like flushed face or skin, crying, or physically holding the area that is hurting. Instead, they may appear irritable, angry, distracted (on their phones, playing games, or watching movies), quiet, and sleeping (Berghs, Horn, Yates, et al., 2022).

With the historical and present beliefs that black people can tolerate pain at much higher rates (Hoffman et al., 2016), the implicit biases held by practitioners towards patients of color may lead to inadequate or delayed care and mental health diagnoses that is necessary or required to treat or provide proper follow-up care for their condition (Adegbola, 2012; Brooks & Hopkins, 2017).

With the disproportionate mood, personality, and substance use diagnoses amongst EMRs of black patients (Whaley, 2001, 2005, 2011) and particularly Black adults with sickle cell disease (Brennan-Cook, 2018; Brooks & Hopkins, 2017), there lies a disconnect between how this group may express distress or manage symptoms, and the accurate diagnose and treatment of their mental health symptoms. A failure to accurately conceptualize their presentation/symptoms leads to a high potential for misdiagnosis or underdiagnosis, negatively impacting health outcomes (Meyer, 2003; Brennan-cook, 2018; Brooks & Hopkins, 2017), poor provider/patient relationships, and decreased help-seeking behaviors of this group (Grier & Cobbs, 1968; Whaley, 2001, 2011).

Historical Context: Racial Health Disparities

The Center for Disease Control defines *health disparities* as “preventable differences in the burden of disease, injury, violence, or opportunities to achieve optimal health experienced by socially disadvantaged populations” (CDC, 2023e). The historical and contemporary racial and discriminatory practices against Black people within various institutions and systems have increased the prevalence of mistrust among minoritized communities. Historically, mistrust can be traced back to the institution of chattel slavery (Grier & Cobbs, 1968). Terrell et al. referenced it as the original “offense” that started a mistrustful relationship between Black and White people (1981; 2009). He references, “unique to African descent is that, for the most part, this ethnic group was transported to the United States against their will, enslaved, and treated brutally by a dominant culture once they arrived.” That treatment has continued today (Terrell et al., 2009, p.299).

At the time, not only were enslaved people treated inhumanely, but they were being used in the name of science and discovery. Dr. James Marion Sims, the father of Gynecology, experimented on enslaved Black women without anesthesia. The experiments resulted in him gaining notoriety in the field of Gynecology for his novel surgical techniques (Holland, 2017). Though the institution of chattel slavery has ended, there continue to be documented examples of Black bodies used in the name of science that contribute to poor health outcomes and increased mistrust in healthcare.

At the same time, the Eugenics movement, a movement started based on the notion of ‘natural selection,’ gained prominence based on their theory of “racial improvement” and “planned breeding” (Guthrie, 2003; Farber, 2008). The goal was to “purify” or weed out the population of certain diseases, disabilities, and undesirable traits through methods such as forced sterilization. Individuals or groups who exemplified these “undesirable traits” would be medically castrated or sterilized so they could not bear children and transfer them to their children (National Human Genome Institute, 2022).

The monumental Tuskegee Syphilis experiment also ran from 1932 to 1972 (CDC, 2022). This experiment, created and conducted by the United States Public Health Department, was one of the many studies to set a precedent for conducting ethical research (Shavers, Lynch, Burmeister, 2000). This study had a lasting impact on Black culture as it was a study that lasted for about 40 years and marketed to help a group of Black men by treating them for syphilis. Instead of helping, these researchers willfully withheld treatment, telling the participants they were receiving treatment to study the disease's progression and impact on the body (Center for Disease Control, 2020). There remains a reverberation of pain, trauma, and mistrust among the descendants of these men (Crutcher, 2018). The consistency of these traumatic events and others like them has profoundly impacted the ability of the African American/Black Culture to trust in systems of government, policy, health, and ethics in the United States (Crutcher, 2018).

Cultural Mistrust. At the end of the civil rights movement, a movement to seek and attain equity and justice for African Americans in America, two Black Psychiatrists, William Grier and Price Cobbs, published their landmark work, Black Rage (1968). Grier and Cobbs wrote this seminal work to culturally and clinically define cultural paranoia (Grier & Cobbs, 1968; Terrell et al., 2009). *Cultural paranoia* is a healthy adaptation among Black Americans toward White Americans as a response to the historical and present-day context of racism (Grier & Cobbs, 1968). They found that this cultural response style was a normative experience for Black Americans as it functioned to preserve their livelihood and as a means for survival to ward off discrimination and oppression towards themselves and their communities.

Frank Terrell became a noteworthy researcher for coining the term “cultural mistrust” and laying the foundation for the study and measurement of the concept (Terrell & Terrell, 1981). Cultural mistrust refers to the attitudes and dispositions of people of color toward individuals of White/European descent or Caucasian individuals in positions of authority (Grier & Cobbs, 1968; Terrell & Terrell, 1981). Terrell and Terrell theorized that this phenomenon of mistrust was a response to chronic mistreatment and deception by Whites. Eroded trust resulted from historical mistreatment and discrimination towards Black people. Initially considered cultural paranoia, the ontological understanding of the term was predicated on a consistent and collective mistrust of White folks that permeated Black culture and lifestyle (Grier & Cobbs, 1968). These attitudinal factors hinge upon the presumption that social and systemic institutions created by this group are inherently racist. Therefore, the (White) person assuming authority upholds these institutions and cannot be trusted (Whaley, 2001). White folks created these spaces to maintain the social privilege and upward mobility of racially homogenous people (Lindner, 2018). Growing up Black, there was a sensitivity to these spaces because, as a community, they were not afforded the same privileges and access. This level of hypersensitivity left an ingrained hesitancy or mistrust when engaging in specific systems and institutions (Lindner, 2018). Notably, an amount of cultural mistrust can be a healthy coping mechanism, but undoing the mistrust entirely is impossible without purposefully creating and responding to opportunities to build trust. Racial health disparities will persist without intentional changes surrounding unconscious bias and more significant equity within healthcare systems (Brooks & Hopkins, 2017).

Medical Mistrust. Out of cultural mistrust is a sister concept nested within the term — medical mistrust. Medical mistrust is similar to cultural mistrust, but it is specific to the interactions between providers within healthcare systems, with implicit bias leading to discriminatory practices (McGuire, 2019; Moseley et al., 2007). Research in this area grew to include an index to measure levels of mistrust within medical systems (LaVeist et al. 2000). The subsequent research in the area led to the term being recognized as a social determinant of health because of the multiple levels of impact it had on health disparities among minoritized communities (Nelson, 2003). These effects were not only found amongst affected minoritized communities but were a byproduct of the attitudes and beliefs of physicians and medical providers (Nelson, 2003). Citing the systemic under-treatment of pain for Black Americans relative to White Americans, Hoffman et al. surveyed at the University of Virginia, finding that about half of their medical students and residents believe Black people are biologically different and have a higher pain tolerance than White people (2016).

Patient/Provider Relationship. Racial health disparities will persist without intentional changes and more significant equity within healthcare systems (Brooks & Hopkins, 2017). Adjacent to this factor are the attitudes and beliefs of physicians or providers. The ability to communicate, show care and compassion, and be culturally responsive makes a much more significant difference in how to begin rebuilding trust (Brooks & Hopkins, 2017). Similar to the study conducted at the University of Virginia, certain attitudinal factors and biases influence perceptions and beliefs about patients of color. These beliefs further contribute to the further marginalization of communities of color. The Minority Stress Model (MSM) signifies the relationship between status, proximal stressors, distal stressors, and health outcomes (Meyer, 2020). This framework serves as a template to exemplify cultural mistrust and its impact on patient health outcomes (Figure 1).

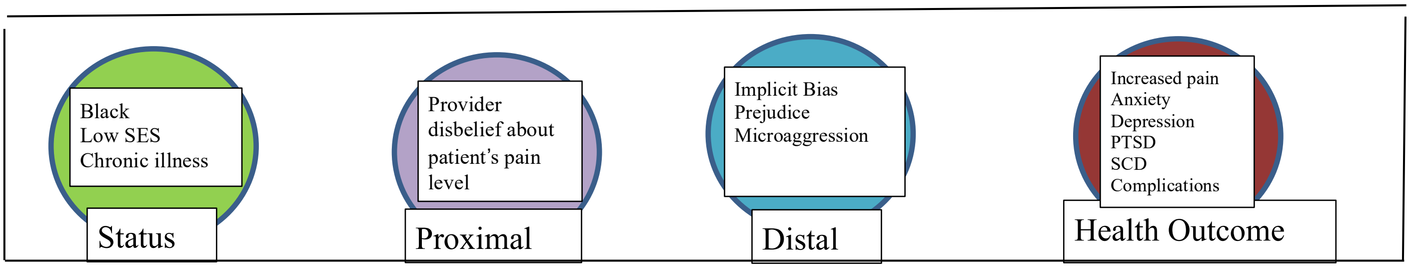

Figure 1. Minority Stress and Cultural Mistrust

The provider-patient relationship is vital to the well-being and treatment of individuals with sickle cell disease. With the prevalence of negative beliefs and implicit bias among medical providers, this relationship has the potential to become complicated and underscored by chronic mistrust and negative misconceptions (Zempsky, 2010; Royal et al., 2011; Berghs, Horn, Yates, et al., 2022; Sinha, Bakshi, Krishnamurti, 2019). A study found a significant discrepancy between Hematologist's and Emergency Department (ED) physicians' beliefs and attitudes about pain in sickle cell patients (Shapiro et al., 1997). ED physicians believed that vaso-occlusive pain episodes lasted for 3-4 days (Shapiro et al., 1997), when, on average, these episodes lasted for 3-9 days (Zempsky, 2010). More significantly, there were found to be higher beliefs of drug-seeking behaviors among SCD patients by nurses and mid-level professionals than among physicians (Zempsky, 2010), along with a third of nurses endorsing a lack of comfortability giving patients the recommended dosage of pain medication (Pack-Mabien, Labbe, Herbert, et al., 2001). These beliefs and attitudes have implications for patients' pain management. If pain treatment times are cut shorter, or patients are not given enough pain analgesics to manage the episode, patients may be discharged prematurely. Without proper management, patients are more susceptible to pain flare-ups and recurrent episodes that will send them back to the ED (Zempsky, 2010). Subsequently, this led to increased misconceptions and attitudes about drug-seeking behaviors—furthering a cycle of pain undertreatment and increased patient disease complications (Figure 2). One qualitative study in 2018 noted patients' accounts of spending countless hours in the hospital waiting to be seen and, upon being seen, being questioned about the validity of their pain. Patients are inundated with questions like, "Why haven't you used your at-home medications? You were just here earlier this week, weren't you? Haven't you been playing on your phone for the last few hours? You cannot be in that much pain!" (Mickelsen & Beach, 2017).

Patients expressly note feelings of frustration, anger, and confusion about the lack of consideration they receive when seeking out pain management (Zempsky, 2010; Royal et al., 2011; Sinha, Bakshi, Krishnamurti, 2019). Patients in a study published in 2022 recount feeling a lack of control over their health, as they feel a need to be hyper-vigilant when it comes to their healthcare as they have recurring experiences of not being believed or seen as "not as sick" because they "do not look sick" (Berghs, Horn, Yates, et al., 2022). One respondent from this study recounted a time they feared losing their life or becoming significantly impaired by a stroke because a nurse accused them of "faking" (Berghs, Horn, Yates, et al., 2022).

Conversely, some patients report a different experience where they do not endorse having difficult conversations or receiving negative messages from their medical providers. Participants expressed the sentiment that some providers are better educated on how to support patients with sickle cell disease (Berghs, Horn, Yates, et al., 2022). This observation is a testament to the increased research on health outcomes and racial bias in sickle cell disease and improving critical discourse within medical education (Puri Singh, Haywood, Beach, et al., 2016). Other studies found that other patients report similar sentiments but for different reasons. Researchers found that patients purposefully altered their presentation in the ED to appear more agreeable (Berghs, Horn, Yates, et al., 2022). They believed their provider would be more accepting of them in hopes that it would lead to a less contentious interaction, regardless of whether their pain gets fully addressed (Royal et al., 2011; Berghs, Horn, Yates, et al., 2022). This complex relationship has implications for the perceptions SCD patients have of themselves, how they navigate seeking care, increased mistrust of healthcare, self-efficacy, and poor health outcomes overall (Royal et al., 2011; Berghs, Horn, Yates, et al., 2022, Orfali & Anderson-Shaw, 2005; Tanabe et al., 2010; Pokhrel et al., 2023).

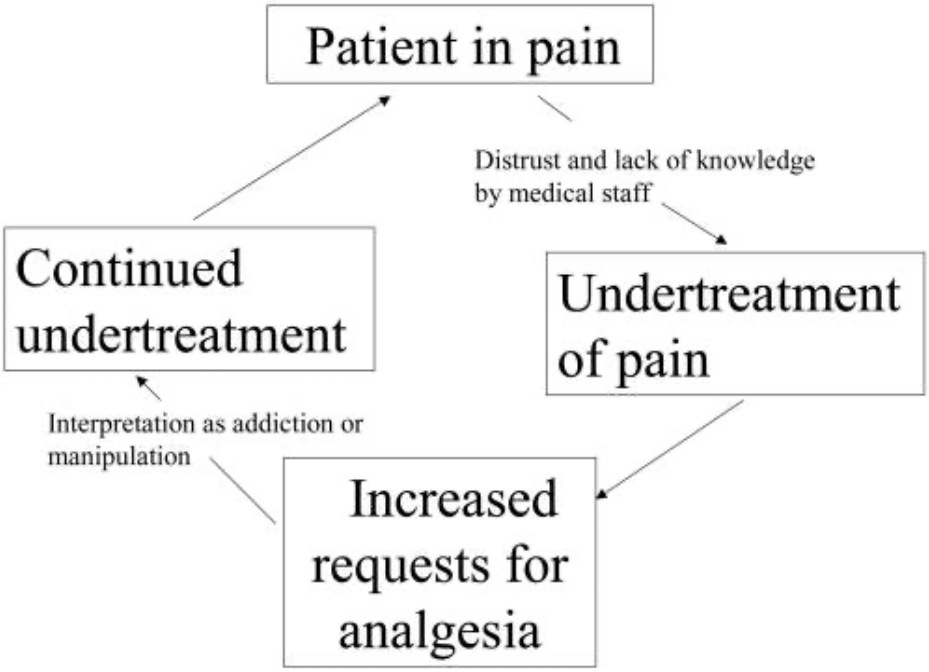

Figure 2. Cycle of pain and undertreatment for SCD

A Curative Treatment: Hematopoietic Stem Cell Transplant

Hematopoietic stem cell transplant has historically been a curative treatment for cancers and hematological malignancies (Bazinet & Poradi, 2019). Its use among patients with sickle cell disease as a curative treatment has grown more common and successful.

Transplant regimen

This curative option takes the stem cells of haploidentical (sibling- or blood-related) donors and transplants them into the patient using a chemotherapy preparative regimen to suppress their immune system. This suppression allows the implanted donor stem cells to engraft fully, resulting in the patient having new stem cells that produce healthy red blood cells instead of sickled cells (Krishnamurti, 2007; Kanter, Liem, Bernaudin et al., 2021). Conversely, this curative option has potential complications, including organ injury, graft-versus-host disease (i.e., graft rejection), and infections that not only increase the physical burden but also exacerbate the mental and emotional burden on the patient (Krishnamurti, 2007; Badawy et al., 2020). For a transplant to be considered a successful engraftment, patients will no longer have sickling blood cells and have a blood phenotype AA or return to a blood type with only the recessive sickle trait remaining (Krishnamurti, 2007). Even with the successful implantation of new stem cells with no complications, there remains an arduous recovery process with a standard time frame of 100 days. Though hematopoietic stem cell transplant has indicators of success (i.e., a disease-free state), it does not reverse the complications patients had while living with sickle cell disease. Therefore, patients may still have various complications including, but not limited to, hemiparesis, or muscle weakness secondary to a stroke, avascular necrosis of the organs (i.e., tissue death), chronic pain syndrome, or central sensitization secondary to decades of opioid use for pain management (Shenoy, 2013, Krishnamurti, 2007; Carroll, Lanzkron, Haywood, et al., 2016).

Psychosocial Impact of Stem Cell Transplant

Post-transplant Impact

After undergoing stem cell transplant, patients report overall positive feelings, noting improvements in multiple quality of life domains (physical, mental, economic, psychological, social) as they no longer experience many of the complications of sickle cell disease (Bruce, Guilcher, Desai, et al., 2022; Bhatia, Kolva, Cimini, et al., 2014). Most individuals report physical improvements, such as decreased hospitalizations, improved sleep, reduced sickle cell-related pain, and increased energy (Bruce, Guilcher, Desai, et al., 2022). Pursuant to their personal life goals, patients noted some variation in the timeline, but on average, it took 1- 4 years for them to pursue their personal goals (Gallo et al., 2019). Equally, another perspective emerged within stem cell transplant research. Though improvements came as a result of the curative treatment—no longer having severe disease complications or physical limitations—undergoing this curative treatment led to difficulty approaching a new sense of reality (Dovern et al., 2023; Orfali & Anderson-Shaw, 2005; Gallo et al., 2019; Hamayel, 2021; Bruce, Guiltier, Desai, et al., 2022; Bhatia, Kola, Cimini et al., 2015; Badawy, Beg, Liem et al., 2021). Researchers found that individuals with sickle cell disease normalized and accepted living an adjusted life, underscored by a chronic illness (Dovern et al., 2023; Charmaz, 1995). It is important to note that having sickle cell disease can be a traumatic event, leaving the patient, post-transplant, still contending with the negative experience of the disease, such as, depression, anxiety, and post-traumatic stress symptoms (Amonoo, Massey, Freedman et al., 2019; Fenech, Benschoten, Jagielo, 2021; Griffith, Fenech, Nelson, 2020). The healing process post-transplant further complicates this, the follow-up medical treatment, and the new occupational and social possibilities to explore. After undergoing this process, most patients are immediately relieved to no longer have sickle cell disease and embrace the new health improvements, but they consistently express a need for psychological counseling to address the nuances of this unique experience (Dovern et al., 2023; Hamayel et al., 2021). Many patients reflect on the need to process their experience of having sickle cell disease and understand what their new health status means for them (Dovern et al., 2023; Bruce et al., 2022; Orfali & Anderson-Shaw, 2005). Multiple studies looking at the various stages of the transplant process (pre-, during, and post-) maintain a consensus that it is vital to have specific knowledge and skills to adequately support this patient population even after the physical cure of SCD (Dovern et al., 2023; Hamayel et al., 2021; Bhatia et al., 2014; Gallo et al., 2019).

From a healthcare team perspective, research has found that medical professionals need to better prepare and support patients about their expectations of the stem cell transplant process, including remaining pre-transplant SCD complications (i.e., avascular necrosis and organ injury), to the potential psychosocial implications and varied meanings of success with a curative treatment. This study highlighted the contextual issues and complex circumstances in which SCD patients find themselves post-transplant. Gallo et al. assert that healthcare providers who prioritize treating the condition but do not treat the whole person increase the likelihood of contextual errors, which can exacerbate life challenges (2019, p. 12). Assessing life context, understanding unique needs, prioritizing a plan that includes both short-term and long-term goals, and considering other psychosocial and medical factors were found to be imperative in preparing patients to undergo transplant and improving the potential for better health and mental health outcomes post-transplant (Gallo et al., 2019).

Identity Development

Erik Erikson, a psychoanalyst, was a researcher on psychosocial development. He wrote the seminal work on lifespan ego development, where he conceptualized identity as the ability of an individual to integrate various values and personal choices as attributes, or self-assets, to construct a coherent self-identity (Erikson, 1968). Erikson theorized eight stages of psychosocial development. These stages have a progression across the lifespan that requires a crisis before resolution occurs. This resolution could be positive or negative. As a person develops, they may reach an impasse or critical event in life that requires returning to past stages to renegotiate or re-resolve previous stages, thereby moving through their current life stage. Erikson theorizes that development through these stages results in a healthy personality and the acquisition of essential virtues (1968). The first stage of development is Trust vs. Mistrust (Erikson, 1968). Metaphorically, trust is like the water consistently poured on the seed to enable it to grow. Inconsistent and variable watering, or chronic mistrust, can negatively impact or delay the plant's growth. This metaphor is attributable to theories discussed earlier, conceptualizing cultural and medical mistrust. Erikson conceptualizes trust as being built by consistent presence, responding to needs, and a consistent, reliable frequency of both (1968). Inconsistent trust is associated with increased fear reactions, anxiety, and suspicion (Breakwell, 2020).

Erikson’s general framework requires a precise and proper application of his stages within cultural and social contexts. The framework helps understand the individual's stage and how they may try to negotiate any issue in their life that has arisen. This notion corroborates research findings on medical mistrust and the implicit bias experienced by patients with sickle cell disease. Though fundamental trust is first negotiated within the child-caregiver relationship, as new critical areas of life emerge (i.e., chronic illness) or incongruence and inconsistency in the world become present (implicit bias and discrimination), a reworking or renegotiating of trust in one's relationship to themselves, other's, and institutions must be contended with (Erikson, 1968; Syed & Fish, 2018). Syed and Fish's work conceptualized Erikson's theory as a metaphor to understand the erosive nature of mistrust on the psyche and relationships. This parallel exemplifies sickle cell patients' experience of medical mistrust as a byproduct of implicit bias and the racial health disparities experienced within the medical system.

Identity and Chronic Illness

Erikson's theory of psychosocial development is a foundational concept to define the relationship between chronic illness and identity development. Charmaz's take on illness identity is found within the sociological literature. She conceptualizes chronic illness as a pivotal event or, based on Erikson's theory, a crisis (1968) that must be reintegrated into one's identity. In Charmaz's terms, this process was an adaptation described as altering one's life and self to accommodate physical impairments or "losses" due to the chronic illness (Charmaz, 1995).

This process is termed illness identity (Charmaz, 1995). Out of the literature on illness identity, measures of illness identity were created to identify various dimensions of one's identity with a chronic illness (Oris et al., 2016; 2018). Oris highlighted that the four dimensions of chronic illness identity found in the research were included in his Illness Identity Questionnaire (IIQ): Engulfment, Rejection, Acceptance, and Enrichment (Oris et al., 2016). A study by van Bulck et al. found a correlation with an increased healthcare utilization rate for patients with high indicators of engulfment, or a preoccupation with illness that dominates one's life, relative to their illness identity (2018).

Identity and chronic illness research has also identified the role of social relationships, like the medical system, as the context in which one's identity is defined (Mathieson & Stam, 1995). This research reflects the idea of renegotiating one’s identity through research on the illness narratives of individuals living with cancer and the impactful role on how one’s identity becomes enmeshed, or deeply interwoven, into the role of a patient, and life lived within the medical setting (Mathieson & Stem, 1995).

Within the literature on chronic illness and identity, the concept of biographical disruption is where one’s life is impacted by the onset of a chronic illness (Bury, 1982). This biographical disruption is a concept that occurs later in the lifespan and ‘disrupts’ the life one has lived up until that point (Bury, 1982). One study uses this concept to understand the transition from young adulthood to adulthood with individuals living with a chronic illness (Steinberg, 2020). The researcher notes the bifurcation of identities, or the “before and after identities,” that one experiences as impacted by a transition, in this case, a life transition.

Other studies indicate a specific shift in identity, specifically with the curative form of transplant for hematological malignancies. Halpin, Konomos, & Jowers noted a variation in the transformation of identities, specifically during stem cell transplants for individuals with Multiple Myeloma, and noted the concept of interrupted identities (2021). These researchers conducted a study using Interpretative Phenomenological Analysis (IPA). They found that going through the transplant process was considered an interruption to their past illness identity as a person with Multiple Myeloma (2021). Participants noted a need to reconcile their past and new patient identities and found the process mentally and emotionally taxing (Halpin, Konomos, & Jowers, 2021). This study speaks to the beginning of the identity transformation post-transplant, which may begin during the transplant regimen.

Another IPA study conducted with individuals over 50 explored the impact of hematopoietic stem cell transplant (for various hematological malignancies) on one’s meaning-making process post-transplant. Gilfillan found superordinate themes of the identity transformation, including 1)Shifting one's sense of self, 2) Adaptation and managing impact, 3) A new perspective on life and living, and 4) Changing over time (2011). He discussed the future direction of this research, exploring self-identity amongst this community and how these individuals experience and negotiate a loss of self (Gilfillan, 2011).

The Role of a Cure

Only one article specifically explored sickle cell identity after a bone marrow transplant. This study was a case study exploring the impact of a curative treatment on two adult participants' identities—one with chronic kidney disease since the age of 6 years old and the other with sickle cell disease since birth (Orfali & Anderson-Shaw, 2005). This study is one of few that critically examines the role of a cure on adult identities who had illnesses they were born with or acquired in early childhood. This study situates these two cases in the context of the role and purpose of a cure based on medical standards. They note that from a medical perspective, a cure is an unquestionable positive in the lives of patients whose bodies have been weakened by disease (as were the two patients in the case study who had severe complications from both illnesses). A cure, though a medical innovation to be marveled at, cannot compare to the lack of preparation the medical field has with supporting patients, whose lives have been constructed within the medical setting, adjust to "cure, health, and normality" (Orfali & Anderson-Shaw, 2005, p 286).

From a patient perspective, this study found that the two patients who received curative treatments also held positive expectations of the cure and were surprised by the complex and conflicting feelings they experienced afterward (Orfali & Anderson-Shaw, 2005). Some patients refuse treatment or have mixed feelings about success, and their expectations of a cure do not always align with their health status after the cure (Orfali & Anderson-Shaw, 2005). Orfali & Anderson-Shaw situate the patient's perspective with the cure as a form of biographical disruption (Bury 1982), but in reverse. They highlight a paradox where these patient's sense of normalcy is their life with the chronic illness or disease, not without it. These patients were well adjusted to the unique conditions of a life lived with a chronic illness since childhood, and the cure is a “violent disruption of the self shaped within the medical context” that they must now try to make sense of and adjust to (Orfali and Anderson-Shaw, 2005, p. 288). This idea is similar to research done on individuals in the deaf community who choose to remove their cochlear implant (Dahm, 1998; Cooper, 2019), yet the health circumstances are different as individuals with a chronic illness like sickle cell are negotiating a life or death issue based on the severity of symptoms that would indicate an immediate need for stem cell transplant (Orfali & Anderson-Shaw, 2005). However, similar to the thoroughly researched concepts of illness identity (Charmaz, 1995; Oris et al., 2016; Bury, 1982), the plight of the chronically ill patient after a curative treatment is also to adapt and build a new formation of their self-identity. This conflict illuminates a gap in the literature where most literature looks at the experience of identity from health to illness and not from illness to health (Orfali & Anderson-Shaw, 2005). Orfali and Anderson-Shaw suggest future directions in the literature for the field of medicine to recognize the impact on adults who have been chronically ill since childhood and subsequently have no conception of health. They suggest more studies highlighting patients' distinctive and unique experiences in their own words to better prepare them both medically and psychologically for the experience of a cure and the new role of “health” in their lives (Orfali & Anderson-Shaw, 2005).

Racial Identity

Given the sparse literature on the concepts discussed in this study, no research examines the aforementioned factors alongside race. Minimal investigation has been conducted on the role of racial identity development for individuals living with sickle cell disease. A study by Royal, Jonassaint, Jonassaint, et al. found within-group differences in the salience of identity among individuals with sickle cell disease and how relevant their race is to them concerning their chronic illness identity (2011). They employed the Sellers Multidimensional Inventory of Black Identity-Short Form (MIBI-S) to assess racial identity (1997). The MIBI-S, based on the Multidimensional Model of Racial Identity (MMRI), is a content model that contextualizes behaviors related to race and how individuals derive meaning from specific characteristics that reflect their racial identification (Sellers et al., 1998). The MIBI-S measures four dimensions: 1) Centrality, 2) Salience, 3) Ideology, and 4) Regard (Sellers et al., 1998). They found that the centrality of race, according to Sellers' Multidimensional Model of Racial Identity, was the most significant predictor for patients who consistently define or identify their race as central to their self-identity across various settings (i.e. healthcare, school, work, community) (Sellers et al., 1998). Furthermore, racial salience pertains to the extent to which race is a fundamental aspect of self-concept within a specific context or situation (Sellers et al., 1998), such as experiencing discrimination or bias during visits to the emergency department for sickle cell complications. Contemporary literature indicates a strong correlation between racial centrality and healthcare mistrust (Cuevas & O'Brien, 2019). However, patients who endorsed a more humanist ideology, meaning one's concept as a human individual with similarities amongst other humans takes precedence over their racial orientation, did not perceive a relationship between their racial identity and the severity of their disease or their hospitalizations. Notably, some patients did not identify as Black, reporting no connection between their identity and experiences with sickle cell disease. Additionally, other participants with non-U.S.-born parents regarded their minority or immigrant identity as more central than their racial identity (Royal et al., 2011). Although there is limited research in this field, these findings suggest that the centrality of racial identity may influence how sickle cell patients perceive their identities in relation to their illness. In light of this study, a gap persists in the literature regarding the role of race and meaning-making following curative treatment for sickle cell disease. A systematic review of SCD-related stigma towards Black/African Americans living with sickle cell disease revealed descriptive literature on patient’s healthcare experiences but limited information on the causal relationship of stigma and its implications for long-term healthcare decision-making (Bulgin, Tanabe, Jenerette, 2018). The authors recommend that future studies employ conceptual and theoretical frameworks to better understand the interaction between individuals' intersecting identities and their relationship to health inequities (Bulgin, Tanabe, & Jenerette, 2018).

CHAPTER 3

METHODOLOGY

Introduction

Qualitative methodology is the ideal approach for capturing the nuances of a population's lived experience and the meaning they attribute to a phenomenon. The nature of qualitative research is emic and ideographic-- pronounced by inquiry of lived experience through capturing deep, rich data (Hays & Singh 2022). This empirical research method considers interpretation and naturalistic approaches to understanding phenomena and how people experience them (Denzin & Lincoln, 2000; Hays & Singh, 2022).

The philosophical assumptions of qualitative research methodology are undergirded by four perspectives: ontological, epistemological, rhetorical, and axiological (Hays & Singh, 2022). These philosophical perspectives take an active and progressive approach to perspective-taking, knowledge construction, and research findings distribution, respectively (Hays & Singh, 2022). These are the bases for which a research question is created and understood, a study is directed, and the methods of inquiry employed.

This study aims to understand how Black adults describe their experiences and self-identity after undergoing a stem cell transplant as a curative treatment for sickle cell disease. It is essential to capture the voices of individuals affected and the nuances within their iterative process of meaning-making to fully understand this experience. This process highlights the nuances in how individuals negotiate their identity, both personally and systemically, in relation to their sickle cell diagnosis. This inquiry will utilize illness identity as a framework in which participants describe and understand their sense of self in relation to their SCD diagnosis. A critical research theory will examine healthcare as a system with structural forces that drive racial inequalities and medical mistrust. Including this critical perspective will serve as the lens to contextualize the role and impact the medical setting has on how participants negotiate their identity. Core tenets of this theory will also serve to center and highlight the voices of a racially and medically minoritized community.

Theoretical Framework

The following sections will outline the intentional use of theoretical framework and methodology as foundational to the qualitative inquiry of this community.

Critical Race Theory

Within communities of color, qualitative research can promote health equity for underserved populations, given its philosophical assumptions. As qualitative inquiry of individuals with sickle cell disease and hematopoietic stem cell transplant is few compared to the copious use of quantitative methodology in these areas, there is a need to center the voices of this community to understand the nuances of experience (Campbell, Dennis, Lopez, Matthew, and Choi, 2021). Positioning the biographical perspectives of participants in a particular way illuminates and centers the perspective of a minoritized community over the dominant voices and perspectives within the system (Zewude & Sharma, 2021; Ford & Airhihenbuwa, 2010; Delgado & Stefancic, 2012). With the harmful and exploitative history of research against Black people, there must be an understanding of how mistrust is woven within these communities (Guthrie, 2003). Researchers employing the use of qualitative research within minority communities must prepare to navigate responses of distrust or reluctance to disclosure with intentional reflection on the methods used and, ultimately, the impact this line of inquiry will have on the community who is participating (Campbell et al., 2021).

To more directly address the depth of experience of racial minorities enmeshed within the healthcare system and contextualize how that system has historically viewed and medically treated this community, the current study will utilize Critical Race Theory (CRT) as a theoretical framework. This study will use Critical Race Theory as a lens to frame medical mistrust as a byproduct of racial health disparities due to implicit bias experienced within the healthcare system. To incorporate this theory in a study aiming to understand self-identity in Black adults cured of sickle cell disease, there must be an acknowledgment of the healthcare system's integral role as the primary context in which they received treatment for their chronic illness. And now, serving as the primary setting for the curative treatment, this study will critically examine how self-identity is navigated in the medical setting.

Critical Research Paradigms

CRT is a critical research paradigm with an ontological, epistemological, axiological, rhetorical, and methodological basis. A critical research paradigm assumes 1) that reality is defined by those who hold the most power in society and simultaneously does not consider other ways of knowing, 2) knowledge is co-constructed so that intersecting cultural identities are essential for generating distinct ways of knowing, 3) researchers personal values are essential to acknowledging social injustice and promoting change, 4) highlighting participants voices by centering them in the research findings, and 5) designing studies that minimize exploitation during the inquiry process, use relevant data collection methods, and have results with a long-term, positive social impact on the participants (Hays & Singh, 2022).

Assumptions of CRT

In the 1970s, in the wake of the civil rights movement, legal scholars noted the barriers to promoting racial equity within the movement. Derrick Bell, a legal scholar, is credited as the founder of Critical Race Theory (Hays & Singh, 2022). CRT was used to address the unique needs of various communities (e.g., Asian Americans, Latinx). Legally, discriminatory practices were widely used against minority communities based on personal opinion. The discrimination based on opinion led scholars to use the legal system for "social transformation strategically" (Delgado & Stefancic, 2012).

CRT is based on theory-informed action and pedagogy to understand what structural or systemic factors propagate racial inequalities in contemporary society and work towards addressing them (Zewude & Sharma, 2021). There are six basic tenets of CRT: 1) racism is socially constructed, 2) racism is a normal part of society, 3) interest convergence, 4) differential racialization, 5) intersectionality, and 6) voice-of-color (Delgado & Stefancic, 2012).

CRT and Healthcare

CRT and medicine have a growing body of scholarship that examines how race and racism affect racial and ethnic minorities' experiences in healthcare. Utilizing CRT in the healthcare system, medical school curricula, and health policy has become a more prominent source of research inquiry (Zewude & Sharma, 2021). A critical examination of a racialized history in America is fundamental to understanding health inequities experienced by racially minoritized groups within the field of medicine, acknowledging racism as a social determinant of health, and contextualizing the pervasiveness of racial health inequalities among racial and ethnic minorities (Fernander, 2022). The relevant tenets from the literature underscoring the use of CRT in healthcare as a theoretical framework in this study include 1) Differential racialization, 2) Intersectionality, and 3) Voices-of-Color.

Differential racialization assumes an attribution of certain stereotypes or uses of race within a medical context that asserts negative beliefs about racial and ethnic minorities (Delgado & Stefancic, 2012). For example, there is a belief that Black people have a higher pain tolerance than White people (Hoffman et al., 2016). This implicit bias directly affects the population highlighted in this study as there is a pervasive experience of individuals with sickle cell disease noting they are not often believed about their level of pain by medical providers (Brennan-Cook, 2018; Bergs et al., 2022; Adegbola, 2012; Brooks & Hopkins, 2017), resulting in undertreatment of pain related to vaso-occlusive pain episodes (Todd, Green, Bonham, et al., 2006; Zempsky, 2010).

Intersectionality, as a key concept of CRT, posits that we all do not have one singular identity (Delgado & Stefancic, 2012). Our multifaceted identities converge on race, gender, sex, disability/health status, etc. With this notion, our identities comprise several components that cannot be separated. The convergence of these identities informs our social contexts and the particular ways we may experience inequalities (Kolivoski, 2022). In the current study, this concept will center on the interconnectedness of the participant's health status and race as a central thread interwoven within their identity and lived experiences. This concept will inform the interview questions surrounding the impact of medical mistrust on their identities post-transplant and how they negotiate their identity after transplant within the context of the medical setting.

Voice-of-color is another tenet of CRT that highlights "centering the margins" (Zewude & Sharma, 2021). Its purpose is to shift the broader discourse that holds the majority perspective to include and highlight the voices of minorities (Delgado & Stefancic, 2012; Ford & Airhihenbuwa, 2010). This concept validates that the representatives of marginalized groups embedded within the healthcare system are unique and valuable, not to be reduced to diagnosis or scrutiny. As race remains a significant factor in health disparities among racially minoritized groups, this invaluable perspective brings to the surface the history of discrimination and oppression amongst these groups that are not considered or known by the dominant race or culture (Delgado & Stefancic, 2012; Ford & Airhihenbuwa, 2010). This tenet is a thread through which this study is focused—centering and highlighting community voices to draw out the complexity of their experience and how a significant life event, like a stem cell transplant, impacts their identities.

Illness Identity

Kathy Charmaz's extensive research on the role of chronic illness is an impetus for a form of suffering (1983). She theorizes three sources of suffering that characterize a loss of self. These sources include 1) living a restricted life as the result of a chronic illness undermines one's autonomy or sense of control, 2) people living with a chronic illness receiving conflicting messages or comments that discredit their experiences, and 3) feelings of being a burden surface as their illness progresses and they lose the ability actualize their life goals in a way they once could or in the ways they hoped they could (Charmaz 1983).

Charmaz's works on the self, the body, and its intersection with illness lead to the theoretical concept of illness identity. Illness identity refers to the extent to which a chronic disease becomes an integral part of one's identity (Charmaz, 1995). As a sociological concept, illness identity aims to codify the process and impact of living with a chronic illness (Charmaz, 1995). Charmaz posits that there is a "threat to the integrity of the self" when having a chronic illness (1995, p. 657). She explains this intersection of the disease and the self in one mode of living. This mode is adaptation— the alteration of one's life and self to accommodate physical impairments or "losses" due to chronic illness (Charmaz, 1995). This adaptation method implies acknowledging that the illness affects their life and adapting to it reintegrates or reunifies a sense of self. She also recognizes other ways of living that people with chronic disease often negotiate at different stages of their lives. These include ignoring, minimizing, struggling against, reconciling, and embracing the illness. These ways of living are often contextualized by their life circumstances, multiple identities, and social settings (Charmaz, 1995). Adaptation is complicated by health status, as the person with a chronic illness may experience declining or failing health, which includes more acute episodes, crises, or complications of the disease (Charmaz, 1995, p. 658). One's illness identity requires a negotiation between an integrated sense of wholeness while simultaneously experiencing loss and suffering as the illness progresses. This negotiation involves renegotiating identity when presented with disruptive episodes or deteriorating conditions (Charmaz, 1995; Mathieson & Stan, 1995).

For individuals with SCD, illness identity serves as a framework to understand how the individual has come to understand (over time) what a chronic illness means to their identity and how they have negotiated that fact for themselves (Oris et al., 2018). This framework functions as a foundational assumption that each participant has an integrated identity with sickle cell disease that has culminated in "losses," adaptations, and renegotiations of their self, their body, and as the disease progressed, with more severe physical pain and complications, the ways they have constructed what their future can look like. Being born with this chronic illness, the process of adaptation in this community has spanned across decades of their life, with no other conception of reality outside of living with this illness. The concept of illness identity will frame stem cell transplant's impact on their self-identity. This assumption will be the basis for understanding how the participants developed an identity with sickle cell pre-transplant and, through the interviews, inquire if and how that identity was disrupted or changed after stem cell transplant.

Interpretative Phenomenological Analysis Methodology & Method

Given the exploratory nature of this study to capture Black adult's self-identity after receiving curative treatment for sickle cell, this research study will use Interpretative Phenomenological Analysis (IPA) as a qualitative methodology. IPA aims to understand individuals' subjective experiences with a phenomenon (Smith et al., 2022; 2008; 2015). In this case, the exploration of self-identity after undergoing a stem cell transplant. IPA will also serve as a methodology for analysis.

Interpretive Phenomenological Analysis was developed by Jonathan A. Smith with the primary aim of "exploring experience on its own terms" (Smith et al., 2022). First established in the Health Psychology field, this approach has been widely used and is best suited for in-depth analysis of the significance of experiences with chronic diseases, pain, and identity (Smith et al., 2022; 2015). IPA was chosen as the preferred qualitative method primarily because it is concerned with exploring participants' perspectives on their lived experiences, the meaning the experience holds, and the process of making meaning within that experience (Smith et al., 2022; Smith & Olsen, 2008). The IPA methodology has three influences: phenomenology, hermeneutics, and idiography.

Phenomenology, as a theory, seeks to understand lived experiences. Philosophically, phenomenology asks what the experience of being a human is like. Inquiring about what matters to individuals, what constitutes one's lived world' (perspective and context in which one is embedded), and how one comes to understand what their experiences are like (felt experience) underpin the approach of phenomenology (Smith et al., 2022). Researchers must "disengage from the activity and attend to the taken-for-granted experience of it" (Smith et al., 2022, p.8). This assertion points to the reflexive nature of the concept, where one looks inward to one's own experience of an event rather than solely focusing on it. IPA uses the theoretical basis of phenomenology by focusing on a person's lived experience in an event. It is also concerned with putting their internal experience in the context of factors like culture, language, and relationships (Smith et al., 2022).

Hermeneutics is a theory and approach to interpretation. It concerns the intricate relationship between parts and the whole (Smith et al., 2022). Hermeneutics aims include the purpose of interpretation, the possibility of uncovering the writer's original meaning, and the relevance of that meaning based on the context and time it was written (Smith et al., 2022). Smith et al. note that the significance of this writing is important not only to the time it occurred but also to the relevance of its interpretation at the time it is engaged with by the reader (2022). This approach considers grammatical and psychological interpretation—the objective textual meaning and the writer as an ever-evolving spirit. Combining these factors creates a body of work where the writer uses objective language to shape and convey their meanings. This meaning becomes potentially new as the reader or interpreter engages with the writer's discourse. Smith et al. explain how this process is considered an art that necessitates skill and intuition (2022). With IPA, the underpinnings of hermeneutics and its part-whole relationship, or the hermeneutic circle, inform the iterative approach to analysis—a dynamic and rhythmic process based on interpretation of a single word within the context of the whole sentence, the individual interview within the context of the whole research project, and the single event within the context of the whole life (Smith et al., 2022, p.23).

Idiography is concerned with detail, more specifically, the depth of analysis. It aims to understand how a particular group understands their experience in a specific context. With its focus on depth of understanding, idiography contrasts with the use of nomothetic inquiry, which is primarily concerned with collecting data and transforming it in a manner that can be generalized through measurement and inferential statistics (Smith et al., 2022). IPA considers this approach contrary to understanding individuals as it reduces the person to what is consistent across the majority rather than particular to the case. With IPA's distinction between detail and individual experience, there is value in the use of the single case or small purposive sampling, as it "demonstrates existence, not incidence" (Yin (1989) as cited in Smith et al., 2022, p. 25). Within IPA, idiography is used to highlight and understand multiple realities across the sample, not to make general claims, but to highlight and amplify the voices and unique realities of how a community or population experiences an event (Smith & Osborn, 2008; Smith et al., 2022).

IPA works well for this study because it aims to explore the details of an individual's experience and is essential to the method, make sense, and draws out the meaning that the explored experiences hold for the client. This method works well with sickle cell patients who have undergone stem cell transplants because it seeks to detail the nuanced and impactful ways their change in health status has affected their identity. IPA is also a promising methodology to explore the quality of life in individuals over 50 who underwent hematopoietic stem cell transplants for various hematological cancers (Gilfillan, 2011).

The basis of IPA is phenomenological. Phenomenology seeks to understand lived experiences (Giorgi, 2012). IPA takes this understanding a step further by having less concern with determining a specific concept or statement that perfectly defines the experience but instead highlights the dynamic process of making meaning of the experience—teasing out symbolic meaning rather than focusing solely on the generalizability of data. The researcher takes an active role in this process by getting as close as possible to the client's 'life-world' or personal, internal state of being. IPA assumes that completely grasping an individual's 'life world' can never happen directly or completely. Though complicated, the researcher must use their conceptions to make sense of the individual's world through a double hermeneutic (Smith & Osborn, 2008). Using a double hermeneutic is important to the sickle cell community because to understand their life-world, one must consider the intersecting systemic factors that contribute to how they see themselves and understand their world. These factors comprise the aforementioned theoretical frameworks—illness identity and its intersection with the healthcare system. IPA as a methodology works well with cultural issues and focuses on the context of experience (Smith et al., 2022). The concurrent use of these frameworks alongside this methodology further supports conducting meaningful research that centers on and highlights the participant, rather than overlooking important aspects of the client's identity, which would be reductionistic and extractive, only propagating mistrust and harm towards this community.

Data Collection and Analysis

Recruitment

IPA espouses the use of smaller sample sizes. Though IPA can include sample sizes as small as one case study, for individuals conducting studies for doctoral research, Smith et al. recommends 6 to 10 interviews (2022). Keeping the sample small further supports the aims of IPA to recruit participants who are the experts of the phenomena under examination.

Purposive sampling is vital to maintain the homogeneity of the sample. This sampling method aims to maintain a sample for whom the research question is meaningful and relevant

(Smith et al., 2022). Their rationale is to propagate breadth and depth of the research (Smith et al., 2022).

Due to the nature of IPA seeking very rich and individualized data, this sample will need to be as similar as possible and their similarity will be within the boundaries of the research topic. To keep the sample homogenous, the participants must have gone through the same medical experience, have a similar health status post-transplant, yet not be psychologically or cognitively impaired (i.e. no active psychosis, ability to communicate, read, write). However, participants may have varying physical complications, secondary to sickle cell disease, which the stem cell transplant does not reverse. Though this study cannot maintain 100% homogeneity, the variance of related complications only adds to the depth and richness of individual experience (Smith et al, 2022).

After receiving Institutional Review Board (IRB) approval from the researcher’s home institution, recruitment began from a large metropolitan hospital with a stem cell transplant program in the southern United States. Participants will be recruited using purposive sampling with the medical director of the stem cell transplant program. The medical director and clinical team identified a list of patients who met the study's inclusion criteria, and participants were approached and provided with recruitment flyers. Individuals who expressed interest in participating in the study were screened to ensure eligibility. Out of the six individuals screened, six met the study's criteria.

Inclusion Criteria

The screening tool included questions about the inclusion criteria for this study to confirm participant eligibility. Eligibility requirements included: (1) individuals of African descent, self-identifying as Black and/or African American, (2) at least 18 years or older, with a

(3) past diagnosis of Sickle Cell Disease, who are (4) at least 1-year post-Hematopoietic Stem Cell Transplant, (5) medically cleared of sickle cell disease by hematologist [e.g. blood phenotyping should be AA or align with trait typing, and resolution of active complications (no SCD related pain, anemia, no jaundice, not hospitalized for SCT complications)], (6) no longer taking immunosuppression medication, and (7) no current or active psychosis, or cognitive impairment inhibiting ability to communicate, read, or write.

Data Collection

Demographic Questionnaire

Prior to each interview, a brief, demographic questionnaire was disseminated by phone to establish and orient participants toward the sample's overall characteristics. Questions inquired about age, race, ethnicity, sexual orientation, education level, regional location, marital status, indigenous group, nationality, and gender. Additional questions included health history, such as sickle cell type, history of SCD complications, date of transplant, length of hospital stay, date of medical clearance from SCD, complications from stem cell transplant, and length of medical follow-up for transplant (see Table 1).

Semi-Structured Interviews

IPA recommends the use of an interview protocol that incorporates semi-structured interviews. This method serves as a guide and starting point for conducting the interviews, leaving room for the interview questions to change. This evolution of questions in real-time can create an interview catered to the participant to more fully describe or highlight the participant's experience (Singh & Hays, 2022). A semi-structured interview protocol can also evolve in the cadence and pace of the line of questioning and allow for the omission of certain questions to further hone in and amplify the voices and experiences of the participants (Singh & Hays, 2022).

The rationale for using this structure lies in the aims of IPA to gather rich data as it elicits feelings, thoughts, and related stories about the phenomena in question (Smith et al. 2022). Smith & Osborn note several advantages of using semi-structured interviews for IPA including, facilitating empathy and rapport building, greater flexibility in areas of inquiry, breadth and depth of data, and maximum opportunity for the participants to tell their own story (2008, p. 59). This process allowed for the researcher to enter, as far as possible, "the psychological and social world of the respondent" (Smith & Osborn, 2008, p.59), where the participant and researcher share the direction the interview takes, bringing up topics the other may have not thought to ask about. This type of collaborative relationship in the interview highlights the participant's role as an 'experimental expert' (Smith & Osborn, 2008).

Participants

A total of 6 individuals participated in the study. **Table 1** organizes all demographic data relevant to participants' transplant history. Participants ranged from age 26 – 48 at the time of data collection.

Participant Demographic Information

Lushay, 48, Woman, Heterosexual, Black/African American, Southern United States
Cash, 33, Man, Heterosexual, Black/African American, Midwestern United States
Reese, 33, Woman, Lesbian, Black/African American, Southern United States
Jullian, 26, Man, Gay, Black/African American, Midwestern United States
Nicole, 35, Woman, Heterosexual, Black/African American, Southern United States
GiGi, 47, Woman, Heterosexual, Black/African American, Southern United States

Table 1: Participant Transplant History

Pseudonym	Transplant-Age	Medically Cleared-Age	SCD type	SCD complications	SCT comp	Post-SCT complications	Length of f/u (years)
Lushay	44 years	46 years	**SS**	ESRD, Iron overload	GVHD; Meningitis; Stroke	None	**1.5**
Cash	(1) 22 years, (2) 25 years	25 years	**SS**	Stroke(s), Migraines	Liver Failure,	None	**7**

					Renal Failure		
Reese	28 years	29 years	**SS**	Gallbladder removed, Hip replacement(s), Pneumonia, Collapsed Lung	Fatigue, Dysuria	Night sweats, fatigue, hot flashes	**4**
Jullian	19 years	24 years	**SS**	Gallbladder removed, Appendix removed, Pneumonia, Priapism	None	Mental health diagnosis	**4**
Nicole	25-26 years	27-28 years	**SS**	HTN, Kidney issues	Wisdom tooth infection	Hormonal changes, Menstrual changes	**2-3**
GiGi	43 years	44 years	**SS**	Pulmonary hypertension, Acute chest syndrome, pain crises, headaches, Gallbladder removal	Tremors, skin breakouts, GVHD	Eczema	**3.5**

Procedures

Once interest and eligibility were confirmed, each interview was scheduled, Zoom information was shared with each participant, and consent forms were shared and reviewed with each participant prior to the interview. The consent process included one consent form (Appendix A). The researcher carefully reviewed each section of the consent form, including participant rights, risks and benefits of participation, confidentiality, and compensation schedule. Participants were asked about any questions or concerns. Participants shared their signed consent forms with the researcher, and they were securely stored on a password-protected computer. Participants were then provided with a demographic questionnaire to gather further supplemental information.

The semi-structured interviews, which lasted 60-90 minutes, were conducted in English via Zoom, a video conferencing platform, to accommodate the participants' locations and the researcher's distance, and were audio and video recorded. The interviews were guided by the interview guide (Appendix B). After the completion of the interview, all participants were asked about their experience and given instructions about next steps. Each participant agreed to participate in member checking. Each participant was then given a virtual $40 Vanilla Visa gift card to thank them for their participation, and each confirmed receipt of their gift card via email.

Data Analysis

Each interview was de-identified and transcribed using transcription software, and then checked for accuracy by the researcher and the research team, which included one master’s-level graduate student and one doctoral-level graduate student. This information and data were uploaded to an IRB approved secure, cloud-based storage site on a password-protected computer. Participants were engaged in member checking to ensure accurate representation of their interview or any clarifications they desired to make. The researcher was solely involved in updating, redacting, or editing transcripts based on participants’ feedback.

IPA aims to employ a thoughtful, in-depth approach to analysis to gain insight into the participant's psychological world. It is not a prescriptive process but one that the researcher can adapt. IPA's methodological inquiry is a personal process that requires interpretative work at each research stage.

The initial analysis begins with an in-depth iterative review of a single case (i.e., an individual transcript) before moving on to the others (Smith et al., 2008; 2022). Each transcript "represents a piece of the respondent's identity" (Smith et al., 2022). Instead of generalizing themes, the emphasis is on understanding the complexity and centrality of identified constructs

(Smith et al., 2008). The intention is to take an idiographic approach to analysis by identifying patterns within the dialogue. It shifts in expression in the use of language, the ways the person talks about themselves, and the amplifications of points and contradictions that may be present. This step included reading and re-reading the transcript to increase familiarity with the participant's interview while also consistently checking in on the researcher's own reflexivity through memoing, reflexive journaling, and consultation.

This process naturally lead to the second step of IPA analysis, where emerging themes are identified and documented utilizing Nvivo 15 software. These themes will draw out theoretical connections to the themes while also capturing the specific statements of the participants. Adjacent to this process, the research team will take notes on the content of the transcript as well as personal and professional knowledge that parallels it. These statements will delineate the shift from working only with the transcript to the interpretative aspect of IPA, where the researcher's interpretations (i.e., experiential statements) are also used for analysis. This process leads to mapping and organizing Personal Experiential Themes (PETs). PETs, or overarching themes derived from the single case transcript), include sub-themes from the experiential statements. The research team engaged in triple coding of each transcript to support in-depth interpretation of the themes and reduce researcher bias.

This process was replicated for each of the remaining transcripts. Then, cross-case analysis occurred where each PET was reviewed to find patterns of similarities and differences. The results from this higher level of analysis were used to create Group Experiential Themes (GETs). These themes highlight the unique and shared qualities of the experience among the participants. This process is iterative, as a comparison of data at the different levels of the analysis, as mentioned earlier, is reviewed in greater detail to uncover overlap or significant divergence from the group. Several questions will be considered during this cross-analysis process, including, "How does one sub-theme in one case reverberate across another? At which level is the commonality shared? Are there experiential features that are obviously universal?" (Smith et al., 2022 p. 100). The GETs were mapped and reviewed by the research team to represent overall themes found across participants and ensure they were informed by the PETs.

The last step of the IPA analysis process involved a formal write-up of the analytical process from the beginning to the end. This step offers fidelity to the process, where the researchers' steps for conducting the analysis are outlined indicating the stages of the interpretative process and how the data was used. This method enhances the trustworthiness of the data (Smith et al., 2022). The final write-up includes the meanings and inherent themes interpreted from the participant's experience. These themes will be transformed into a narrative. IPA denotes that the number of participants present in the study informs the researchers. With the recommended number of participants falling between seven and nine for doctoral graduate-level research, the researcher will be selective in using participant accounts that will be represented. Narrative arguments will be commingled amongst the overall themes, taking special care to delineate between the participant's verbatim accounts and the researcher's interpretation of those accounts (Smith et al., 2007; 2022).

Trustworthiness

Trustworthiness is the extent to which the qualitative study reflects participants' views and the context from which this study is inquiring. Hays and Singh state, "Can the findings be trusted?" (2022). Employing strategies to promote trustworthiness is vital to advancing the study's credibility, dependability, transferability, and confirmability (Hays & Singh, 2022). These methods include memos, consultation, member checking, and peer debriefing.

Memos

The researcher incorporated the use of memos during the data collection and analysis process of the study. Memos in the data collection and analysis phase included records of findings as they developed. Memos are like field notes where the researcher immerses themselves in the data and thinks critically about the meanings one finds (Birks et al., 2008). As the researcher noted their thoughts, it allows for in-the-moment perspectives and opinions to emerge. The use of this method also helps reduce researcher bias. Memoing explicitly increases the study's credibility, confirmability, and authenticity (Hays & Singh, 2022).

Consultation

In this study, the researcher engaged in frequent consultation of the data collection and analysis processes with three qualitative doctoral researchers who specialize in qualitative research design, one who specializes in the use of hermeneutics in qualitative research, one who utilizes interpretive qualitative analysis, and one who utilizes qualitative research methods such as grounded theory within marginalized communities. This ongoing consultative relationship supported the researcher in incorporating interviewing strategies and techniques to maximize participant voices, implement a robust interview protocol, and support the iterative analysis process (Hays & Singh, 2022).

Member Checking

As an additional measure to ensure trustworthiness, the researcher will use member checking during the data collection process to ensure accuracy in findings for analysis and ensure trustworthiness of the study (Hays & Singh, 2022). Member checking includes participants' review of interviews and transcripts with additional follow-up conversations with the researcher to ensure accuracy of the transcript, clarify meaning, and update information that participants wanted to clarify or update to ensure the accuracy of their narrative voice and portrayal of their experiences. All six participants were contacted by phone to review their transcripts and data.

Subjectivity Statement

My interest in this topic grew from my personal and professional experiences. I am a Black woman who grew up in the southern United States. I was raised in a multi-generational home where most of my family was raised. It started as a two-room home where my great-grandparents, Annie and Bernard, raised my grandmother. I lived with my mother, little brother, grandmother, and great-uncle. Embedded in my upbringing, I saw my family live with various chronic illnesses - diabetes, high blood pressure, and heart disease—and others succumb to them. I remember a little green plastic box on the counter in our kitchen where my granny would keep her blood pressure machine, blood glucose test strips, and needles for insulin.

The insulin vials would sit on the top right corner of the shelf in the refrigerator door. I would get the rubbing alcohol and cotton balls from the bathroom and sit at the dining room table and watch her take her blood sugar, take my uncle's, and give him insulin and his medicine for the day. So, understanding the impacts of chronic illness on the body and medication adherence was something I was very well aware of. But my family was shocked when my younger brother was diagnosed with Type I juvenile-onset diabetes at 15. It was the first time we heard of diabetes that wasn't acquired but a genetic disorder that no one anticipated or knew to prepare for. It was devastating to my mother as she was afraid she somehow failed and caused this to happen to him. She worked tirelessly to learn everything she could about how to help him manage this disease. The doctors assured my mom that he would live a relatively 'normal' life if he managed the condition properly. But for my brother, it was a huge transition. He was an active kid, and it was as if, overnight, his world changed. We notified his school and athletics coaches, his diet changed, and he started learning to give himself shots four times daily, monitor his blood sugar, and treat highs and lows. At this point, I slowly watched the light go out of his eyes. He was angry, easily irritated, began to isolate himself, and had trouble managing his symptoms. He hated that he was "different" and couldn't do what the other kids did without knowing he would have a life-threatening illness for the rest of his life.

I remember the day my mom told me. I had moved out of the house and lived in another city. I sat on my bathroom floor and wept. I was confused, angry, and afraid. He was just a kid and never bothered anyone. I tried to grapple with why this happened. I later suggested to my mom that he might benefit from a support group with other boys with diabetes, but he was reluctant to go. His doctor was unaware of many mental health options tailored to living with a chronic illness. It felt like a mad dash to deal with the physical implications of the disease. We did not have much time or financial resources to support this area of his health. Not much of a priority was given to the mental and emotional transition he would make as an adolescent with this life-long illness.

This impact on my family was also pivotal as I was trying to discover what I wanted to do post-grad. I'd wanted to be a psychologist, but out of fear and self-doubt, I chose to go a different route and seek a healthcare career in occupational therapy. While applying to programs, I decided to take a job in research administration in a large academic medical center in their Hematology/Oncology department. I wondered if someone was supporting individuals diagnosed with cancer with their mental health. In a past medical practicum site, I saw firsthand how acute traumas or terminal illnesses transformed people's lives. Most of the time, providers only attended to their physical conditions, but what about their mental health? In my new role, I began researching and learning about psycho-oncology and the intersection of psychological and physical health. I began to be mentored by a hematologist who cared for patients with sickle cell disease. I could share my newfound interests and curiosities on mental health and chronic illness. This physician educated me on the condition and the population it most affected—primarily Black and African American communities. I became curious yet conflicted because these people looked like me. They were dealing with a disease that was not only physically debilitating but included a mental and emotional burden. This realization was a pivotal moment in my life. It was as if my home life and my career were colliding. My brother was dealing with a physical illness, but it was my first time seeing the emotional burden so clearly and how it impacted many areas of his life. I was now learning about the burden on this young community of individuals with sickle cell. For me, it was a full-circle moment. Like the quote from Heraclitus, "No man ever steps in the same river twice. For it's not the same river, and he's not the same man." I had run away from the mental health field due to fear and doubt but ultimately returned with clarity and a new passion.

I pursued a master's degree in Clinical Mental Health counseling. During my internship, I worked with sickle cell patients as a student clinician and learned their unique stories. I got the privilege to serve these patients for a year as their therapist, understanding and supporting them through the struggles they were experiencing with their mental health. Many described struggling with the physical complications of the disease and how it negatively impacted their life. I remember one patient I worked with to advocate for herself when she would utilize the ED for pain. She felt she wasn't listened to about her pain or ignored for hours when she would express how debilitating the pain had become. Another patient I worked with would recall being told her pain couldn't be as bad as stated if she was "always on her phone playing games." I worked with another patient who was afraid of dying. Though he was so young, I learned how the life expectancy with sickle cell disease is about 42-48 years old on average (American Society of Hematology, 2023), and his 40th birthday was quickly approaching.

Patients often talked with me about their hopes and dreams. Many would share how they dreamed of attending college and starting a career. Others talked about how nice it would be to start a family. But as they lay in the hospital bed getting their monthly infusion treatment or blood transfusion, it was as if they quickly reminded me of how this disease was ultimately standing in the way of that dream. They eventually had to leave school because they missed so many days due to pain. They had to quit their job because the working conditions were too cold, and it often triggered pain crises. Some women believed they may never have the chance to become a mother due to the toll pregnancy would take on their bodies. Others shared the internalized guilt of potentially subjecting one of their children to a life with sickle cell disease if the parents passed it genetically.

My curiosity peaked as I became more immersed in the experience. I was deeply moved by how their backgrounds reminded me of my family. After being diagnosed with a chronic illness, my brother navigated what trade he could have that would accept him having diabetes. My mom and grandmother still experienced difficulty advocating for themselves in medical settings but often got their symptoms misunderstood and ultimately underdiagnosed.

I hold a special place in my heart for the sickle cell community as they hold similar identities to myself, as a Black woman, and those I grew up with in my family. Their unique experiences are complex as their identities have been woven within their health status since birth. But now, a stem cell transplant reverses the sickle cell diagnosis. It often leaves them navigating and adjusting to a new way of life and being in the world. This feeling reminds me of my little brother's experiences with a contextually opposite experience. He lived a life for 15 years without a chronic illness. After being diagnosed, a significant adjustment occurred--not only physically but how he understood himself with this illness. I believe having this perspective will bode well for my position within this research as I know the ways integrating this "new normal" can look. However, as an able-bodied person who does not live with a chronic illness, I am an outsider to some degree and do not have a fully embodied understanding of this community's experience. I don't know how it feels. This difference in positionality could impact my interview questions and how I may approach the study. It will be essential for me to have the advisory committee to share my role in the research and gain perspective from others who lived with this illness, what types of questions or explanations will help get to the issues of identity and lived experience post-transplant.

Using a critical research paradigm was also informed by how I've observed my family navigate medical settings and my experience working at the hospital for three years. Knowing the gaps in care for accessing medical care and the disproportionate effects of chronic illnesses on Black people has informed my line of questioning. The goal is to critically examine the healthcare system and how a sickle cell patient's identity is constructed and maintained. Secondary to its use within the research, I have recognized some of my blind spots. Thinking more critically about issues and problematizing the status quo is challenging. I realized that the system I have been embedded in for the last 20+ years has propagated a particular perspective and use of language based on theoretical psychology terms and the medical model. If not critically contextualized, this stance can reflect a hostile or deficit-based perspective of behaviors and feelings that do not capture the essence of the issue or population being discussed. For this study, instead of conceptualizing this community as "stuck" or having an "identity crisis," I have critically problematized this language and considered the ways this form of messaging places a negative connotation on what it means to be well or "healthy ."Problematizing this language also reflects how the unconscious bias already showing up toward this community only increases the negative stigma.

Even in my short time learning, researching, and spending time with this community, I have been humbled. With that position, I can learn and truly meet people where they are. It is that humility that I hope to reflect in this labor of love. This community is extraordinary and awe-inspiring. It is a gift to work with this community and a blessing that I can learn from them and share this work with the broader medical community by highlighting their stories and prioritizing their needs. It's the type of work I hope will honor my family and make them proud.

CHAPTER 4

RESULTS

The results of this study are presented and organized based on the identified Group Experiential Themes. These group themes evolved from the idiographic nature of the IPA process and the identification of Personal Experiential Themes across each participant's narratives. Group Experiential Themes include, 1) **The 'War' with Sickle Cell –** Impact of Living with a Chronic Illness, 2) **The Role of Medical Trauma--**Navigating Medical Settings, 3) **Light at The End of the Tunnel -** Adjustment during the 1st Year Following Transplant, 4) **As the Dust Settles--** Navigating Survivorship**, and 5) Evolution of Self-Identity After Transplant**. Themes are organized below in **Table 2** by theme and sub-themes.

Group Experiential Themes

Table 2: List of Group Experiential Themes

	Theme 1	**Theme 2**	**Theme 3**	**Theme 4**	**Theme 5**
	The 'War' with Sickle Cell – Impact of Living with a Chronic Illness	**The Role of Medical Trauma--** Navigating Medical Settings	**Light At the End of the Tunnel -** Adjustment during the 1st Year Following Transplant	**As the Dust Settles: Navigating Survivorship**	**Evolution of Self-Identity After Transplant**
Subtheme 1	*Realities of Life's Limitations*	*My Pain is Invisible, But I'm Not - Receiving Dismissive Health Care*	*The Rebirth with Recovery*	*Echoes of the Past - Lingering role of SCD after Transplant*	*I'm A Survivor: The Gift and the Grief*
Subtheme 2	*Navigating Life with SCD*	*Finally, Someone Who Gets It!*	*Embarking on Uncharted Territory*	*The Duality of a Cure*	*Unveiling a New Reflection and*

		- Receiving Intentional Health Care			*Casting a Brighter Light*
Subtheme 3	*Psychological toll of living with SCD*	*Taking Matters into My Own Hands - Navigating healthcare post-transplant*	*The Battle Between the Past and Present - Reimagining a new daily routine*	*The Weight of "What If?"*	
Subtheme 4	*Looking in the Mirror, And All I See is the Disease Staring Back at Me - Identifying with SCD*				
Subtheme 5	*Undergoing Stem Cell Transplant*				

The 'War' with Sickle Cell – Impact of Living with a Chronic Illness

Participants highlight the significant ways SCD shaped their lives and personal identity, like the reality of a shortened life and the burden of isolation and invisibility. Subthemes include: *1) Realities of Life's Limitations, 2) Navigating Life with SCD, 3) Psychological Toll of living with SCD, 4) Looking in the Mirror, And All I See is the Disease Staring Back at Me - Identifying with SCD, 5) Undergoing Stem Cell Transplant.*

Realities of Life's Limitations

Participants identify the limitations placed on their lives by living with SCD. Many identified the ways in which their view of themselves socially was constructed as they began to learn and internalize what this disease would mean for them.

Reese describes key memories from childhood with SCD that shaped her. She states,

> *I feel like I missed out on some experiences that other people had when they were younger. It affected my school life because I missed a lot of classes, often being in the hospital every month. I'd be in the hospital, doing homework, and trying to catch up with the other students. I feel like that set me back a bit in terms of my education. But going through all of that made me more determined to do better, catch up, and continue thriving as an adult. So, in a way, it helped me, but it also gave me certain core memories that have shaped who I am.*

Cash describes the depths at which he had to evaluate any activity he engaged in because of SCD. He describes,

> *Like, I know sometimes, like, I couldn't really spend a night over people house as much as I wanted to, just because they don't really... a lot of people don't really know about sickle cell or, like, what to do in that situation. So, I didn't really spend the night over people houses much as other people did. People have the night at my house, because, you know, my parents didn't want anything to happen or things like that. And if I did spend a night of somebody else, sometimes I did have to be rushed to the emergency room. So that's one of the examples. Because, like, like, they'll have me sleeping in front of a fan when I can't sleep in front of fans, and then it cause me to go into a crisis, and it's just little stuff like.*
>
> *I feel like I didn't get to experience some things that other people got to experience when they were younger. Also it affected me as far as school went because I missed a whole bunch of school because I was in hospital, like almost every month. So,*

> *I'll be like, in hospital, doing homework and stuff and trying to catch up with like the other students. So, I feel like that set me back a little bit as far as like my education was."*

GiGi explains the earliest memories that remind her that she had SCD because of the social implications it had. She describes,

> *So being in the education realm, I was exposed early to kind of like extracurricular things that you get into because of your academic achievements. Yes, and I remember, you know, quite often I would be the only black person in the room at times. And so, there was this event, and I'm trying to remember details, because it was middle school, so I can remember, but we were in this, like little conference room. It had been at least 50 of us kids that were invited to this, and it was a great thing, you know, teaching us about different academic things in medicine. So, I was like, oh, yay, you know, yes. And lo and behold, here comes sickle cell anemia, full blast on screen. And I'm like, wow, we're learning about something I have. So, I was so excited. I was so proud in that moment, I raised my hand, and I was like, I have this disease (laughing) trying to share with the whole group, and I'll never forget it. All of a sudden, all the kids just kind of looked at me like, What? Like, it was the most embarrassing thing in my life. And I learned from that moment, I'll never mention it (laughing) from then on, because it was so embarrassing. Just to find out it was almost I, I made it equivalent to, as if I said I had AIDS or something in the 80s. That's how bad I felt about even admitting that I was going through something like that. Because a lot of these diseases and disorders, they're looked at as if it's only in the books. You know, we don't expect real people to come out of those pages, and you know, be living and breathing with these things. So that was a pretty traumatic kind of event for me (becomes tearful).*

She provides another example of the mental associations she began to make with memories that were meant to be positive.

> *Yeah, very similar, like just or I could just remember, because I do remember we had like, a three-day pass to Bush gardens in Virginia, and I think I was one, the kid, the only kid that got sick the first day. So, whereas they have other memories of enjoying the whole three-day pass, you know, mine kind of stopped with the hospital out of town, you know. So, but, yeah, yeah, I guess it's, it's just just feeling like I would have enjoyed the experience more if I never got sick, or the vacation, or during this event, or, you know, I hate that. I always associated events with sickness."*

She expands on the difference she felt and how she began to question herself as she saw all the things everyone else could do but she could not.

> *It was the only time that I was limited in life. When you you know you want to do certain things, you start asking your parents, why am I so different? Why is this happening to me, especially when you have a rambunctious little brother who could do any and everything he wanted to do. He was involved in every sport, you know, things like that. But I just, you know, started going towards more academic things, which was fine, and I did find my calling in education, which is great and, you know, but little things I wish I could have done, like be a cheerleader, or, you know, I wanted to play softball. You think of things you wanted to do, but you just think that the disease really held back a lot of things.*

Jullian describes his high school experiences socially and the ways he attempted to overcome being ostracized in order to fit in.

> *Sickle cell, personally, defined me back then. My eyes were always yellow (speaker furrows brow). So, I couldn't hide anything (speaker shakes head). Even if I tried. So...feelings...I don't know. Feelings? My dad used to always be like, "Are you being bullied at school? Are you being bullied at here, A, B and C?" And my answer was always no. In hindsight, yes (speaker slightly smirks and tilts head to the side), a little I was. But I never really paid attention to it. I was more excited just happy to be in the room (speaker furrows brow in concentration). It really didn't matter how I got there. So, I'd never- I'd never really thought of myself as lesser than. I still had a very high sense of self-worth, just maybe not...I wasn't conscious of it.*
>
> *I was a bit- I was a people pleaser. In high school because I was sick so much, I made sure that when I was at school, I was in everything. I was in every club. I went to prom all four years because I set it up (speaker raises eyebrows and moves head to emphasize their school involvement).*
>
> *I managed the basketball team for four years to keep me out of the house. I was on every committee that I could. I said yes to a lot of things that I shouldn't have. But it shaped my high school experience. I knew- everybody knew me in high school. Teachers that didn't know- that I didn't have. Students that I wasn't friends with. I was known. Which, I guess, kind of made it harder for people to bully me, but it still happened. But when everybody's looking out for you, it's easier.*

Another participant describes losing work into adulthood because of SCD.

Lushay shares,

> *Because I even tried working in a dentist office, but that only last so long, and that was my dream, was to become a dentist. But when I got sick and I was out for a whole month, I got replaced. So, then I gave up on that dream of being in the dentist office (speaker shrugs shoulders). I'm like that'll never happen, because I'll be letting my patients down. If I'm in the hospital and can't be there now, they gotta find another dentist (speaker motions head to the side to place emphasis on 'another dentist').*

Navigating Life with SCD

Participants describe the unique ways they learned to navigate various challenges living with a chronic illness. They describe how navigating medical settings as children affected their self-identity. Reese describes how she navigated disclosure about her health status in occupational settings. She only spoke with her supervisor but made it a habit of never disclosing any of her health challenges with co-workers.

> *So, my job, I actually emailed my boss and talked to him on the phone and told him, like, hey, I'm going through this transplant. Like, I'm gonna be out for like, seven, eight months or whatever. And he was like, that's fine. And he let me off and went through the transplant, told him I was ready to come back. I came back, and, you know, we kept it pushing so, yeah, so I like that, because, I mean, not all jobs will do that. So, I mean, I think I have a really good boss, so that was nice. But, yeah, he was the only one I told about, like my sickle cell and history and stuff, because obviously I had to be off work if I was sick or things like that in the hospital. But nobody that I work with knew anything. Like, I don't really talk to people at work. Like, I go to work and my co workers and then I go home. Like, I don't really consider them like friends or nothing like that. So, like,*

> *whenever I had a job, I never told people about my history or background or nothing like that. Like, I just went to work. I work and I left.*

Professionally, GiGi also was hesitant to disclose her health status for fear of appearing incompetent or unable to be effective.

She explains,

> *Even sharing that I have a limitation with sickle cell because I never wanted people to feel like I couldn't do my job because it had nothing to do with my job. Me having to be hospitalized didnt take away my knowledge and my experience in my training, you know, absolutely, so it definitely was something I definitely did want to share in residency, you know and just haven't had the need to, because I feel like I've been blessed to be a good Doctor. Yes, that I will continue to be and now I won't have any limitations for real, for real that you would have to hide.*

She describes an example from residency,

> *Oh, yeah, like I told you after that one raising my hand in middle school, I never volunteered the information again, and if I could have gotten away with it, I would I remember being in residency, and I was having a crisis, and it started my legs and and I went to the hospital and everything, and I came back to the clinic and just told my co residents, oh, they said It was just a blood clot in my leg, and it didn't. It's gone away now. (laughs) I literally was an adult lying to grown adults because I didn't want them to know, you know.*

Participants explained other ways they had to navigate life with SCD for self-preservation.

GiGi describes,

> *So, [the hospital] became a big part of my life and Clarksville, being a smaller town, as you know, being from Tennessee, you know, it didn't have the greatest hospital. So, a lot of times I would be transferred up to [the children's hospital] to get the ultimate care. So, I'm great, very grateful for that. And I so, you know, yeah, that that was basically my childhood, just knowing that I had to be careful with my body. And you know, some of the crises were very extreme."*

Cash states,

> *Honestly, it made me cautious of how I operated as far as going out in certain weathers, like when it got cold outside, and Ohio was cold a lot. I had to dress warmer, and I was a very active kid, so I had to be cautious of staying hydrated, which I learned early on was key to being able to continue being an athlete (rubs eye). But swimming was the, probably the most difficult one, because I love the water, so I would have to dry off completely before going inside to an air conditioned, you know, house, or, you know, say, like a shelter at, like a full place, a pool park here in Toledo, so I'd dry off completely because I knew that could throw me into a crisis, just me not drying off completely so and then after my first stroke, that's really when I, you know, started to understand, like, this is pretty serious, because I had my first stroke at five while I was cleaning my room. So once the doctor explained to me how everything you know happened or why it possibly happened with the stroke, they came in like they literally asked me, would I have to, would I be okay with receiving a treatment that would help, or supposed to help reduce strokes, which was blood transfusions at the time, and I was like, okay, because I don't like this feeling. So, if I don't have to feel it again, then I'm all for it. And then they talked to my parents (rests head on hand), and we all just started, you know, we got on board*

with the program, but I still was moving cautious, because I didn't want to have another stroke, especially being a young not understanding, like, what caused it, like, all the way, so I would just be, like, more aware of what I did.

I mean that awareness never left. But as a kid, like my parent, my especially my dad, if some don't feel right, let me know…like when I had I had my second stroke in school, and I was seven, and I knew what a stroke felt like, and I knew what numbness felt like…I had the like elmer's glue bottle, and I went to squirt with my left hand. Left hand is numb, and so I told her, my hand is numb. I'm having another stroke. And she said, another one. She said, Go, sit down. So, what I did was I walked out of class at seven to go to the nurse's office so she could call my mama, and on my way to the nurse's station, I collapsed in the hallway and had to literally army crawl to the nurse's station. I yelled, help. Nobody was in the hall. Nobody heard me. And then I finally made it to the nurse's office, and laying on my back, I like looked up. I said, I'm having a stroke. Call my mom. So that right there taught me, Hey, I gotta, I gotta look out for my own help, because this lady who's supposed to care for the students didn't give a rat's butt about me in that moment.

…I realized, look, I didn't cause anything. I did everything I was supposed to do, right. I've been going to all my transfusion appointments. I drink a lot of water, because early on, I learned that that was the best thing for me while other kids are drinking juice and pop. My mom was like, No, you can have it, but you have to have a small amount. Because as active as I was, I learned that drinking soda and all these sugary drinks would dehydrate me quicker than water would. So, (inaudible) water or Gatorade was my go-to.

He elaborates on how he internalized this experience, feeling unable to separate a personal sense of identity from his identity living with SCD.

> *I'll say, but to me living with sickle cell, and I said this because I actually started writing the book, it reminded me of, in a sense, being imprisoned, in your own body, because it was unknown, you were prisoned. Because I didn't know if I was going to have a stroke or have a crisis, but I that's what I kind of associated with, because I never knew what was going to happen. So I definitely would move. I would move, you know, yeah, in the sense that was kind of protective of myself.*

Psychological toll of living with SCD

Participants share the psychological impact of living with the disease, noting a necessity to be strong despite being faced with the strong possibility of an early death due to disease complications.

Participants describe that they had to be strong, and they learned this very early. It permeated their identity not only as people living with SCD but Black men and women living with SCD.

Cash states, *"Yes, because my mental, my mental toughness, is just, it's just unwavering (shakes head), like nothing. Nothing phases me like if I knew, if I and then knowing that I could, I could go through all that and still be standing to this day."*

GiGi states,

> *You think of things you wanted to do, but you just think that the disease really held back a lot of things. But I mean, I, I really did. I was able to really overcome a whole lot and be ...I feel really bad for some patients, because they didn't have as great of a life. And I did.*

> *(cries more intensely) but I really have to be grateful. You know, by God's grace, I was able to have a really, I am able to have a really amazing life.*
>
> *You know, um, it, it really, yeah, I don't know, like it, like I was saying before, it kind of makes you have that mentality of, "I can't, I can't, I can't", like, physically. And so I always found strength in my mental strength and but I still have my brain. If I can't move my body, I can still think, I can still read, I can still learn, I can still, you know, grow some kind of way in that."*

Reese states,

> *I think it shaped me to become a stronger person. Just because all the stuff had to deal with growing up, people also treat you differently when they find out you have sickle cell. Yeah, so I think it made me stronger person. It made me become the person I am today.*

Two participants highlighted the requirement to be strong as it pertained to their identity as Black women. They saw strength as a requirement to navigate life as Black women with SCD and as Black mothers.

Nicole describes her experience as a Black woman navigating SCD, identifying as caring and taking care of others as part of this identity.

> *Um, as a black woman, it has made me a lot stronger and more independent, because I went through a lot on my own, you know, ended up, you know, at 10, having a stroke. So, like, it, it has shaped me in different ways that I guess if I didn't have it, I wouldn't, you know, understand and like, I'm more caring for people. I love my job taking care of people. Um [pause]…Um. It just made me a stronger woman altogether.*

She describes her experiences as a Black mother battling with SCD and seeing her overcoming potential death as a sign of strength.

> *The positive is like, um like, for instance [wipes tear], with me being sick, having sickle cell, having my child. I almost died having him. I made it through that. And it's just like it's whatever life throws my way [wipes tear] I can, I know I can make it through it.*

Lushay shares that she had to display strength even when she didn't want to. She then shares how living with sickle cell as a mother deeply impacted her.

She shares,

> *I had to be strong even when I didn't want to be…and the fact that I felt like most of the people that I knew actually they had sickle cell were females. So, I felt like it really didn't affect men as much as it affected females.*

When reflecting on motherhood, she states,

> *It was complicated, because I missed a lot of important milestones in my kid's life… Because I was in and out of the hospital a lot. And so, I had to heavily rely on family and friends to be able to take care of my kids every time I was in the hospital… I felt like I was an unfit mother, because I couldn't be there for them when they needed me the most.*

Participants explain the bleak realities of living with SCD. They describe the various times in their life when they were faced with the high likelihood of an early death—a common complication of SCD. They recount the ways this shaped their view of themselves and how they thought about their future.

Julian describes his mindset when it came to the impact of an early death from SCD. He notes he did not think of himself as having a future, and unfortunately, neither did his family, which continues to impact him today.

He states,

> *I was realistic. A bit more of a realist. And honestly, my mental health was trash. I could not- it was very hard for me to think positively about myself. Especially in the later half of high school, let alone the future. My future was pretty bleak. In that I did not see it. Like, I fully did not see my 21st birthday, let alone my 26th (speaker blinks slowly and makes direct eye contact with the camera). So, no, I never thought about anything (speaker rocks back and forth in chair) probably further than three days away.*
>
> *I guess it felt normal. That was just my normal. Even now, I still struggled to really plan. I have no real direction (speaker leans forward for emphasis), because I've realized, even my family did not expect me to get this far. We're here. I don't know what to do (speaker shrugs shoulders in uncertainty).*

Nicole describes how she resigned herself to an early death in her 20s from the complications of SCD. She states, *"No, honestly, I thought I would die before, at an early age, before I would ever be sickle cell free, because that's how bad it was."* She notes her doctors also gave her a prognosis of an early death from the amount of pain medication she needed to manage the disease. She recalls, *"And then one day a doctor was like, you know, we don't get this under control, you'll probably die from somebody giving you too much pain medication before you're 40 [crying]."* She elaborates on how it felt to hear this news and how it impacted her as a mother. She describes, *"[crying] [I felt] Heartbroken. I didn't know what to do, because I was like, I can't leave my child here without a mother or a father, because his father [wasnt] in the picture. Um, it was just like hopelessness."*

In the wake of this psychological turmoil, participants identify how they made sense of the distress they were navigating. When asked about mental health treatment, Nicole notes that though her mental health was severely impacted, in hindsight, she could not identify the severity as her physical health was paramount and didn't necessarily see attending to her mental health as significant.

> *I kind of felt like you have the right to be sad, you have the right to be depressed. maybe I shouldn't have looked at it that way, but that's the way I felt…Honestly, I felt like I didn't need [mental health therapy]. That was the last thing that I needed. Like I needed to be I felt like I needed to be whole in that name, in hindsight, your mental health is a lot to be whole. But I felt like if my health was failing, then what is my mental health? It's not that big of a deal.*
>
> *So I feel like if I'm having strokes, and I got problems with my kidneys, and I've got a heart murmur, and I've got, I'm in the hospital all the time, and I'm having transfusions back to back, and I've got iron overload, and I've got, you know, I've got to live off pain medication. What is the fact that I'm sad today? What does that really have to do with anything besides that, I know why I'm sad. I know why I'm depressed. I know why I don't want to get out of it, but that this, that was like minor to me at that moment.*

Cash describes the state of his mental health living with SCD and the ways he attempted to cope. He notes placing a lot of emphasis on his first transplant working, but noticing how holding in all his emotions may have led to his mental health worsening after his first failed transplant.

> *Yeah, I know it's a lot of especially with the sickle cell. It's tough. Like, and everybody, like, no one, likes to talk about how hard it actually is to deal with them, like, the illness period, and it's tough. Like, my watching my big brother go through things, and because*

> *he's the king of I'm "shutting down. I'm not saying nothing," and me, I'm like, I used to do that, and it didn't help me. It actually, that's actually what I think was a build-up to the depression that I had after my first transplant because I had such high hopes for it working after doing my research.*

Lushay explains the chronic suicidal ideation she experienced while living with SCD. She states,

> *With sickle cell it's a mental- with me it was mental. Like, really, really bad. 'Cause there were days where I just wanted to jump off a roof or open the car door and roll out while people were taking me to the hospital, because I was just tired (speaker shakes head in defeat). I was- I couldn't- I was like, "I can't do this." I just couldn't. It was hard.*

Looking in the Mirror, And All I See is the Disease Staring Back at Me - Identifying with SCD

Participants identify that living a life with SCD took many different shapes as far as how participants faced it—broadly shaping how they identified with the disease.

Despite the impact SCD had on their life, some participants refused to let SCD define them, some were enmeshed with the disease, and others found ways to accept the disease.

Jullian describes how his life was deeply intertwined and enmeshed with SCD. He explains,

> *My whole identity was sickle cell. So I couldn't escape it. Every science fair project was about sickle cell, every history project was about sickle cell. I had to send letters to teachers every year explaining what it was. I had to- I was a literal walking postcard everywhere I go, because my eyes were yellow (speaker closes eyes and leans body forward) and I have to explain to people, that's just it."*

Lushay describes how she empowers the younger generation by letting them know she played varsity sports as a teen despite living with SCD.

> *And so a lot of them was like, "Can you talk to my child? Because I feel like-" And then they be like, "The doctors say they can't play sports but they really want to play sports." And then explain to them, I played three sports in school. I played basketball, volleyball, and softball.*
>
> *And those are some extremely extensive sports. And I was just- they was like, "Well, how did you manage that?" And I was like- I was like, "Yeah, my doctor told me not to play sports either, but I just forged my mama's signatures on paperwork." (speaker begins to laugh) And, you know, so she thinking, I'm at- just at school for tutoring. No, I'm on the court playing. And it was until I got ready to graduate, and I got all these sports medals and stuff. And she like 'What?' Yeah, yeah. Like, most improved, MVP.*

Cash also describes playing sports with SCD when he was younger as an outlet from SCD.

> *But my outlet, the outlet for me, was sports. So basketball has always been my safe haven. I played basketball since I was like, two or three, so that was my outlet. I learned early on, like, when I'm playing basketball. Basketball, I'm free, like nothing. There's no judgment, like there might be from fans, but there's like, for me, I've learned how to block all that noise out on the court, and I played in front of hundreds and hundreds of people playing travel basketball. So wow, that was how I dealt with everything. I played basketball. I got my black belt in karate when I was eight. I played baseball. So sports was my outlet, because you definitely need to release.*

Reese describes how she lived her life despite SCD, even if it caused her more health complications, because she refused to let SCD stifle her life.

> *I still hung out and did things I probably shouldn't have been doing with sickle cell—going out, partying, drinking, and living the college life. It probably wasn't the best for me, and that's why I ended up in the hospital more often than not. But honestly, I lived like I didn't have sickle cell. So, there wasn't really a change in that aspect for me, whether socially or mentally. I've always been the type of person who decided I wasn't going to let sickle cell stop me from living my life the way I wanted to and missing out on experiences—unless I had no other option, like when I was younger.*

GiGi describes how she was pushed throughout life to fight back against the disease and live her life, and not become consumed by SCD. She explains,

> *But my parents were never that way, and I think that's how I got as far as I got. You know, and still being pushed. And I was fortunate to meet certain doctors like Dr A. (began to cry) I get emotional about him too, because he's so much like a father or Big Brother, I should say, because I'm 43 or 47 you know, by now. But I was 43 having the transplant, but anything I asked him about, like when my husband, I got married, I was still terrified about trying to have a baby, to have one anyway, he's like, sure, have a baby you know. (Laugh). Whatever you want to do, just do it! Oh I want to fly out the country. Yeah, let's go. Let's go. You know, just, just do what you want to do. Why are you letting this disease in this mindset, limit you. So I appreciate people that have been in my life the whole way. Just encourage me to keep going. You know, don't limit yourself. Keep dreaming. Just, just do what you want to do. Do not let the disease put in your mind that it's going to be halted at all.*

Cash describes how he changed his mindset to no longer let SCD control him, but adopted more of a mindset of acceptance.

> *Um, honestly, as a kid, I had low self esteem for a while, until I learned to accept the fact that I didn't cause this is something that just I was born with. So I also started, then I started living by the motto, the disease doesn't have me, or have to have me. I have a disease. So it's really about how I take care of myself, eating, right, exercising, trying to get the proper sleep.*

Undergoing Stem Cell Transplant

Participants describe their experiences of undergoing a hematopoietic stem cell transplant. Major highlights include the risks participants took when deciding to undergo transplant, the importance of family support, the difficult physical experiences of undergoing transplant, and the desire for mental health access. Participants describe what led them to seek out transplant as a curative treatment for sickle cell disease, highlighting the physical and emotional burden of living with SCD.

Gigi states,

> *Um, I, I really didn't seek it out. Um, I heard about it, but I thought it was just for young kids when I had heard, you know, they're doing it for young people. You know, I was in my 40s. I was, you know, dear, 43 and well, 43 when I got transfer, I started hearing about it, like 41 ish or so, okay, and, um, I remember having a doctor's appointment, and that's when the pulmonary hypertension had started, got it okay, and I remember thinking, Okay, I've lived and I've enjoyed life all these years. I've accomplished all these goals, and I've lived with the disease, and that was the first*

> *time I felt the disease. (begins to cry). I couldn't breathe. I was like, I just lost all hope. I never lost hope before. You know, just having to be on the oxygen, and I was literally in my office, I would... for an eight-hour day, I would, in between patients, put myself on oxygen in my office. It had just gotten so bad. Yeah, I just knew I couldn't survive, and something had to change. And I just remember talking about my quality of life had just diminished when that happened. So when I was diagnosed with pulmonary hypertension. And I was, I was seeking out something else, and that's what Dr. A asked me, if I had any siblings. I was like, why I have one brother? You know that. You ask me questions, and he already knows the answers, I felt. But I was like, Yeah, I've got one brother. And my mom was with me, and he's and he said, you know, let's look into something. I've been talking with your pulmonologist, and we think this may be an option. And he said, 'Well, in order to reverse pulmonary hypertension, we have to reverse sickle cell anemia'.*

Participants ultimately described excitement at the possibility of being cured of sickle cell, but they explained that the disruption of undergoing transplant would require dedicating several months to undergoing the transplant.

Gigi explains,

> *It was a great feeling, because there was always the feeling of, Oh, don't reject this. You know, I hope my body doesn't reject it at all. That was a big fear to have halted your whole life. I, you know, I had to get a substitute for my office because I'm the only dentist there, and I remember we had a date set, and I'm looking I'm talking to temp agencies. I've called all my friends just trying to see who can take time out to help me for six months because they told me it would be, you know, that's the time frame we were looking*

> *at to sneak out of the office for six months, and I was scared of my business failing if I didn't have somebody there, you know. But, and all in all, I was ready to risk it all, you know. And if I had to start over, I was going to start over, because I was just looking forward to a new life, and fortunately, God bless, I literally found the girl to substitute for me one month ahead of my transplant, one month ahead of the time I was supposed to check into the hospital. Gosh. So I got to work with her for two weeks before I went in. So she got to learn how I do things at the office, meet my staff, because I was scared of losing all my staff. I mean, if you don't have a business to run, you don't people stick around, you know, and I couldn't afford to pay them for six months, you know, to do nothing. So, you know, it was a blessing to find her.*

Participants describe how pivotal it was to receive support from their families as they decided to undergo a significant life-changing medical procedure.

Nicole describes,

> *It made me feel like whatever I was getting ready to go through next I had it, but with God and my family, I could get through it. And I knew the whole time I have a child I have to go home to so I'm going to make it through.*

Participants describe significant moments undergoing transplant that brought the risks and benefits of undergoing transplant clearly into view, leading to feelings of fear, anger, and overwhelm as they were once again faced with the possibility of death.

> *At first, I was so excited. I was like, it's something new. He was like, Well, okay, you know, we gotta find somebody that can be a donor. And so that kind of discouraged me a little bit, because you like his heart finding a donor, he was like, but I really think this is the best thing going for you. You know, I was so excited, and then my mama ended up*

> *being my donor. So that was even better, because I do have a half sister and a half brother for my father, but they're younger than me. I'm the oldest, so I'm like, 10 years older than both of them. So okay, their parents didn't even want to let them get tested. So luckily, my mama was able to do it, but it was like, I was so excited. I was ready, but at the same time I was going through medical assistant school, I was trying to get my life together. And so the day they called me and was like, she's a match. We got you set up. You gotta get here. We're going to do this. It will take six to eight months to feel at home here. I was like, okay, we can still do this, but it's like the day that I got there, and we were going through everything, and it's like a switch or something flipped in my head, and I was just evil [gestures hand]. I was mean to everybody. Mom was like, what's going on? I was like, I don't know. She was like, No, something's going on. You just being mean and rude to everybody. And then I said, you know, now that's here. You gotta think about the 10% or whatever death [crying], because I had to do my will and testament for my son. I had to do all of that stuff. It's just like I was so excited. But once in the game, it was like, what if this is it?*

Participants describe the physical and psychological toll of undergoing the regimen for stem cell transplant.

Reese explains,

> *I feel like I would, I feel like I would have been ready for certain things, like dealing with, Uh, dealing with, like, the after effects of the chemo, dealing with the complications of actually going through the process of getting the stem cells into my body. Because, like, my brother, like I said, he was the one who was my donor, and he had left, he had been discharged, and he went back to his girlfriend House, who lived in Nashville at the time,*

> *and I was on the phone with them. We was like, just talking my parents haven't got something to eat. And I was getting my my stem cells, and I got off the phone with them, and next thing I know, I felt like I was about to die. And I was like, What in the world is going on? So, yeah, if I had known or done more research, I could prepare myself mentally, because I just didn't know what was happening. I was in a whole lot of pain, and I just wanted to stop, like I didn't even care if they like OD'd me with pain medicine, like I was, it was crazy. So I think that would have changed that experience for me.*

Jullian described his experience of undergoing a transplant at a young age and making sense of what it meant to be in a research study with a significant amount of medical complexity.

> *I just- for so long, my body had...it wasn't my own. I never was fully autonomous in my body. And even in that transplant (speaker shrugs shoulders), it wasn't mine. I am the government's property right now. For the next five years until this works. It's not mine (speaker shifts in their seat)... It's just something that was done to me, not something that- you know, I mean, yes, I technically (speaker uses air quotes) had to choose it. But no. To this day, I still don't know what they did. You just told me to be here. Get hooked up to this chemo. Do this. Do that. Now you're fixed. I don't know what you did, but thank you (laughs).*

Participants describe how needing consistent or more mental health access during transplant would have benefited them, given the multiple emotional and physical stressors they were navigating at once.

> Jullian describes the lack of mental health access would have resulted in increased financial burdens,

> *Oh, I tried. They would not offer (speaker shakes head). Like, even in the hospital I asked to. So I think I saw maybe one (speaker squints eyes and furrows brow), one psychologist. While I was there during that 100 days, and then after that, it was always 'Our study doesn't focus on that. So it's a you thing.' And a you thing for a 19 year old is, 'I don't have money for that.' (speaker furrows brow and shakes head) You're paying for all the other medical things I definitely don't have money for this. And this was going to take a lot to unpack (speaker chuckles).*

Reese goes on to explain that despite the family support she had, it would have been helpful to have additional support outside of family to reduce caregiver burden.

She states,

> *I would talk to my wife or whatever, but it felt like I was dumping a lot onto that one person. And my wife was already helping me through so much and I don't know what she was dealing with mentally. It's nice to have a second outlet—someone who specializes in it and can give you useful feedback and tools to help you get through it. And you can reach out to them when needed. Going through the transplant, you have your high days and low days, so having someone you can reach out to would have been really helpful.*

The Role of Medical Trauma--Navigating Medical Settings

Participants describe how their experiences navigating medical settings, both positive and negative, impact their approach to seeking out and engaging with healthcare services post-transplant. Subthemes include*: 1) My Pain is Invisible, But I'm Not - Receiving Dismissive Health Care, 2) Receiving Intentional Health Care, 3) Current relationship to healthcare post-transplant.*

My Pain is Invisible, But I'm Not – Navigating Trauma in Health Care

Participants identify the poor healthcare experiences they've had that have impacted their view of the healthcare system. Lushay describes accounts of a common experience she had when visiting the ED for pain crises.

> *When I would have to go to the ER, because I felt like...they didn't look at us, look at me, as being really, really in the amount of pain I was in, because I have found coping mechanisms to help me cope with the pain, because I knew I was going to be sitting in the waiting area for several hours. Because six hours is a long time to go without any liquids and pain meds, and it only makes it worse. So I figured if I'm able to be on the phone to talk to somebody, or if I'm playing a game on my phone, it helps block some of the pain because I'm focusing on something else. And so they will take it as, "Oh, she ain't in that much pain. She's on her phone, or she's talking to some-" (speaker shrugs shoulders in agitation), you know, and that will bother me the most, because I'm like, I can't sit here in front of a room full of people and just be crying, and they looking at me like I'm crazy, and then having y'all telling me to be quiet, because I'm not the only person that's sick. You know, but you in excruciating pain, so you do what you have to do to manage so that people don't look at you like that, because it's embarrassing going in the emergency room in that amount of pain, and they're not doing anything.*
>
> *And I've been in emergency waiting areas where I've seen it be crowded (speaker places emphasis on "crowded"). And then it gets empty, and I'm still the only one still sitting there waiting to see a doctor and then it be labeled as a pain med seeker. It's just unfair. It's really unfair because I don't really even want the pain meds. I just want the IV fluids to help get my cells back going through my body. And they don't be understanding*

> *that. And one time when I got admitted and they put me on a PCA pump, they was just pumping morphine in my system, no IV fluids or nothing. And I said something, and it was like, "Well, we thought you just wanted pay meds." No! (shakes head in frustration) Yeah, I'm not- I don't want to be addicted to that. I've seen several of my friends get addicted to the pain meds, and I didn't want that for myself. And so I was like, "Can I please get some fluids?" I can't just sit here and just get all this morphine in my body. It's poison.*
>
> *And it's just a band-aid 'cause it just helps me rest. It's not really working. So I'd rather have the IV fluids versus the pain meds, because I'm used to the pain at this point. Yes, it hurts a lot, but least I know I'm not getting addicted. That's the part that hurts the most. When they label us. They just here for pain meds. Not everybody is like that.*
>
> *But then when I look at I'm like, but y'all the ones that made them addicted because of how much y'all would give them when they come in. And even when they tell you it's not working, then y'all just up the dose, and that doesn't help us either."*

Nicole describes unfair stereotypes she experienced in the hospital.

> Um, some of them were not positive, because a lot of people, especially here [gesture "here" by pointing down], that's how it ended up in Nashville, okay, like you're speaking, like you want to just want pain medicine, and you're not in pain, or, you know, like you should be able to live with This. You've been through it for a long time.

She shares an example describing the way her illness and pain experience were categorized as a mental illness.

> *One day I was in the hospital, and I was asleep, I finally got some rest, and the way I was hurting, I was laying in the bed weird, but one of the docs, like they sent a mental doctor*

> *in because they said that they didn't, they didn't know what else to do. It had to be mental [cries]. And he said that I was overmedicated and cut my pain medication.*

She recalls the provider's rationale for cutting her medication. *"[crying] Because he said I was laying in the bed weird. That doesn't make sense to me, like, if you're in pain and you finally get some relief, the way you're going to go to sleep is where you get relief. But yeah. So he shut it off, and he was like, I...he was like, I believe that you're over medicated, and this is just, just looking for medication."*

Nicole describes how these experiences impacted her. She states, *"[Brief pause, gazing into space] It was infuriating, heartbreaking, like I just didn't know what to do. My family didn't know what to do. They done some research, and finally figured out how to get to A."*

Jullian describes his experience in the hospital for a pain crisis that was also interpreted as a mental health crisis.

> *Boom, I'm on the floor in like 10 seconds. And I had to, like, call my neighbor that was across the hall to call an ambulance to take me- literally my dorm was literally- they shared a parking lot with the hospital. I was so pissed (speaker rolls their eyes). And I ended up going there, these doctors, and not really know sickle cell, they called me a drug addict. They did not believe my pain. So much so that they put me on...what is it, a 5150?*
>
> *Yeah, for like 72 hours. They refused medicine, and they sedated me, and tied me down. And then when they eventually did talk to some doctors that knew sickle cell they were like, 'Oh my gosh. Sorry.' It was a whole thing. I was- and I ended up, the trip that could have been like a two-day thing turned into almost two weeks.*

Jullian shares the feelings he had about this encounter, but describes the way he rationalized this mistreatment by taking the blame for choosing to live/go to school in a place known for a high incidence of medical racism.

> *Anger, I mean... (speaker chuckles and shakes head) I can't fault them for not knowing- well, I can because you're doctors and this was a big hospital. You're a teaching hospital at the biggest school in the state. But also still can't fault them. (speaker shakes head) Medical racism is there, and I knew where I was. So that's on me choosing to go to school there (speaker tilts head and leans forward)… Yeah, I put myself in that situation. I did not have to go to college there (speaker shakes head).*

GiGi describes the impact of these stereotypes on her as a Black person and how she'd held these experiences in because of how hard they are to discuss.

> *But the other thing that's hard, and I know I need to talk about, is whenever you went to the hospital as a black person. I almost felt like one, nobody knew what the disease was, that was very hard. And two, you were always viewed as a drug seeker. That's always hard for me to talk about. I always admire people that can talk about their lives and their stories with a smile… (tearful) But it didn't matter how smart you were, how far you got in life, the minute you came in with that kind of pain that no one can see, no one can visualize that you broke your arm or your leg and to have such extreme pain and you can't explain it, and no one understands it was one of the hardest things, and it almost felt like we were ostracized because it was a black disease. You know, that's just how it felt. So glad I got that out (laughed).*

Some participants describe reactions they've received from new providers who realize they have SCD.

Reese states,

> *When they understood what it was, it made for a positive experience. But if they didn't know, they would refer me to another doctor. I had one doctor who, after seeing my medical record—which is pretty long—told me I needed to go back to my regular doctor because they didn't want to treat me due to my sickle cell history. That was really frustrating because I wasn't even having a crisis at the time; I just had a normal sickness. It was crazy.*

Jullian states,

> *And so those resources out there were severely lacking. Oftentimes, I was taken by ambulance from West Virginia to D.C. for treatment. So that happened at least- (speaker smiles and shakes head in disbelief) at least seven times, in a five-year period. The medical system in West Virginia was...lackluster and a bit naive. So most of the doctors wouldn't treat me. Well, not the pediatric doctors. The pediatric doctors would not treat me (speaker closes eyes and slowly shakes head). And I ended up getting, the adult oncologist that my mom was seeing to treat me. So still not the right doctor. But it was someone.*

Participants share similar reactions to how they've made sense of these providers and their treatment—one that refuses to give providers reactions credence but instead reframe those experiences to focus on what they can control, such as choosing a different provider, rather than focusing on those who refuse or circumvent responsibility to care.

Jullian states,

> *At first, I was mad at the pediatric doctors, but in hindsight, no, great (speaker widens eyes). If you don't think you can do it, don't touch me. Don't- don't do it (speaker shakes*

> *head). And they didn't. That was great. And he said, ‘I'm wiping my hands of it.’ (speaker uses hands to motion "wiping hands") Don't- I mean, as a patient, that's hard to hear… But as someone who's like, I get- you don't want to mess me up. I get it. Don't-*

Participants describe the impact of learning at a young age how to navigate medical settings because it was not feasible for their families to attend every appointment. Cash explains that he struggled with his parents not being present during these visits, but as he grew older, he understood the financial sacrifices they were making for him.

He shares,

> *I mean, going through all of that, you're in there a lot by yourself, because hospitals in general, because and kids don't understand, like, or we understand mom and dad gotta work, but when we're in there by ourselves, like, Why you gotta work today? You can't, you know, take off to be with me. And then the older I got, I started to understand mom and dad gotta have money to pay these hospital bills. Um. Because the first time I saw a bill, it came in my name and not my mom. So I opened my mail, of course, and I said, Oh, snap, this wasn't meant for me. So then it clicked. It clicked that, hey, that's why mom and dad have to work. But my parents always have prepared me to, you know, because they've always said it one day mom and dad won't be here, so you got to know how to take care of yourself. Um, so my parents, from my early age, taught me how to take, when to take my medication, like the proper dosage I needed to take, if it wasn’t on the bottle. So I've, from the age of, I want to say, like seven or eight. I've known when they get up and take my medicine at first, it was the maximum folic acid, but then they then research came out that that after you about seven or eight has literally no effect. So they moved us to hydroxyurea, and then they had me on an iron chelation drug as well, which was*

> *getting poked and getting a needle put in my leg every night while this machine was sent to me. And (pause) that that sucked as a kid. You know, I always really I might do what my dad said. Always told me you got to do what you got to do to make sure you survive. If you getting poked in the leg every night. I gotta do it. Sometimes my leg will swell up from the needle or whatever, and I might have to go to school, walk to school. I have to go to school with a limp, yes, but the next that, that next night, I just use the other leg.*

He describes how these experiences he had as a child impacted him into young adulthood. He explains how he went to therapy to process the impacts it had on him and recognize the various beliefs he internalized about himself due to managing SCD.

> *After the first transplant I did, because that was the first time I experienced depression. And so we had a, we had a therapist, we had a counseling service on campus. So my girlfriend, at the time saw me, like change, like my attitude and behavior had change, like you maybe do want to go talk to the people. So I went to the counseling center, and I spoke to one of the therapists in there, and she was like, she told me, I had some unresolved issues, because the main one was um and it doesn't bug me anymore, but it used to. The first time I had to go to get my transfusion by myself was my mom pulling up to the in front of the hospital, saying, All right, go ahead. You know where to go. And I looked over and I said, You're not coming. She said, No, Mom, mommy, gotta go to work. And she said, you know where to go. You know who not to talk to and who to talk to. And so I went in there to the I went to my point about myself, like, your mom's not coming. I was like, no, she has to work. And that first moment, like looking at that as a kid, I cried before they actually started my IV for my transfusion, because I'm like, Damn, I'm in here by myself, and it was scary. But you know, my dad's words have always stuck with me.*

> *You gotta do what you gotta do for yourself so you can survive, because mom and dad won't always be here. And at the age of eight, just having to go through that process by myself.*

Julian describes the loss of boyhood due to having to mature quickly to become his own advocate in medical settings. He learned to find his voice and challenge the actions of adults at the behest of his mother's teaching because she also had to work and could not always be present with him at the hospital.

> *I really often wasn't allowed to be a kid or a boy (speaker closes eyes in reflection), because of my sickle cell and because of the spaces I had to navigate. Sometimes, I had to be my own advocate. I would have to, you know, stay at the hospital by myself. Talk to people with multiple degrees and tell them what's happening. And actually speak well enough to get them to listen.*
>
> *Usually, when I speak, people listen. My mom that's testament to her. She taught me- yeah, she taught me how to communicate, especially with doctors. She also had sickle cell. And so it was a- I had a great teacher. So by the time I was like seven, I could run down my medical chart. I was filling out the papers they hand you in the ER. I was answering the questions. Because she had to go to work (speaker laughs). So 'you need to- you need to be able to be me when I'm not here' (speaker lightly hits table with hand for emphasis).*
>
> *So I have had some nurses were very mad at me. I can remember being in children's hospital here in Detroit and calling the floor nurse. And because my nurse was just- like, she had violated my privacy. I was not having it (speaker furrows brow and*

> *shakes head in irritation). And that nurse did not like that, I called her boss. I was like, "Well, you have to do a better job." (speaker shrugs shoulders and slightly chuckles).*
>
> *Just because we are children does not mean you don't not knock. You don't- You don't get to do that (speaker shakes head). I can remember that instance, because it was the first time an adult was really like, "Oh, this is- I was called out by a kid. Like hold on." (speaker chuckles) No, she was very mad, and I had to end up switching nurses because she became vindictive (speaker furrows brow and scratches head).*

Finally, Someone Who Gets It! - Receiving Intentional Health Care

Participants then juxtapose these negative experiences to positive experiences they had with healthcare services throughout their lives. Lushay describes her experiences navigating different Emergency Departments. She explains,

> *One time I was in a crisis and I was in (speaker places head on forehead in reflection) Murfreesboro. And going through the ED was totally different than going through an ED in Nashville. They took me back right away. And the same thing in Smyrna, because it's richer neighborhoods (speaker twists both hands to emphasize "richer neighborhoods"). They took me right back in no wait time. So yes, I do notice the difference (speaker nods head), but then it's like, but who want to drive out that far (speaker leans head to the side to express the physical distance) just to get good health care?*

Jullian describes the quality of the healthcare system based on location. He states, *"Well, the healthcare system in Detroit was pretty smooth. They have one of the largest sickle cell populations in the country here. Where it changed is when I moved, we moved to West Virginia when I was in eighth grade (speaker closes eyes in reflection)."*

GiGi explains her perspective on the ways healthcare has improved especially for individuals living with SCD.

> *Oh, yeah, yeah, a lot more, especially the further along the research has gone with sickle cell. You know, as much it has it, it has advanced just so much. And rarely do you say, Now, I have sickle cell anemia, and people don't know what it is anymore, not like it used to be, you know, people like, oh, okay, yeah. And they actually can mention a friend or a cousin that may have dealt with it, or a family they know, yes, and so we're not like this invisible disease anymore, and people are better understanding how our bodies are... or were.*

Lushay describes the positive treatment she received that led to her finding out about stem cell transplant.

> *Yeah. And I was like- we was in the stem cell clinic. So I'm just thinking it's just for cancer patients, not thinking that they was using for sickle cell (speaker rests hand on chin). So I saw Dr. A because, of course, they do last first before you see them. So about time he saw me, he said, "I could tell you everything that's wrong with you, and I could fix it." And he said, "You're an iron overload. I need to put you on this (speaker uses index finger to place emphasis on "this"). You've had too many trans- blood transfusers in your life span. It's causing your liver to fail. That's why you keep getting sick." (speaker places emphasis on 'sick').*
>
> *And so I started his treatment and regimen, and I know the sickle cell crises. And then one day I just asked, I said, 'Why are you down here in stem cell and not up on the hematology floor in the hematology clinic?' And that's when he explained to me that he*

> *see cancer patients too, and he's done stem cell transplants. And I just started inquiring about it (speaker scratches forehead).*
>
> *And he told me I would be the perfect candidate, and the rest is history (speaker shrugs shoulders).*

Reese and Jullian describe positive experiences with Black physicians.

Jullian states, *"My first impression of him was good because I hadn't had a black doctor in five years. Let alone a man (speaker widens eyes for emphasis). So that was, you know, a high."*

Nicole describes her experience with her transplant team.

> *The only positive, trustworthy experiences that I've ever had with a doctor is with Dr. A, no matter what I went through, no matter what I've told him, he has only done was best for me… Um, [wipes face] he told he told me, after we doing everything we could do with the transfusions, the medication. And he was like, you know, I feel that we're at the point where we need to try this transplant. He was like, because I don't, he told me the truth. He was like, we can keep doing what we're doing, or we can try this because there's nothing else left to do for you. He was like a year too young to die from being over medicated or from a problem from sickle cell… I love them like they were great. They took care of everything that I needed from health to somewhere to stay, to just everything I needed. Like, I have no complaints about them.*

Reese states,

> *The only positive experiences I've had were with Black doctors, or when I came across someone who was familiar with sickle cell. Not everyone knows about it, even though many do. When they understood what it was, it made for a positive experience. But if they didn't know, they would refer me to another doctor. I had one doctor who, after seeing*

> *my medical record—which is pretty long—told me I needed to go back to my regular doctor because they didn't want to treat me due to my sickle cell history. That was really frustrating because I wasn't even having a crisis at the time; I just had a normal sickness. It was crazy.*

Jullian explains what defined his improved relationship with healthcare.

> *Oh, I became extremely trusting of the medical system. Probably thanks to Dr. A. Yeah. He kept his promise, which was a very, very strong promise. (speaker nods head and chuckles) And I don't think a doctor has done that, or at least for me. That was- like, when I say that, my first conversation with him was very like, "What just happened? Who was this man? He's legitimately crazy." (speaker leans body forward for emphasis) I have never had, like, it was the shortest doctor's appointment ever (speaker leans back and clasps hands together).*

The majority of the participants describe their positive experiences with their transplant team as receiving holistic patient-centered care, which felt compassionate and proactive.

Lushay states,

> *I would be in there crying, so that they would hear me in the hallway (speaker uses hand to motion to the "hallway"). And come rushing in. "You okay?" I'm like, "It just hurts." (speaker holds up their hand and clenches their hand to emphasize the pain) 'Cause my kidneys were contracting so bad doing that part that I couldn't wait for that to be over with. But I just thank God that Dr. A and his team were proactive on everything that they knew was going to happen and how to treat it.*

Jullian states,

> *Oh, they were great (speaker rocks back and forth in excitement). They were great. If I could still see them every year, I would. I liked them (speaker nods head). They're great. The whole team was Black. The hospital food was good. My room was private. They stand by their word. Okay, I got this transplant. I didn't have to pay for anything… Um, so they- they kept [their word]. And they were- they discussed what possibly could happen. I was very well informed of what to expect. Um, they were not- it wasn't like a "Oh, we don't know what's going to happen this. And we'll see." No, they knew (speaker nods head). And they told me. And they were like, "Don't freak out." And they were, it's very- it allowed me not to care as much. I was able to put my trust in someone else.*

GiGi explains how she saw her relationship with the team.

> *I was fortunate to meet certain doctors like Dr A. (began to cry) I get emotional about him too, because he's so much like a father or Big Brother, I should say, because I'm 43 or 47 you know, by now. But I was 43 having the transplant, but anything I asked him about, like when my husband, I got married, I was still terrified about trying to have a baby, to have one anyway, he's like, sure, have a baby you know. (Laugh). Whatever you want to do, just do it! Oh I want to fly out the country. Yeah, let's go. Let's go. You know, just, just do what you want to do. Why are you letting this disease in this mindset, limit you. So I appreciate people that have been in my life the whole way. Just encourage me to keep going. You know, don't limit yourself. Keep dreaming. Just, just do what you want to do. Do not let the disease put in your mind that it's going to be halted at all.*

Taking Matters Into My Own Hands - Navigating healthcare post-transplant

Participants reflect on what they've learned about the healthcare system since undergoing transplant and how their past experiences have shaped their healthcare decision-making process. Participants continue to highlight the lack of knowledge and competent care of SCD in emergency departments. They also highlight the role of medical racism and systemic factors such as insurance that deepen the divide and negatively impact the quality of care they receive. Lushay identifies what she has learned about the healthcare system.

> *It really needs to change, because even in school, medical school, they don't even teach you all the side effects and things that sickle cell does when a person has a crisis. And my thing is, with the lack of knowledge...that's one of the reasons why, when we're in the ER, we're not getting back as fast as we should. Because of their lack of knowledge. Because one thing I hate the most when going into the ER, is a doctor asking me, "Well, how long have you had sickle cell?" (speaker leans head forward and squints eyes in agitation)… It's a trigger, 'cause it's like, if you know anything about sickle cell, you know it's something you're born with. You can't just- it just don't occur overnight (speakers shakes and leans head forward to express agitation) You know? So then that makes me agitated and I don't even want you to be my doctor (speaker shakes head). Give me somebody else.*

GiGi shares how her role as a medical provider impacts her perspective on the lack of knowledge and experience with individuals living with SCD.

> *Oh, yeah. I mean, you just have to, well, I do have a different perspective being a provider now that sometimes we just don't know everything. Sometimes you only know what you were taught in the book or in that lecture. And I mean, as we know, even with*

> *talking about black history. There are certain parts of history we never learned about, you know, until now. That's sad to say, but people don't elaborate, or they just kind of stop the the information, you know, can be very limited in certain books, and of course, some of them are the same books we've been using for years.*

Nicole reflects on why she struggles to trust the healthcare system.

> *They look at you different as a black person, for some reason, especially here, they're kind of racist here. I mean, the main thing was, it just goes back to but I think it was more of not them being racist. They just didn't know what to do, okay, and so their answer was to feed you, pain medicine, pain medication, and give you just blood transfusions and fluids, because they didn't know what to do.*

Jullian describes his lack of trust in healthcare, but rather in his family. He states, "*I ain't trust any of them (speaker furrows brow and shakes head). I trusted my mother. So my mom was like, 'We're gonna do this. This is my doctor, who's gonna help you.' I'm gonna trust her. Yeah, that's really it. I didn't really, I wasn't really thinking of like, the medical system as a whole back then.*"

Participants described their reactions to the changes in the quality of healthcare they receive now that they no longer have SCD. Lushay describes her experience going to the same hospital that stereotyped her as drug seeking when she would visit for pain crises.

> *[I feel] Indifferent, because now, like, if I go to [the hospital], so that's where I go the most (speaker brings hands together and interlocks fingers). So if I go in there now and I'm sick...like I could- one time I was there...what was I there for? It was something serious but I didn't even think it was as serious. It's just my doctor's office was closed, and the ER was what was open. And they took me straight back. And I was like, "Now, if I*

> *was here in a pain crisis, y'all wouldn't have took me straight back in a hospital full like this." 'Cause when I tell you, it was full full (speaker leans head forward to emphasize on "full"), there was nowhere to sit (speaker shakes head).*
>
> *And they took me straight back. And then I was thinking, if I would have said I'm here in a sickle cell crisis, how long would I would have had to have to wait?... But now it's different. When I go in, the wait time is not as long as it would have been if I was there in a sickle cell crisis.*

Reese describes her experiences navigating healthcare post-transplant.

> *Thankfully, I haven't had to go to the emergency room. The doctors here in Memphis are really good and pretty nice. Now that they know I've had a transplant, they treat me differently. They seem to care more. They'll ask, 'So, you're cured of sickle cell now?' and I'll say, 'Yeah,' and then they move forward. But I feel like if I still had sickle cell, I'd be running into the same issues I faced before.*

Nicole describes her reactions to the new treatment she receives from healthcare providers after the transplant.

> *It was kind of frustrating. I mean, I guess maybe I should have been happy, but I was more frustrated… because it was like, I guess I feel like I wasn't believed then, but now, because I'm not on any pain medication, and I'm not there a lot I'm not it's fine. Now you know what I'm saying.*
>
> *...Everything's kind of easy and basic. Now, it's my goal. Get my... I still have blood pressure and kidney stuff to have to take care of, but I take care of that. My kidneys are doing good. My blood pressure is lately has been low, off the charts, but I've been going through some stress and some some other stuff, but I feel I'm like a normal person*

> *because I'm not on pain medicine and they don't have a reason, look at me as I'm seeking. And that was a big like, I keep saying that, but that was, like, a big part of it.*

Lushay describes the changes she has seen and learned about in the quality of insurance and how this translates to a difference in care.

> *Ugh, some things are never changing in the healthcare system. And...I look at it as...that's just how the healthcare system works. It's like, I feel that depending on your insurance, because I noticed the difference in my insurance and my daughter's insurance. Mm hmm. The treatment because, like- because I have Metro insurance, because I'm a with Metro government now. It's like, "Oh." You get better treatment than you did when you just on Medicare or TennCare. There's a total difference in the rooms, the type of food you get, even though it's the same menu, but it's just the quality.*
>
> *And the better rooms that you get to get. 'Cause my daughter's like, "Every time I come see you, they got you in the newer part. And you this, you that. But I'm always over in the old hospital." (speaker leans head to the side to emphasize the different hospitals) 'Cause [they] has two hospitals.*
>
> *And she's always in the first hospital. She's never in the [hospital]. She's always at North and I was like, "I think it's the insurance." And then...with being...insurance. You know, working in the insurance. I noticed there's a bias with the insurance. With your age, your geographic figures, and income and the different types of insurance that you get. It's like, the more benefits and the more you pay for your health care coverage, the better your experience will be (speaker motions hand to emphasize each variable). Versus when you're in lower class, how you're treated. Yeah. And based on the communities as well… it's called a culture indifference.*

She shares information she learned after intentionally seeking out training in sickle cell care to learn more about the quality of care and disparities in healthcare for this community.

> *I learned that when going through...the...I did some training on sickle cell healthcare work, becoming a community healthcare worker in sickle cell. You learn the difference. And then it was like, 'In different neighborhoods, they have this. In the poorer neighborhoods, they don't have this, but they need it in their communities.' (speaker leans head side to side to emphasize the 'different neighborhoods'). And that plays a role in it as well. They look at all- the health care system looks at all of that in judging which patients they gon' help first. You know, and things like that too.*

Participants now identify certain qualities they look for in providers when engaging in healthcare.

Reese states,

> *Whenever I get a doctor, I make sure they're Black. I've had experiences with doctors who didn't believe I was in pain because they said I didn't look like I was in pain. One time, a doctor refused to give me any pain medication, so I was just sitting there in pain until I had to tell another doctor, and she finally gave me something. It's been very difficult. Because of those experiences, I make sure all my doctors are African American who are educated on sickle cell, including my hormone replacement doctor, who is also Black and understands sickle cell. Being Black is hard enough, and being black with sickle cell has been really tough, so I need to feel understood and supported by my healthcare providers.*

Reese further explains,

> *I still prefer to choose African American doctors if I can. If I have the option, I will, but if I can't, that's fine too. I don't have an issue with it. For example, one of my doctors isn't African American, but she's really good. She takes care of basic things like colds or the flu, and she's very nice and helpful. So, if I can choose a Black doctor, I will, but if not, it's not a problem.*
>
> *It's just a preference. But if they're not Black, they still need to be non-discriminatory and, you know, treat me well. They have to be a good doctor and be skilled at what they do, absolutely.*

GiGi describes the type of care she hopes for in healthcare and attempts to exemplify as a provider.

> *And so a lot of times, I I've been very impressed with doctors and physicians that, um, don't give me a blank stare, but they're like, "Yeah, I've been looking into this", or, you know, "I've, read about, I'm very interested in that", or just as simple, "I understand". I've learned that me saying that to my parents and patients, you know, I understand what you're going through, because you can always pick out something that you can relate to. There's always something, instead of looking at people like, Uh you don't brush?, like (laughs). why would you not brush, you know, yeah. But how many times have I been sick in a hospital and just didn't feel like doing it, you know? And easily get a pass, you know? And I mean, everybody I don't know, I don't want to believe, and maybe there are people out here like that, but I don't believe there's anybody that hadn't taken a day off of brushing their teeth. So honestly, you know, as any type of physician, they can relate to a child who just needed to jump in a pool, but still got a sickle cell crisis, you know, instead*

> *of just being mean about it, or, you know, how dare, you know, how this will make you feel. You know, as a sickle cell patient, you can't do such and such, you know, instead of the ones like, just try, you know, and. Just relax or calm down or don't do it as much if you feel like. I did have one physician tell me learn your body, your body is different, you know, and learn how it affects you, especially when I was learning more and more about how some patients deal with things that I never dealt with, or, they didn't deal with what I did, you know. So you really have to take it as an individual basis, you know. And I'm almost glad we don't all fit in a box, you know. People do have to take time to get to know each and every situation. So it's a good thing too, you know, so.*

At the same time, some participants identify that their negative experiences in healthcare when living with SCD have now led them to avoid going to hospitals.

Jullian explains,

> *Oh, no, I am healthy. There is no reason for me to go to the hospital (speaker shakes head). I do a sniff, a cough. I had COVID before they realized, like, what COVID was. I had been sick for three weeks. Just guzzling water. Still couldn't go to classes, still missing stuff. And I'm like, "Why am I doing this? I'm healthy. What's going on?" And my dad was like, "Jullian, go to the hospital." I'm like, "No." He's like, "Go to the hospital. You are completely dehydrated. Go to the hospital.*

GiGi explains,

> *But that is the mentality of my sickle cell. As soon as I felt better, I feel I can go back to life as normal, you know, I and I think that was an easy way for me, I guess, not to be addicted to medication like people wanted to assume you would be, because it was only used to get me out of pain once I'm better, I can be just like you, and I can continue on*

> *with my life. I don't need the feeling of, gosh, what they say, being high. I want to be out of pain. Yes. So a lot of people don't understand that, like, once we're done with it, we're done with it, you know, we're ready to move on to the next one. I don't want to stay in this hospital number one…I know some people are very comfortable, you know, the minute they have a sniffle, I gotta go to urgent care, and I'm like, No, I'm gonna try everything I can until I absolutely need to go for sure.*

Light At The End of the Tunnel - Adjustment during the 1st Year Following Transplant

Following the first year after undergoing stem cell transplant, participants identified several sub-themes related to the initial adjustment period following transplant. These themes include *a) The Recovery Process, b) A New Life Imagined, and c) The Fear of Trying.*

The Rebirth in Recovery

Most of the participants described navigating the initial recovery process after undergoing a medically extensive, multiply traumatic, and time-intensive transplant. For example, Lushay described her experience attending several follow-up medical appointments and the emotional and physical toll it took on her. She explained,

> *I gotta get up every morning and come back for 100 days. Y'all could've kept me in the hospital for this. You know, 'cause there were days where I was just trying- so tired I didn't want to get out of bed (speaker rubs the side of their face to emphasize fatigue). But I had to push through it and go to these appointments. And I'm like, I could've stayed at home, you know?*

Jullian described,

> *And then I had- I was even more frail than I already was (speaker clasps hands together and bring them to their chest) I need to find- I need to go look at these medical records*

> *and see how small I got during my transplant (speaker claps for emphasis)… But I was small. I solidly was 125, maybe, maybe (speaker emphasizes maybe) when we started. So I probably easily went down to like 97, 100 pounds.*

And similarly, Nicole shared,

> *Um, it was basically healing, you know, getting my hair back, getting my health back, because I had a few complications afterwards [wipes around nose]. You know, where they had left my line in my arm and stuff, because they I wanted to go home. It was Thanksgiving, and gotcha, get my the line out there for my IV, my cell. Your line out in time. And I ended up getting like, three blood clots and my arms, so I had to deal with that. Of course, you know, you got chemo and radiation. So, you know, you gotta get your hair back, you gotta get your skin and stuff back together. You gotta get healthy. So basically, it was basically just trying to spend time with my child and get myself back healthy. And my mom, at that point in time, was living with me, taking care of me, trying to make sure that everything was together.*

Embarking on Uncharted Territory

As participants neared the end of the acute recovery period, participants identified the significance of embarking on a life without SCD. Reese described the reaction she had when first realizing her blood levels were stabilizing deeming her officially medically cleared of SCD. She stated, "*My blood work was still a bit off at first, but after a few checkups, it started to normalize. It felt surreal.*" Conversely, Jullian describes his reaction to the recovery process and the variability in the timeline as he waited a few years to see his blood levels normalize and remain consistently stable. He described,

> *Um...I really didn't take [it] that seriously then. Because I still was having a lot of the side effects from the antivirals and the steroids. And I was still taking stuff. So I still had something. And it wasn't, 'You don't have sickle cell anymore.' It was, 'We don't see it in your blood currently.' A big difference in the wording that came in 2023… It was 'Okay, we don't see it.' Then it was like, 'Okay, we don't see it in your blood right now.' And then, in 2023 it was like, 'Nope. We tested you four times in the same room. It's improving, improving, improving. We haven't seen it in your blood in however long and-' They were thinking confidently so, you don't have it. And then they told me my hemoglobin, it was a lot. It was the highest I've ever heard. And it was wow, it was a lot (speaker closes eyes and leans back).*

Lushay described her reaction to being medically cleared of SCD as, *"Joy. Happy. Like, thank God. And knowing that, what he said- God said He was going to do, He did. Because a pastor had told me years ago, God is going to heal you."* She goes on to highlight how she shared this reaction with her community, she stated *"And when that, so when that day come, it was tears of joy. I mean, I cried. The whole world, or whoever was on social media got to see me cry, because I was documenting my process every day and posting it in a group, on sickle- on a sickle cell group, and on my stories."*

Cash explained how he found out he was medically cleared of SCD, and it was confirmation of a hope he had always held onto, especially as this was his second attempt at stem cell transplant.

> *…the freedom I felt when that, it wasn't even Dr. A who told me I was cured. It was, I think, I don't know if she was a doctor. She was a resident. She may have been a resident, and I'll never forget her name was (inaudible), and she walked into my room and she*

> *took my vitals, and on her way out, she stopped at the curtain and said, Oh yeah, by the way, you're cured (gestures hand). I broke down and cried right there, because I'm like, this is because I had always told my mom, I'm going to beat this. And she would look at me like I was crazy, because I was like, I beat this. If there's, if somebody said there's a cure, I'm getting it.*

Many participants described the new world of opportunities they were presented with, many of which were once impossibilities when living with SCD. Reese states, *“I was happy. I was like, oh, man, I can go to go out the country to this place, or go this place. And I was like, now I can go to Colorado, because I was told I couldn't go to Colorado because of my sickle cell. I was like, oh, and I can go to Colorado. Like, you know, I was like, super excited.”*
She further elaborates on why she couldn’t make this type of trip with SCD, *“Yeah, the altitude was a big concern because it’s so high up, especially with my collapsed lung. So, they told me, 'Nah, you can't go to Colorado.' But I’d always heard it was beautiful. So, when I realized I could finally go, I was excited.”*

Nicole describes past opportunities she had to put on hold because of treatment that she can now pursue. *“The first thing in my mind was, well, you know, let's go back to school. Let's, let's finish school. Because I was so close to the end of it before the transplant, I was so close to the end of it, so I had, like, six months well, so I was like, let's finish that.”*

The Battle Between the Past and Present - Reimagining A New Daily Routine

Participants then identify ways their lives changed after transplant. Reese states, “mostly, my daily routine changed.” Participants explain ways they adjusted to their daily routines, indicating similarities and differences in the ways they lived their lives with SCD compared to without. Cash describes what it was like not to go to the hospital for SCD or take several meds for transplant.

> *I would say (pause in reflection), not going to the doctors, not going to the hospital and getting labs drawn every four to six weeks, because I was in such a routine of doing that from the age of 5 to 26 it was like, it was a part of me that was like, dang, I gotta go. No, I don't! For the first like, I want to say, Yeah, eight months, like, it's time to call and schedule my labs, but then it's like, you don't, and then not taking all those medications that they had me on, because the first transplant was like 25 pills a day. The second transplant was like around 36 different pills a day. So not having to be in that medical realm mindset was a huge adjustment, because I'm I was so used to, you know, going to hospitals. And now, when I walk to hospitals, I kind of feel uncomfortable because it's like, and I get like this, and I would get this nervousness over me, like, Okay, I used to be in here all the time, but now, since I haven't been like, having to go as like, at all, really, yeah, it's been the that's been a big adjustment, too. But hey (shrugs), I'm here, so I'm thankful.*

Julian described the emotional experience he had when realizing he no longer needed to follow his regular disease management routine after forgetting to carry along his daily medications.

> *The first time that I had that realization was probably a few months before that, and I was driving to school from Michigan (speaker leans body forward for emphasis). And I had- I was, like, at half. I had just got into Pennsylvania, so I'm more than halfway through my drive, and I realized I forgot my pill bag. And I had to pull over, and I had, like, a slight panic attack, and started crying. And then I had to go through a list of pros*

> *and cons. Like, do I need this? (speaker squints eyes and leans body forward) Do I really need this one? When's the last time you used this? When's the last time you opened this? When's the- do you need this? And I came to the conclusion that I didn't and I kept driving. But I think I cried for about 30 minutes (speaker begins to chuckle).*

Other participants described that their daily routines didn't change much. When asked what new ways of living she had to get used to, Reese goes on to state,

> *No, because even when I had sickle cell, I still lived my life as if I didn't have it. I didn't want to be limited by something I had no control over. When I was younger, for example, I played basketball—even though the doctors told me not to. I still made the basketball team and played, and I also bowled. I kept doing normal everyday activities. So, my life didn't change that much, except for the daily routine of managing my condition, like taking my meds and making sure I stayed hydrated. I don't have to take meds anymore, but I still stay hydrated and keep up with other healthy habits. Mostly, my daily routine changed, but not my ability to live and do the things I enjoy.*

GiGi further purports that her lifestyle and daily routine remained the same after transplant.

> *Hmm adjustment? I don't know. I you know, I've just continued life as usual. I know some patients like, maybe they they were held back from continuing their education, had to drop out of school, or, you know, didn't move to where they wanted to be, or, you know, I just didn't have those limits thankfully, you know. So I'm very, very blessed that I can just continue on with life as usual, you know, and just keep looking forward to bigger and better, you know, to my business growing, it's been thriving.*

Participants shared physical changes, leading to a new relationship with their body. Identifying the impact of no longer having pain crises and noticing improvements or changes in how their bodies responded to their environments. Lushay explains, "*Yes, when the weather's changed (speaker slightly chuckles). I know I'm like- I'm not in pain. I'm not getting sick. I could go out in the rain, and if I get wet, I'm not worried about, 'Oh, I'm fixing to start aching in that spot.' Or being able to go to the pool and not have to dry completely off and go in a heated room now. I could be in the AC still and don't get sick. And that's when I was like, 'This is real. I am really cured of sickle cell' (speaker nods head slowly to place emphasis on each word).*"

GiGi describes how she knew the transplant worked by her experience doing a regular activity, traveling. Where once she had to prime her body with Tylenol to reduce the chance for pain episodes, she found that she made it through her travels without any SCD symptoms.
She states,

> *I wanted to, you know, just kind of thank my mom for being there the whole time. So I took her on this conference, and it was to Phoenix, Arizona. Okay, so that was another thing about going to a higher altitude place. I was terrified. I was like, Oh no, not only am I getting on the plane, but I'm in Phoenix, but this will be a real test, you know, and this was not quite a year after my transplant, it was end of March. And so my transplant was May 6, so it was end of March, not quite a year, and I went through that whole trip with no symptoms. I didn't have to take Tylenol. I didn't take it before the plane ride. I didn't need it during the trip, I didn't have any symptoms at all. And it was the greatest feeling ever, like it was, yes, it was like, it really, really worked, you know. So that was my first experience realizing that I just had the trait, you know.*

Cash describes feeling more in-tune with his body and adjusting to new sensations. He states, *“I'm more. I’m more in tune, um, I'm definitely more in tune with, like, my body. So something like, what I've always been so something doesn't feel right. I'm saying something I'll get like, but now, thank God, everything's been feeling regular, if that makes sense, so I haven't had any complications or anything.”*

Reese elaborates on her relationship with her body as she engaged in exercise, a hobby she had before the transplant. She states,

> *I still wasn’t sure at first, so I had to ease my way into it, testing how far I could push myself and learning my body all over again. Yeah, you really do have to re-learn your body after something like that. I think it worked out pretty well, especially with having a coach who could guide me through the process.*

Julian’s new observations about his body were solidified after experiencing a traumatic event. He described how this experience led him to realize his body reacted differently and wouldn’t be sent into crisis under these dire circumstances.

> *What solidified would be... (speaker scratches head and runs hands down their face) I was drugged in college. And we were at this river, and before I found out I was drugged, I had gone over. The current had taken me on this floaty, and I had gone over like, two waterfalls. It was very traumatic and definitely could've drowned. And I eventually did get out of that water, but I was like, thanking God for not drowning… And I ended up walking like 10 miles to get away from them because I didn't have cell service. And that was, like, a big thing. I had done so much that day. I had swam in a river, never done that. I had, well, gone over two waterfalls. But, you know, still protected my, you know, vital organs in my head and stuff. And I used knowledge I had learned from Cub Scouts*

> *and my dad. And then I also still consciously, you know, left the situation. And I was able to walk and just keep walking. And before, I could not walk that long. So I remember that. And then I remember getting home that day and going to bed and like, I woke up the next day like it was normal. Like nothing happened, and it- I was shocked. I didn't have to take Motrin and I didn't have to take anything to make me feel better or anything. It was very like, 'Oh, you're normal. This is what they do.' Like you can go through something and then just wake up the next morning like nothing happened.*

Reese and Nicole described the experience of having more energy in a way they had not before or during the transplant.

Reese states*, "I have more energy now, and I feel stronger. I don't feel as weak anymore. It's hard to explain, but it just feels different—like something shifted inside me. You really have to go through it to understand it on an internal level."* Nicole states, *"Once I started healing and stuff, I had more energy. I was not lethargic. I was not in pain"*. She elaborates, noting this energy was not just physical in nature but it had an impact on her mood and disposition—*"My outlook on life changed. Like I was happier. I was just full of energy. I was just, it was just different, like, it was just, I can't really explain it, it was just like it was something in the air."*

Conversely, participants identified other changes to their daily lives after transplant outside of the physical experience—they highlighted the unique losses they had to adjust to. Nicole described the difference transplant made in her life in part due to financial adjustments that were triggered after being medically cleared of SCD.

> *And then the next part was, cause of this whole time, you know, it's just me and my son, so I'm taking care of him. And then it's like, well, you know, eventually, because I was on Social Security, you know, eventually you're going to get cut off social security, because*

> *you're considered, 'well now' so now we gotta find a job. We gotta be able to take care of ourselves. You know, we're stepping into what I called "adult world" now, because I was sheltered like my whole life, I was sheltered my family, they wouldn't let me outside that much. They wouldn't let me do hardly anything because I was sick. So it's going from being… even as an adult, because I didn't get, you know, my transplant until later in life, I was still sheltered, like I had my my social security check, but I still lived with my mom for a while, and then when I finally got into my own apartment, it was based on income, so it wasn't Like I had real responsibilities, if that makes sense. So it was just like, basically, like, it's time to just become an adult. It's time to adult.*

Jullian further expands on this sentiment when describing the multiple losses he realized he faced after transplant. He states,

> *Like everyone who went through this, yes, their whole life has changed. But for me, in a- excuse me, In a 24 month period, I had lost my high school. Lost my friends, my house, my dog, my mother. A decent relationship with my dad. Lost some organs, and now I've lost one of the major parts of my identity. All just back to back to back to back (speaker widens eyes and claps hands for emphasis). And it was non stop, and I was just expected to just keep going (speaker rocks back and forth).*

Similarly, Nicole reflects on the magnitude of what she lost after transplant. She shares,

> *Um, it was happiness. It was kind of unbelievable. It was kind of sad at the same time for the unknown, because it was like, Well, I've been sick from the day that I was born. So what am I supposed to do in my life? You don't know nothing but hospitals and doctors and medicine and so it's like, what do I do next?*

As the Dust Settles: Navigating Survivorship

Participants identified the group experiential theme of Navigating Survivorship as it was salient across their narratives and reflections of life after transplant. This theme offers a glimpse into the 4-7 years following transplant, where participants continue to live sickle cell-free lives. Subthemes include *1) Echoes of the Past - Lingering role of SCD after Transplant, 2) The Duality of a Cure, 3) The Weight of "What If?".*

Echoes of the Past - Lingering role of SCD after Transplant

Participants identify that after the recovery process, there are lingering complications from sickle cell or stem cell transplant that continue to impact their lives well into survivorship. This includes living with lingering complications.

Cash describes the lingering effects of complications from several strokes he had as a child.

> *I just happen to have multiple strokes, yes, and then the fact that I have very few residual effects from the stroke, like my left side is weaker, because all my strokes hit my left side. They affected my left side. Every single one. But they don't just because, like, they don't see it like, Oh, you look fine. I am, but you know, stuff is no one's perfect.*

Nicole describes some residual complications of sickle cell that she lives with.

> *I still do have, like, aches and pains, like my hips and back and stuff sometimes are, you know, don't feel the best, but, and I still have kidney issues, but I think that, you know, it all stems from sickle cell, and I feel like to get away from for what I do have, I came out lucky because I didn't have, I haven't had to have a transplant for, you know, like a hip transplant or a knee transplant, or, you know, repair or anything, which I think probably in the next two years I probably will with my hips, because, you know, they're just that*

> *bad. I go to bend over like they get stuck or or something, but I feel like I have came out pretty good.*

GiGi shares, *"So I still am on night oxygen, you know, like I said, and so I still am reminded about sickle cell. And so maybe that's where the hesitancy comes, because it's still in the back of my mind that, okay, I'm slowly healing from some things, not as quickly from as others, you know, but, but yeah, yeah, yeah, but it is much better."*

Participants describe the complications they experience that linger from transplant. Reese explains, "*After the transplant, though, my hormones were out of balance, and I was dealing with hot flashes until I started hormone replacement therapy, which helped a lot. But that's a whole other topic."*

And GiGi shares her experience,

> *I so I talked about those areas of my skin that will often break out, like extreme eczema or something. So I still, you know, am really careful about what I put on my skin. I don't try to try all the products or anything like that. I still, I mean, I don't feel like I have sickle cell pain, but I feel like I do get and Dr. A described it as almost like an arthritis kind of feeling. So I can't say I'm completely pain free with things, but I think just being 40, I never wore glasses until I turned 40 either. But, you know, little things like that. I think it's maybe more with age, but, but yeah, even with the with me getting over the pulmonary hypertension, that's still been a process.*

The Duality of a Cure

Participants identified the ways life continued to evolve, impacting their quality of life, mental health, and spiritual growth as they moved past the initial adjustment period post-transplant into survivorship.

Participants identified the best things that have come from undergoing the transplant.

Reese states, *"the best things...not having sickle cell and just being able to live my life how I want to, without having to worry about it.*

Jullian states,

> *The best thing is no pain. I am not drugged all the time. I'm not in pain and don't wake up in pain, don't go to sleep in pain (speaker shakes head). I don't think about it. I don't think about how long I'll have to stand somewhere, or if I can last walking all day when I go somewhere, or things like that. No transfusions. There are no- I don't have any new track marks in my hands or my arms (speaker holds up and shows the back of their hands). I'm warm. I'm not cold anymore (speaker claps for emphasis).*

Lushay describes ways her social life improved. She states,

> *Uhh...I could hold down a job now, because I've never been able to hold down a job. I'll be two years on this one job. That would have never happened (speaker shakes head). You know? My eating habits are different now. Because I'm not doped up all the time on pain meds just to make it through, you know, to keep from going to the hospital for a pain crisis. Because it's like, "Uh uh, let me take pain meds now before it get worse. Let me increase my water intake…Um, like, so even at work, like, it's like...I'm around people. I can tolerate this and that. I don't have to worry about going into a pain episode and have to hide myself in the bathroom or things like that 'til everybody leave, so that I could come out and leave.*

Nicole describes how she is now more social.

> *I'm more social, like, because before, like, I said, I was homeschooled, so I spent a lot of time alone. Because I was homeschooled, I was in the hospital, so, like, I really wouldn't talk, and I still have a problem with it. Like talking to people, like, I have to figure you out and get to know you, and before I really open up to you, but it's a whole lot better. Like my boss told me the other day. She was like, You are becoming more social, and I can see it. She was like, and I appreciate it. So that meant a lot.*

Nicole describes the impact of reaching the goals she set for herself and how she began to see her life change.

> *It was empowering. Like, once I finished school, and I actually took my book, my certification test, and I passed, and then I got my first job, then I got my first check, and I'm looking at this like, No, it's not a whole bunch of money because I'm just a medical tech, but it's more money than I've ever seen so at one time. So it's like [pause] I can do this, like I can do this. I can take care of me and my child. I can now do stuff that I couldn't do in the past. I can if I want to, take me and my child on a trip. I can go if I want to, just whatever I wanted to do I can do now. I don't have to worry about going to the hospital… As I got older, and after I had my kid, I was in there so much, it's just like I didn't have, like I said, I didn't have a quality of life, and it's like, now I have that quality of life and I can do whatever I want to do.*

Reese reaffirms how she can now direct her own life at this stage. She states, *"The best thing is not having sickle cell and being able to live my life the way I want to, without having to worry about it."*

Cash shares how he sees his life now with two birthdays after the transplant.

> *I told my mom the one day, it was like, maybe last year, I said, Mom, I got two birthdays. She was like, What the heck you mean? I said, I have the date that you gave birth to me. And I said, I have the date that I was cured. I was like, so now I have two birthdays. So like, now every year my I post something on Facebook, about it, and I said this this year, on April 17, I'm going to post my story on Facebook just so I can help. I don't care if it helps. If it helps one person, I'm happy. If it helps a million people, I'm happy. I just want to help people. And I feel like that's what God put me here to do, is to help people.*

Participants describe their current mental health since the transplant. Highlighting its relative improvement, better than when they had SCD but noting some lingering effects that aren't fully resolved. Some of which echo the traumas from living with SCD.

Jullian states, "*I'm not in fight or flight mode all the time, so that's a very big adjustment. Which still doesn't feel right, like I'm too comfortable. And something's not- something's wrong because something's not wrong (speaker furrows brows and squints eyes).*"

Reese explains, "Mental health right after transplant-- I think the first part, from Day Zero up until almost a year later, was really tough mentally. Going through all of that wasn't easy—it's a lot to handle. But once I got past that, things got a lot better. It was definitely much better after that."

Reese elaborates on how her strength was a necessity and a part of her identity now that others also affirmed. She considers therapy, but because strength has been a part of her identity for so long, she is unsure how or if she can be untethered from it.

She states,

> *I don't know, honestly. I've been trying to talk myself into going to therapy, but I'm not sure. I think it's because I've always been used to just pushing through tough situations,*

> *especially with sickle cell—I didn't feel like I had a choice. So for me, it's second nature; it's just something I do. My brother once told me, 'You're one of the strongest people I know,' and I thought, 'That's nice.*

Jullian describes how mentally he is still impacted by SCD and feeling lost. He states,

> *Mentally, I'm still very much there. I'm still very much locked in. Don't know what to do, and I have no direction. 'Cause I didn't even expect myself to get this far. I don't know what I want. I did not have that time in high school or just through my younger years to experiment and figure out what I like. And now, you know, I have that time, but I pay for it. I'm an adult. I don't have electives in school. I don't have clubs. Yeah, so I'm just throwing things out there and seeing what sticks, but I'm also very broke. (speaker holds hands out to the side in confusion).*

Nicole describes how her mental health changed, and through diagnosis, she found ways that past treatment from SCD may be impacting her mental health years later. She explains,

> *Um, in the first couple years I I dealt with it good, but then I had, like, a life changing, some stuff that happened in my life, and then I went, like, on a self sabotage [gestures hands], um, spray, um, I was eating, I wasn't cleaning, I started drinking, and then I, something just clicked in my head one day, like, this is not normal. Something's wrong [starts cringing]. And so I went to mental health, and it kind of just put everything in perspective for me, and I kind of wish that I had gone sooner than later, because I came to the realization that I was going in the wrong direction. I was hitting rock bottom and like I was healthy in one aspect, but mentally I wasn't [crying]… But then I come to find out, after I did get in therapy, that a lot of people who have been on pain medication for long years have issues, and they get like bipolar, or they get other issues. So that's what*

> *my problem was. They knew and diagnosed me as having depression and bipolar, and they said that they think that it was just from where I was on pain medication for so long.*

GiGi explains how her fear of disclosure about her health history impacted her considering seeking out mental health treatment post-transplant.

She explains,

> *Well, one of the other things, and you'll probably experience, yeah, I think all of us do when we get a license with the state. There are specific questions. And I know in dentistry, they ask you, have you ever had mental health treatment? Another question is, is there anything that would hinder you from doing your job? You know, thankfully, I've been able to say no to all of that, but that has been one of my hesitations with seeking counseling, you know, because I'm like, Oh, my God, do you have to report it, you know? Like, well, I don't know what happened, you know. And, and I was like, that's sad, because there's probably a lot of medical doctors and licensed people that could feel the way I do, that there's no help for us like you understand that, that we need to talk to somebody.*

Participants describe the ways their faith has grown. Cash references this when stating, *"my spiritual life is definitely stronger."*

Nicole describes her relationship with God,

> [wipes tears] at first, you know, I was just like, Yay, he brought me through. I wasn't going to church, I wasn't praying. I wasn't doing anything because, like, I wasn't in the mental space for it. Like, okay, but now go to church, I pray instead of, like, having my because, like, as my aunts, I have many meltdowns, like when something goes wrong. And instead, I try not to just, like, instantly melt down. I try to pray to him about it. And,

> you know, look, look for the bright side of things, and look for the lesson in things.
>
> Because everything you go through, there's a lesson to be taught.

GiGi describes her faith journey,

> *And it was just the biggest miracle of all, you know, I could think of the scripture that talks about God can do more than you ever could think or imagine it. I don't have the exact words, but yes, you know, like I was saying before I felt like just being successful, successful as I was with my career and owning a practice that that was my miracle, but I I obviously limited God.*

Participants reflect on the several years they have lived sickle cell free. Identifying what this transplant means to them.

Reese states, *"Everything, I mean, because I never thought that I would be sitting here talking to anybody about not having sickle cell anymore. I just figured sickle cell was going to be something that took me out. So it means, it means everything."*

Nicole states*, "Everything. Everything, because without it, I probably would be dead. That's how bad it was before I had it. So it means everything like it's it's the one, one of the best things that ever happened to me."*

Jullian states, *"Everything. It really meant everything. It really changed my life. It gave me a future. And it really put a, I guess, a period on my past, like it's not coming back (speaker begins to cry). Mm, hmm. There's no semi colon, there's no remission, there's no it could come back. No, it's gone (speaker begins to smile)."*

Lushay states, *"I survived something that I thought was never possible in my lifetime. (speaker shakes head in disbelief)...Accomplished. Because doctors said it couldn't be done. Science has even said there's no cure (speaker shakes head) but to have that one person that had an idea.*

Let's try this and see if it could cure sickle cell. And it did just that (speaker nods head and smiles)."

Cash states,

> *Well, so it's not just one, I'll say, definitely blessed, and um (pause). I'm thankful those are the three blessed, because it could have been somebody else who had this opportunity to go through it twice, and not just the transplant itself, but actually getting to meet Dr. A and know him and his whole team down there, because some people have met Dr. A but you know they may not meet the criteria to have the transplant done, or have the family support to have it done, or they're just too flat out scared to go through it, yes and thankful because it worked, and I get a fresh shot at life.*

GiGi states, "besides a blessing… It was my hope again. It was my hope, yeah, because I lost it, yeah, and they gave it back to me. It definitely gave it back. It was, it was all the hope I needed."

The Weight of "What If?"

Participants identify habits they maintain from living with SCD, and concerns about the fear of recurrence.

Reese states, *"I still struggle with some habits I developed when I had sickle cell. Im still sleeping with a heating pad and still not really wanting to go swimming."*

Jullian states, *"I don't know. I will always be the one that takes all the extra health stuff on trips. So I'm not unlearning that."*

GiGi identifies an experience where she was injured and thought the pain was sickle cell-related, though it had been several years since she had a crisis.

> *Um, yeah, maybe the little things where I'm like, Okay, I I have to remind myself that I don't have the disease anymore, even though, you know the clinical results and the blood work shows that, you know, you just still have that hesitancy of the what if I remember, I did have an incident, and this was recent. This was early this year. I fell on my knee just going around my office, and my foot got caught in the cords, the handpiece cords that we use. I was trying to get around a patient, not knocking to them. My foot got stuck, and I fell on my knee. And my brother's a physical therapist, and he was like, Excuse me. He was like, well, you need to ice it. I said, Oh, I don't really like the feeling of ice with my sickle cell, I would use like a heating pad instead, and things like that. He's like, No, you gotta ice it to make sure there's no swelling. So fine. I ice it and I do his instructions, and all of a sudden I just felt like this extreme pain in my knee. And I was really close. It was like 10 o'clock at night, and I was telling my husband, I said, I think I need to go in. This almost feels like a crisis. And I remember calling my mom like, Mom, I, I this just doesn't feel right. And, you know, and, and we literally put some Bengay on it. My husband found so we had tried everything else. I tried telling him every three, and he put some Bengay. And when I tell you that gave it relief, and I was like, Okay, this maybe just was a soreness, whereas in my mind went to the worst, you know, and I was gonna have to go to [the hospital] and explain that I don't have sickle cell anymore, but this feels like it, you know (giggles). But you know, after I calmed down and the pain went away, you know, I was fine, you know, within two days. And so, I was thankful with that.*

Participants identify experiences that they navigated into survivorship, where they were hesitant to do certain activities due to fear of SCD recurring.

Reese identifies the hesitancy she felt in survivorship with bodybuilding.

> *Before my transplant, I got into bodybuilding and powerlifting, and I put on a good amount of muscle. But after the transplant, I lost all of it and came out super skinny. So, I got back into the gym, hired a coach, and started training again. I realized that when I was lifting weights before, I wasn't pushing myself hard enough because I was always worried that if I overdid it, I'd go into a sickle cell crisis. Now, I can push myself without that fear. It's like I was always operating with this limit, wondering 'What's too much?' But now, I don't have to worry about that, and I feel a lot stronger.*

GiGi identifies activities that she has yet to experience and is mentally grappling with the gratitude of being healthy, but the hesitancy that SCD might return.

> *Mentally, the one thing I have not done yet is take a bubble bath. And I know it sounds real silly, but mentally, I can't do it yet. I'm going to. I've talked to Karina about this the nurse practitioner, and she was like, well, it's okay, you know? Because, I mean, I could take showers for the rest of my life and never be bothered, but I would love to experience a nice bubble bath again and not have to worry, because that's happened, about getting out and going into extreme pain, but that'll be my goal in 2025 probably, well maybe after I get through Denver, because I am a little nervous about Denver. But, you know, don't I mean, could, because March is usually my month to go through a crisis, you know, to go from a winter storm, what, three weeks ago, and then now we've got 70 [degrees]. Yeah, I would have been in a hospital by now, almost textbook. Every year I could count on it, and then I'd have acute chest syndrome every March seems like that was my month. But to be completely healthy, you know, it's just such a blessing. It's amazing. I've had colds, I've had I don't I always get vaccinated for everything, so I keep up with my*

> *COVID and flu shots and all that kind of stuff. So I haven't had any of that, but a simple cold I've had, and it never has progressed, you know? So that's been great.*

Evolution of Self-Identity After Transplant

Participants define themes surrounding the evolution of their identity after transplant. They reflect on the ways they have changed and evolved since the transplant, as well as some aspects that remain the same. They identify concepts like a sense of purpose through advocacy and a renewed sense of self-esteem. Subthemes include *1) I'm a Survivor, and 2) Loving the Skin I'm In.*

I'm A Survivor: The Gift and the Grief

Participants reflect on their identity as a survivor of SCD. Some participants differ in how they identify their new health status, whether it is considered cured or not. Participants expand on their relationship to the transplant and how they define their health at this point.

Jullian notes he does not see himself as cured, but instead see's the loss of SCD only revealing other issues that were not easily seen that continue to impact his life. He states,

> *Um (speaker looks away from screen in thought) I will say I don't have sickle cell. I don't know about cured (speaker scrunches up face). I don't- I'm not sure if that'll ever be that. I don't have that pain.*
>
> *Cured means that there are no other problems that would arise (speaker nods head) stemming from that. Right now, there are too many things that have been coming up that, I guess were always there, but sickle cell eclipsed that. I feel like I'm still not done with it (speaker shakes head). Like what else were you hiding? (speaker leans body forward).*

GiGi identifies as being cured despite the lingering health conditions that she is not happy about. She states,

> Yes, yes, I do, I do, um, you know, I feel like, yes, there probably are after effects of this. I still have the diagnosis of, like, chronic kidney disease. I mean, after you, gosh, in medicine, there's so many numbers, like, you can be pre diabetic, you can be, you know, all these things I have, and I do attribute it to the disease or the after effects of it, and that doesn't make me happy."

Participants consider themselves to be someone who has survived the impossible. They have been told throughout their life that they would not survive this disease, and to be in this place in their life is a reflection of the deeply personal journey they have gone through to physically, mentally, and spiritually survive.

Lushay shares,

> *I survived something that I thought was never possible in my lifetime. (speaker shakes head in disbelief). It's a journey. It's a journey, but it's a journey that's worth fighting for. (speaker nods head)…*
>
> *I learned that I'm a conqueror. I'm a survivor of something that could've killed me, but I survived it.*

She shares a feeling of accomplishment to be part of a revolutionary procedure in the lives of those impacted by SCD.

> *Accomplished. Because doctors said it couldn't be done. Science has even said there's no cure (speaker shakes head), but to have that one person that had an idea. Let's try this and see if it could cure sickle cell. And it did just that (speaker nods head and smiles).*

Cash reflects on what it means to him to be a survivor, given all the struggles he has faced and the sobering reality that others do not always survive these complications. He states,

> *Um, the best thing, honestly, to me, is being able to tell my survival story, because I know people who have had just one stroke and they're gone. Some people I know personally had just had sickle cell, and that took them, that took them out. But for me to have to deal with the strokes, crisis, and everything else, and still be here today to tell my story, that's the best thing to me.*

Jullian identifies the random moments when he realizes the magnitude of what it has meant to him to be a survivor. He notes, “It's still very surreal (speaker shakes head in disbelief). It's- I still don't know. It hits me at weird times. Last week, when I was in Europe, it hit me hard. I was like, "Oh!" I never thought that I'd see this foreign mountain. Like, what (speaker leans their body to the side in shock).”

Participants discuss the drawbacks that come with their identity as a survivor. They see the transplant as transformative, not just for their livelihood, but also leaves them contending with their broader connections to the sickle cell community.

Reese notes the questions she asks herself as she reflects on her relationship to the SCD community. She states,

> *I really do care about other people who suffers with sickle cell…I used to be really involved with the community when I was in Nashville, but not as much since I moved ... But it's also an awkward situation for me because it's like am I still apart of the community even though I no longer have sickle cell?... But I plan on getting back involved at some point.*

Reese identifies several examples of remorse she feels, as she thinks about several friends who still live with SCD or who have passed before getting the opportunity to get a transplant.

> *I had a friend, [Nathan], from TSU who was also trying to get a transplant. We used to hang out now and then, and his brother was a match for him, but his brother didn't go through with it. Unfortunately, [Nathan] passed away from complications related to sickle cell. He was also seeing Dr. A, so I don't know what happened there. I know they sent him to some type of institution, but beyond that, I'm not sure. It's strange being someone who has had sickle cell, went through the transplant, and no longer has it, while still seeing others suffering from it. Some people just don't have the financial resources or support to go through with the transplant. There was another guy who was involved with the sickle cell walks in Nashville. He was around 54 or 55 when he passed away from sickle cell, and that hit me hard. When I had sickle cell, I knew that we all could die at any moment, but with sickle cell, it felt like our time frame was shortened. So, now that I'm getting older, I'm just grateful not to have to worry about dying from sickle cell complications.*
>
> *I don't know… I still have a friend, [Ty], who has sickle cell… I visit him in the hospital a lot because he stays at [the hospital] frequently. And honestly, I just feel bad because I'm cured, and he's still dealing with it. It kind of feels like I'm leaving people behind, or neglecting them in a way. I don't really know how to explain it, but that's the part I struggle with the most. It's like I've moved forward, but my people are still stuck in the same battle.*

Nicole shares her experience of guilt. She shares how she would not tell people she was cured of sickle cell disease.

> *It's weird to say, because it's like, as I tell like, as I get to know people and new people, and I tell them, you know, I had sickle cell and and then the first thing I want to say is, well, I was cured, but it's kind of like, why would you say that? But I guess at the same time, I was, so it's kind of like still kind of conflicting. I guess.*

She elaborates further when asked how she defines a cure.

> *Hmm, um I guess, basically, not havin it anymore, not not being sick anymore. So now that you're saying that, it is okay to say that I'm cured, I don't know if I felt like maybe, it's like rubbing it in somebody's face saying that I was cured. You know, maybe that's what it is, and my point of looking at it, so I don't want to say it that way, but it's okay, because I was [cured].*

Unveiling a New Reflection and Casting a Brighter Light

Participants described an evolution of their self-concept after transplant. Having several limitations in their lives due to SCD, they recognize how their sense of self has changed, leading to a greater sense of belonging, confidence, and self-love.

Lushay shares, *"I just feel like a regular person now. Like I belong (speaker shrugs shoulders and slightly smiles). I feel like I belong now and I'm not an outsider".*

Jullian shares how he see's himself more holistically and less limited, like he was living with SCD. He states, "You know, I'm not what I've been through. There's so much more to see. Um...and...just you'll be surprised about where you go."

Nicole share how her love for herself has grown. Reflecting on how she once considered herself broken, she now identifies more self acceptance. She describes,

> *Self love… I guess, because at that point, when I was sick, I didn't understand, so I didn't love myself [eyes water]. It was more of you know, who's going to love some… that's my thing. It was like, who's going to love somebody, want to be with somebody that's sick all the time, in the hospital all the time, you can't have a life with them. Nobody's going to want to be with you [crying]. But now I realize, sick or not, I'm worth it. It took a lot. It took a lot to get here, but it was just like, I don't know how to explain it.*

She describes and expands on how it feels to finally love herself.

> *Amazing, wonderful, amazing, wonderful, um, just, it's, it's just wonderful. And you know to love yourself and know your self worth and not to put up with anything that you wouldn't necessarily put up with because you feel less than…*
>
> *And I felt that then, like broken then, and I don't feel that way anymore.*

Reese shares how her confidence has grown. She states, "I've always been a pretty confident person, but not having sickle cell made me feel even more confident, both mentally and physically. It was like I gained a superpower. Physically, I felt stronger, and mentally, I felt unstoppable. I just thought, 'Nobody can tell me anything now.' It was a great feeling".

Cash describes how his confidence has also improved. He explains,

> *When they showed me the blood test results and they said that they tested and that there were no signs of trait, no signs of sick, no no sickle cell, no sign. I'm like, What about trait? And they said, right here, you see there's no signs of sickle cell at all. When they showed me that on the screen, I said (nods head). Oh, it worked. And that's when I realized I'm like, Man, that was already knew, like, as a kid, like I was, I was a pretty*

> *confident kid, but like, when they told me that, I said, Oh, it's over with, like, I'm about to conquer the world.*

Cash explains this confidence boost has also made him feel more comfortable sharing his story living with SCD.

> *Um (brief pause) I'm definitely more confident and willing to talk about, you know, my experiences as a kid, because, you know, nobody really likes to discuss their illness, because, you know, it can be uncomfortable, not just for the person who had it or has it, but the person who you know you're talking to, can, they'll make faces and like, be like, they give you the Oh, really? Like, no way.*

GiGi shares how she felt more comfortable opening up about a part of her that her friends never knew, once she was going through a transplant.

> *I'll never forget when I was about to have the transplant I called my co-resident, Heather, who I'm still close to, and I admitted everything to her (begins to cry). It was, it was freeing. You know, she was like, I didn't know much about it, but I'm glad you shared that with me. Yes, even one of my sorority sisters, who I've known for years. I never told her I had sickle cell. She's like, oh my gosh, you couldn't even tell me. And I was like, no. I was so embarrassed and I never wanted anybody to look at me differently again. So I was so happy to be able to tell people, along with, I'm getting healed from this, or along with, I don't have it anymore. It's alot easier to talk about. But you know, certain people you don't keep it away from, I remember telling my husband three weeks after we met, you know, so that's a little bit different. But you know, to have some my closest friends that I felt like I could never talk to, who heard about that.*

As those who lived with SCD, participants have now found purpose and meaning in being able to advocate for those who live with SCD, especially the youth. They identify how they remain connected to the community, instill hope in others, and advocate for stem cell transplants. GiGi shares a story of meeting a family in her dental practice and feeling moved emotionally after encountering a young child who lives with SCD. This encounter was surreal for her as she remembers her childhood and the challenges she faced. She considers what it might have meant for her life to get a transplant as a child.

> *So I gotten really emotional because I this past week, I did meet a family, and it was three children, and the youngest, who was four years old, had sickle cell anemia, and I remember, you know, being excited to tell the mom that I went through the transplant process. And she was like, oh my goodness, I heard about that, you know. So I was excited to tell her I was a successful survivor of it, you know, it really has changed my life. And I was basically just telling her, it's one of the best decisions she could make for him, you know, definitely look into it. And she was grateful that I talked to her about it, you know, because I wish my parents had, I know they would have done it. I I'm almost positive they would have done it. And so I'm always glad to run into people. It's so random that this was all set up, and then I run into them this week, and but I was happy I was able to share with her that it is very safe. It's, it's, it's a way out for us. And, you know, just to save him from a lot of just trouble in his life, just being four years old, he probably hasn't even experienced the start of it. So, okay, I was glad she was, you know, she was very receptive to that. She said it made her feel a whole lot better. And I told her, I'm available if she had questions. So, so, yeah, wonderful positive thing.*

Lushay recounts the difficult realities she has to share with kids living with sickle cell the differences they will experience in their healthcare, noting the overall decline in the quality of healthcare for SCD from pediatric to adult care.

She shares,

> *Especially when you see little kids with it and then have to explain to them, oh, you finna start going to see the adults. When you transition from adolescent going into adult, the treatment and care is totally different. And so that's why I try to advocate. You know, for the emergency room, because it's hard. 'Cause you're used to going in and they seeing you right away, but now you're on adult side and it's like you're not a priority anymore. And that needs to change.*

Cash describes what it means to him to be an advocate, from using his voice to speak up for those with SCD, to participating in research to improve the community, and camps for kids with SCD where they can just enjoy being kids.

> *For me, it's meant my voice has to be louder. I have to let people know about it and how that cancer isn't the only disease out there. There are so many other illnesses, not besides that, that affect people. And sickle cell when I first started doing research as a young kid, I learned that it was like one in four people like, had sickle cell. I don't know what the statistic is now, but for one in four people to have it was scary for the fact like, and then I realized my brother and I both have it, so we weren't that statistic, we changed the numbers, and then learning about traits and how that like, how, (gestures hands) if both parents have trait, then you're, you're probably, you're gonna have it right, and both my parents have the trait. So I was all like, even to this day, I'm an advocate. Like, anytime there's something here, like the Red Cross here, asking to speak, I'm going. My parents*

> *had actually started a sickle cell foundation when I was a kid, and we used to go to sickle cell camp. And it was probably about, I want to say, like, almost 18 kids at this camp we would go to. I want to say camp Olivia, a couple, maybe, like, an hour or two away from here, and it was a way to give kids with sickle cell the feeling of, hey, I'm normal. Just because I have this doesn't mean I can't do, I can't do I can't do everything, but I can do some stuff.*

He elaborates further,

> *I love this experience like, I love talking about what, like. I love being able to tell my story so somebody else can get help, whether it's like you, with research or giving somebody else the strength and confidence to go through it, because you have to be mentally strong to go through this process. Because if you're not, you will break down. Yes, and I had my moments, you know, where I would break in my room by myself. But you know it just, you have to have that mental toughness.*

Lushay shares her connection to this community as she continues to empathize with the mental toll this disease can take on the youth. She reflects on teenagers who battle with suicidal thoughts and notes how she, too, can connect with them in one of their darkest moments.

> *And now, when I see stories where people with sickle cell talking about trying to kill themselves, I just share what happened with me. I just share my story. Because seeing little- seeing teenagers it breaks my heart, because I'm like that used to be me. You know, even as an adult. You know, I used to feel how they feel and just to be able to talk to them, give them hope. And I've even met parents at the camp they have here in Tennessee. We go up to into Owensboro. I think, Kentucky.*

In light of the sobering statistics about the high mortality rate, Lushay see’s her life as a testament to beating the odds and showing what it can look like to grow older with sickle cell.

> *And then talking to parents and telling them, "Well, I have sickle cell." And them saying, ‘How old are you and you have sickle cell?’ (speaker leans head forward to represent parents excitement) You know, and just being able to tell them that there's life beyond the age that they've been given with that child.*

Nicole shares how she is an advocate for transplant.

> *I know that if I could tell like anybody, that if you have a chance to have a transplant, to do it, and like, right after I had my transplant, it was some people that I had met and one of the sickle cell things that they have, and it was one lady in particular, and she was really sick, and, you know, I was trying to talk to her and tell her about it, and we lost touch over the years, and I don't know if she ever tried it or whatever, but, I feel like if I had a chance to talk to her or talk to anybody, that I would be an advocate for it.*

Cash shares,

> *There's a cure for it now, and one of my missions now through my job, because we are a mental and behavioral health integrated we are mental health mental health integrated company so we do so much. So my goal now is to raise awareness for a stem cell transplant, whatever transplant somebody needs, and raise the funds for I personally want to raise the money to help somebody else out…*
>
> *… So my goal now is giving back whether I speak to somebody, and I've spoken to like a family or two at [the hospital] because they were getting ready to go through I think it was a young lady getting ready to go through the transplant. So I went and spoke to her and her mom like they were actually in the little conference room in the back of the*

clinic up there, in one of those rooms. So Dr. A had asked me would I speak to her. I was like, Yeah, and I just told her, she going to have to keep her faith, stay strong, and a good family support unit does way more for you than people realize.

CHAPTER 5

DISCUSSION

Study Summary

This study is a qualitative exploration of the experiences that impact the self-identity of Black adults following stem cell transplant for sickle cell disease. This study sought to understand 1) the experience of adjustment following the 1st year after stem cell transplant, 2) how Black adults navigate living with a new health status, 3) the experience of navigating medical settings post-transplant, and 4) the evolution of Black adults' self-identity following stem cell transplant.

While exploring the experiences of Black adults and the evolution of self-identity following stem cell transplant, several themes emerged. However, additional themes emerged that did not directly answer the research questions. It became apparent throughout the interviews that participants needed more of an opportunity to address aspects of their experiences that impacted their identity while living with SCD, before they could really define their experience after transplant. Two prominent themes that emerged were the role of medical trauma and the ways in which sickle cell disease shaped their identity.

The emergent theme of medical trauma infiltrated participants' pre-, during, and post-transplant experiences. The discussion section will organize the review of themes that defined their pre- and during-transplant experiences before addressing the four research questions exploring participants' experiences following the transplant. The discussion of findings will start by reviewing the emergent themes, integrating the theme of 'The Role of Medical Trauma:

Navigating Medical Settings After Transplant' throughout, as it pervades most of the other identified themes. Due to the significance of this concept in participants' narratives, the role of medical trauma and its consequences will be interwoven into the discussion of each theme.

Medical Trauma is defined as life-threatening traumatic events that include life-threatening medical occurrences, diagnoses, or procedures (McBain, 2024). These events are considered medical stressors that result in psychological and/or physical consequences (McBain and Cordova, 2024). Medical trauma is conceptualized through a framework of stress disorder as a chronic, enduring condition that originates in the body, making the body the primary source of threat (Birk et al., 2019, as cited in McBain and Cordova, 2024). The existing literature identifies that exposure to traumatic events like cancer, due to the psychological burden of a life-threatening diagnosis, chronic exposure to healthcare environments, and daily management, can lead to post-traumatic stress symptoms in those directly affected (Amonoo, Massey, Freedman et al., 2019; Padova, Grassi, Vagheggini et al., 2021).

Sickle cell disease is a multi-system, life-threatening, chronic condition that affects individuals due to its significant medical, social, physical, and psychological burdens. Although the literature identifying SCD as a medical trauma is notably lacking, this study's findings, alongside existing research on other chronic illnesses like life-threatening cancers, support the notion of medical trauma. The current literature also includes multiple sources that recognize bone marrow/stem cell transplants as a form of medical trauma, as they are defined as life-threatening events with substantial psychosocial repercussions, including anxiety, depression, post-traumatic stress reactions, and post-traumatic stress disorder (Johnson Vickberg, Duhamel, Smith et al., 2001; Amonoo et al., 2019).

This literature corroborates how similar chronic illness states, with similar medical and psychosocial burdens, disease management trajectories, and long-term implications, provides strong, compelling evidence that sickle cell disease and stem cell transplants are also categorized as forms of medical trauma (Aloa & Soderberg, 2002; Edmonson, 2014; Padova et al., 2021; McBain & Cordova, 2024).

The ‘War’ with Sickle Cell: Impact of Living with a Chronic Illness

Sickle Cell’s impact on the lifespan of individuals is all-consuming, and within the academic and medical literature, it is grossly understudied regarding the complex interplay of identity, psychosocial factors, and systemic impacts. This is demonstrated in the findings for Theme 1: *The ‘War’ with Sickle Cell – Impact of Living with a Chronic Illness, specifically subthemes* ***1) Realities of Life’s Limitations, 2) Navigating Life with SCD**,* and ***3) Psychological Toll of Living with SCD**.* Participants highlight factors with long-term implications for their livelihoods and self-identity, which begin in childhood. Feelings of isolation, ‘othering,’ invisibility, and lack of belonging underscore their experiences. Emotional factors also prominently affect responses within the sickle cell community. Asunkwo, Andermariam, Minniti, et al., found that between 45% and 60% of respondents indicate that SCD impacts their emotional well-being, specifically feelings of stress, depression, and hopelessness; worrying about their future; frustration with symptom management; and fear of dying (2021). The literature corroborates these findings, positing that managing the emotional and social factors associated with SCD among 14-to 18-year-olds negatively impacts their psychological well-being (Ani, Egunjobi, and Akinyanju, 2010). Adolescents and young adults navigating SCD express fears of early death and concerns about disclosing their health status to peers due to fears of teasing or bullying related to their physical health complications, leading to negative selfperception and self-image (Ani, Egunjobi, and Akinyanju, 2010). Additionally, health-related stigma is pervasive in healthcare settings among providers, leading to increased psychosocial distress for adolescents and young adults, heightened mistrust in majority-White healthcare systems, and worsened patient-provider relationships (Hood, Crosby, Hanson et al., 2020). These contentious interactions with providers and the healthcare system further exemplify medical trauma, as they represent 'secondary crises' or additional stressors that compound or precipitate the physical and psychological distress associated with the illness being diagnosed (McBain, 2024; Shapiro & Hayborn, 2024). Furthermore, into adulthood, individuals living with SCD experience workplace discrimination, social disruptions contributing to greater isolation, and an increasing prevalence of significant psychiatric symptoms such as depression, anxiety, and stress reactions (Essien, Winter-Eteng, Onukogu, et al., 2023).

'Looking in the Mirror, and All I See is the Disease Staring Back at Me - Identifying with SCD

The fourth subtheme from Theme 1,' highlights the diverse illness identity dimensions among study participants, emphasizing the impact of SCD on identity. These dimensions inform ways participants related to their illness as an extension of their self-concept. Stages represented by study participants included three of the four dimensions of Illness Identity, 1) engulfment, 2) resistance, and 3) acceptance (Oris et al., 2016; 2018). Two study participants' experiences exemplified engulfment as they were grossly overwhelmed by their disease and hospital interactions. They identify that their lives were consumed by daily management, leading to increased healthcare utilization and negative self-perceptions (van Bulck et al., 2019). Four other participants explained how they resisted life with sickle cell by going against the advice of their family and medical providers by playing sports, partying, and drinking, which led to more hospitalizations and worsening disease complications. Two participants reflected that as they grew older, they began to develop an identity of acceptance, finding ways to integrate their illness into their lives by maintaining healthy habits to manage their condition while living in a way that more so honored their personal goals and desires. Participants described the psychological toll from the disease persisted, but at that point, they relied on their mental strength and fortitude to endure this toll.

Participants equally noted the role SCD had on them socially. Some described often hiding their disease status for fear of discrimination or 'othering' by their peers. Many feared being seen as different because of limitations they faced from the disease and perceived limitations others placed upon them. For participants who were employed, they desired not to share about their health status for fear of discrimination. The literature shows that individuals with chronic illness fear disclosing their health status in the workplace for fear of being undermined or perceived as less competent (Gold, Andrew, & Goldman, 2016; Ganesh & Lazar, 2021). Additionally, the role of health-related stigma and self-stigmatization is common among young adults living with SCD (Jenerette & Brewer, 2010), and this began for this participant at a young age, which has affected her comfort with self-disclosure about her health status into adulthood.

The Role of Medical Trauma: Navigating Medical Settings

From Theme 2, two subthemes from "The Role of Medical Trauma" were particularly relevant as participants recounted how sickle cell disease shaped their sense of identity as Black people living with SCD. A significant aspect of participants' lives is the time spent in medical settings and navigating the healthcare system.

My Pain is Invisible, But I'm Not - Receiving Dismissive Health Care

One significant subtheme was identified from participants regarding the quality of care participants received from childhood throughout emerging adulthood, which was found to be a form of care that was grossly dismissive, laden with several examples of discrimination, bias, and stereotypes. Participants identified the emotional impact on them was significant, leading to feelings of invisibility, frustration, and 'othering' when having to go to the ED, as they knew the wait times would be substantial and that they would likely be questioned about the validity of their pain and often assumed to be 'drug seeking'. Participants describe significantly traumatic examples of involuntarily being placed on inpatient psych holds due to lack of awareness of the impact of pain crises, being refused medical treatment, and being stereotyped about their efforts to cope and self-manage their illness while waiting for care. Participants described as children, losing a sense of childhood due to navigating complicated healthcare settings, managing their illness daily, and undergoing regular painful procedures to manage the illness. Participants internalized that this was also their 'norm' and a way of life they needed to adjust to in order to survive. Participants' attempts to cope with dismissive forms of treatment chose to focus on their care, rather than dwelling on who would not provide them with care or help. Instead, they tried to concentrate on who would offer them care and how they could take care of themselves with as little medical intervention as possible. Participants clearly understood what was happening to them, naming medical racism as the form of discrimination they were receiving. As the stress of trying to make sense of why they were treated this way was unhelpful or was minimized by the need to chronically manage SCD complications and pain crises, they focused on means for physical, mental, and emotional preservation.

As mentioned previously, these examples of dismissive care reflect the role of SCD as a form of medical trauma. Not only does the life-threatening, painful disease function as an assault within the body of the patient, but the ‘secondary crises’ of consistent negative healthcare interactions across the lifespan of their disease became internalized and normalized among participants because of its regular occurrence and the frequency in which they had to interact with the healthcare system. Participants identify these experiences in healthcare within the context of being both Black and living with SCD, highlighting the intersectionality of their experience, and the salience of their Blackness (Sellers et al., 1998) as most prevalent in medical settings. The existing literature on racial discrimination and SCD identifies the high prevalence of reported racial discrimination and racial bias among this community, leading to increased mental and physical stressors (e.g., depression and increased pain) (Bearden, Ono, Cohen et al., 2023).

Undergoing Stem Cell Transplant

Though curative, stem cell transplant is associated with diminished quality of life due to physical and psychosocial stressors associated with the treatment (Johnson Vickberg et al., 2001). This subtheme emerged as participants noted the physical and psychological impact of undergoing the transplant, which further shaped their experiences after the transplant. Study findings included that some participants had to make sacrifices to have the time to dedicate to undergoing the extensive treatment regimen, including finding donors, labs, taking more medications, and completing advanced care planning, as the possibility of death was a risk participants needed to prepare for. Participants described going through a transplant as a type of excruciating pain and shock to the body that they could not anticipate, and due to a suppressed immune system, they mainly remained isolated for several months. Many report being brought to the brink of death with complications, like GVHD, stroke, kidney failure, infections, and severe delirium for several weeks during the transplant (Janicsak, Ungvari, Gazdag, 2021). Participants overwhelmingly identified a desire for mental health services during transplant or immediately after for support to navigate the impact of what they went through, and for some, speaking with a mental health professional who understood the stem cell transplant process would lessen the burden of relying on support from their caregivers (Oko-Odoi, 2019; Dovern et al., 2023). As reflected above, stem cell transplant is a medical procedure with life-threatening potential and an enduring threat to the body that would align with the definition of medical trauma. The literature has further confirmed that as a result, common psychological outcomes of stem cell transplant include depression, anxiety, and post-traumatic stress reactions (Johnson Vickberg et al., 2001; Janicsak, et al, 2021) due to the intensive and life-threatening nature of the treatment in addition to the chronic illness patients have that leads them to seek out a transplant. Further corroborating, the psychological implications of this treatment on a community that has experienced multiply marginalizing and traumatic health care experiences.

Finally, Someone Who Gets It! - Receiving Intentional Health Care

Another significant subtheme emerged from the theme The Role of Medical Trauma: Navigating Medical Settings was subtheme 3, Finally Someone Who Get’s It!: Receiving Intentional Health Care. Participants identified experiences with healthcare that were positive and represented a type of care that was intentional, trustworthy, and compassionate. Participants identified this form of care as monumental and not easily forgotten. Participants reported that the majority of positive healthcare experiences involved encountering providers who were well-informed about sickle cell disease. They described feeling a sense of relief when meeting with their transplant team, as they felt well-informed about their care, believed their providers were prepared to help them, were trustworthy, and were attentive to their needs in the event of any transplant complications. Fuehrer, Weil, Osterberg, et al. identify respect for the patient, curiosity, and intentional listening as key indicators of a positive provider-patient relationship (2024). Others noted the importance and symbolism of having a provider who also identified as Black, having racial concordance. Ultimately, participants indicated that despite racial concordance, it was most important for their provider to be knowledgeable about SCD and for the relationship with their provider to embody holistic, compassionate care. The literature about racial concordance is mixed as race can be important for some, as perceptions of better communication and trust are higher. However, no effects were associated with the quality of care (Shen, Peterson, Costas-Muñiz et al., 2017). However, with individuals who have neutral concordance preferences, preferred cultural awareness, and a willingness to self-educate, as vital for a stronger patient-provider relationship (Moore, Coates, Watson et al., 2022). Participants identified feeling seen as their providers understood and validated the unique challenges they faced living with SCD, not only the medical complications they lived with, but also the ways their lives were affected as human beings. Equally, participants identified how receiving encouragement during the transplant from their team went a long way to help them maintain optimism and resilience through the trauma of the transplant. Oko-Odoi finds that there is a need for intentional care during transplant, which includes encouraging psychological support post-transplant to foster resilience. Providers should also consider the impact of the patient’s experience living with SCD as paramount for “restoring hope and trust” (p. S435, 2019).

Light At The End of the Tunnel: Adjustment during the 1st Year Following Transplant

Theme 3: Light at the End of the Tunnel: Adjustment during the 1st Year Following Transplant. This theme encompasses several subthemes, including *The Rebirth with Recovery, Embarking on Uncharted Territory, and The Battle Between the Past and Present.* The adjustment period following hematopoietic stem cell transplant includes several simultaneous adjustments. *Theme 3 highlights the initial reactions and adjustments of participants following stem cell transplant, including feelings of gratitude and excitement, adapting to a new daily routine, and the physical changes that participants experience.]*

The Rebirth with Recovery

This subtheme exemplifies the initial recovery process following the physically debilitating and arduous wait for donor cell engraftment. After successful engraftment, participants recognize the changes they have experienced and the side effects they are working to heal from. This period signifies a change in their physical identity as they perceive it—hair regrowth, skin changes, significant weight loss—factors that reflect a new beginning, akin to a physiological 'rebirth' as their body undergoes regeneration. Conversely, participants highlighted a need to regain their health as the complications and overall toxicity of some of their treatment drugs continued to prolong the recovery process.

This theme and participants' experiences are reflected in the existing literature on psychosocial recovery, which encompasses the estimated one-year period of physical recovery, readjustment to physical sensations, and establishing a new daily routine that is both positively and negatively overwhelming (Dovern et al., 2023). The literature aligns with study findings, noting relative improvements in physical functioning, primarily due to the cessation of pain medication (Dovern et al., 2023; Amonoo, Lam, & Daskalakis et al., 2023) for pain crises.

Embarking on Uncharted Territory

This subtheme reflects the point at which participants realized they were medically cleared of sickle cell disease. Participants identify the surreal nature of learning that they are disease-free. Participants' demographic information revealed a significant time difference from the end of treatment to when they were medically cleared, ranging from several months to several years. Reactions to the news of being medically cleared of SCD spanned multiple emotions as participants recalled initially being in shock, feeling gratitude, and disbelief regarding what was once an impossibility throughout their lives, now being a viable reality. This reality afforded participants a level of freedom as they began to imagine possibilities and opportunities that were now within their reach. Their lives had been at best, refocused, and at worst, thwarted by living with SCD and navigating life to manage the disease. Participants were now reimagining life with new possibilities such as occupational aspirations and travel goals. These outcomes were consistent in the literature, noting positive variations in reactions to new opportunities among participants (Badawy et al, 2021; Dovern et al., 2023; Amonoo et al., 2023).

The Battle Between the Past and Present - Reimagining a new daily routine

Findings in this subtheme revealed convergence and divergence in how participants adjusted to being medically cleared of SCD. A significant part of living with this disease for decades is daily health management, and the various methods individuals employ to navigate the world with SCD. Participants no longer had to visit the hospital for lab tests or carry out their daily medication regimen. These tasks were more than just regimented responsibilities for managing sickle cell. Participants found safety and security in their routines, as it helped them control physical pain and allowed them to at least stay out of the hospital as long as possible.

Equally, others did not immediately identify changes in their routines, as they worked to prevent their lives from feeling tethered down by the disease, which proved more pertinent to their illness identity than the specifics of the daily management regimen.

Within the subtheme '*The Battle Between the Past and Present,'* participants identify multiple losses they navigate, including low social support, financial burdens resulting from the loss of disability benefits, and delays in returning to work due to acute medical recovery needs (Khera, 2023; Dovern et al., 2023). Participants are faced with a new reality after undergoing a stem cell transplant that requires time to adjust, as they simultaneously experience and adapt both physically and emotionally, and begin to realize new opportunities and goals. Dovern et al. also report similar findings, noting a need for time to internalize what it means to be cured (2023). This indicates that many individuals, after transplant, will struggle to adapt to a new routine. As a result, they are more likely to maintain their daily sickle cell routine, even if it is not medically necessary.

Among the changes that participants faced were changes in their relationships with their bodies. Following the transplant, participants found that a lack of pain allowed them to feel more energized and initially confirmed for them on a visceral level that the transplant worked. They noticed they were no longer being subject to environmental changes that caused severe pain crises. This history of severe pain impacted participants' nociceptors, or pain receptors, which impacted participants' pain experience. Living with a chronic pain condition, participants gain a heightened sensitivity to differing sensations, another requirement for self-preservation, as having a keen awareness of body sensations that feel 'odd' or abnormal was necessary to reduce the chances of a pain crisis or a potential hospital stay. This experience often left participants vigilant about new bodily sensations, which, for some, improved, but for others, took a bit longer. These experiences are similar to literature on post-transplant outcomes for SCD and non-malignant cancers (Dovern et al., 2023; Amonoo et al., 2023). This level of vigilance also constitutes a potential post-traumatic stress reaction that is normative in the context of recovery and for this population with a history of heightened sensitivity towards somatic threat cues, can affirm the complex nature of stem cell transplant as another form of medical trauma (Edmonson, 2014; Janicsak et al., 2021; McBain & Cordova, 2024).

Some changes went beyond the physical. Participants identified system barriers that resulted from being medically cleared of sickle cell disease, which removed their disability status and led to the termination of their Social Security disability benefits. Because of the chronicity of the disease, SCD qualifies for total disability, allowing individuals living with the disease to receive financial assistance. Participants described these changes as stressful, but they led them to begin questioning their own capabilities as adults. They noted this was one of the first times they had to consider what it would mean to pursue or envision a future, and potentially failing. These findings further indicate that the adjustment period is one of significant complexity, encompassing both positive and negative emotions, systemic hurdles, and physical vulnerabilities (Janicsak et al., 2021; Dovern et al., 2023; Amonoo et al., 2023). Additionally, it identifies the role of identity development critical to emerging adulthood, identity vs. role confusion where participants are now rediscovering a new way of life that is no longer based on their physical disease state, but now is measured by their own personal will and desires for their life (Erikson, 1968).

As the Dust Settles: Navigating Survivorship

Theme 4 encompasses several subthemes that outline the timeline post-transplant, categorizing the various milestones or points throughout the post-transplant process that participants identify. This period is defined as occurring after the 1-year mark following completion of the stem cell transplant. Most of the existing literature does not categorize the timeline in this way, but instead delineates early effects, late effects, or only post-transplant effects. Unique to this study, the use of time markers between Themes 3 and 4 reveals some significance regarding meaning-making during significant periods post-transplant and the differences in participants' descriptions of those periods.

Echoes of the Past - Lingering role of SCD after Transplant

This subtheme represents the several lingering complications that participants continue to navigate several years after transplant. All complications range in severity, and some are complications from SCD, while others are a result of the stem cell transplant. Indicating the varied nature of recovery and also the byproduct of transplant that cannot always reverse most complications of SCD. However, participants noted that the complications, though noteworthy, generally paled in comparison to living their life sickle cell free.

There are mixed outcomes in the literature, presenting different perspectives on the types of complications that persist. One study identified that late medical effects or complications can persist after a stem cell transplant, such as pulmonary, fertility, and endocrine issues (Khara, 2023; Dovern et al., 2023). Other studies identify that a different type of pain will linger for up to one year after the transplant due to medication from the transplant regimen, but it is anticipated to completely resolve (Dovern et al., 2023). However, this article also notes that other forms of pain may be irreversible if they result from a complication of SCD, such as avascular necrosis.

One participant described an ‘arthritis like’ pain, while others noted persisting hormonal changes. Like others with lingering complications, participants focused primarily on gratitude for no longer having sickle cell pain despite having to continue to manage new chronic conditions.

The Duality of a Cure

Participants describe a phenomenon in which navigating a new health status is accompanied by changes in their perspective. This experience differs from the acute nature of the initial adjustment period, as participants in this stage reflect more on their journey and recognize that their lives are expanding in new ways. They see that they have an identity beyond that of a patient in a hospital. Their social lives have deepened, and they have been able to pursue and establish new meaningful careers. They feel empowered to envision and pursue new goals that align with their personal values.

Mental health was an essential aspect of embracing their future. Overall, participants noted an improvement in their mental health compared to another subtheme that highlighted the impact of SCD on participants’ mental health before undergoing stem cell transplant. Participants found that, although their mental health was worse prior to the transplant, it improved post-transplant, but still was not at an optimal level afterward (Janicsak et al., 2021; Dovern et al., 2023; Khera, 2023). For some, the chronic use of opioid pain medication had lingering effects on their mental health. For others, the fear of disclosing their health history to their workplace prevented participants from seeking out support. One participant shares that the transplant still impacts their mental health, but in a different way. They felt they lost a sense of direction and developmentally feel delayed as they missed some socially appropriate milestones. Overall, most participants identified that the chronicity, daily management, and physical burden of SCD caused them to minimize or ignore their mental health—seeing their physical health and surviving as more important or necessary to focus on.

Equally, participants identify that their spiritual connection grew as well. Most reflect on how they make meaning of their new health status as a miracle and blessing from God that they could not have expected given what they were told about SCD morbidity and mortality. Participants noted that they had some form of relationship with God or their higher power, but also observed that this relationship grew stronger after the transplant. Participants reflect that this transplant was a second chance at life that they could not imagine ever in their lives, due to the chronic threat of an early death from the disease's course. This level of disbelief was not their own subjective experience, but from a scientific standpoint, they recognized a cure was an impossibility for many decades. They begin to settle into the reality of living with a sickle cell-free body and express gratitude that they now have the privilege to live, make plans for the future, and take chances in life without the looming threat of death.

Study findings indicate both positive and negative experiences among adults following stem cell transplant for SCD. These factors highlight the multiple, varied perspectives that participants expressed, including generally positive realizations such as improved quality of life, spiritual growth, mental health improvements, and immense gratitude. Participants also identify some negatives, such as fear of recurrence and lingering health/medical complications. Yao, Lai, Garcia, et al., posit a similar outcome trajectory for individuals who are cancer-free (2023). Their study indicates the experience for participants was both devastating and growth-inducing, identifying new perspectives that emerge as participants reflected on the impact of their journey throughout survivorship (Almeida, Ramos, Maciel et al., 2022; Yao, et al., 2023). Similarly, this study conceptualizes the experience of cancer as a trauma and disruption to participants' lives and conceptualizes their reactions to the concept with factors, such as an appreciation for life, spiritual changes, personal strength, and greater relationship to others (Tedeschi & Calhoun, 1996).

The Weight of "What If?"

Participants note that several years into survivorship after transplant, they observe that maintaining health habits from their time living with SCD remains essential. These behaviors signify the safety and predictability in these habits that were crucial to the participants, potentially providing a sense of security and consistency during a time in their lives that was highly unpredictable and filled with pain.

Participants navigate the fear of SCD's recurrence. Despite having several years without pain, receiving lab results that confirm they are medically cleared, and attempting various activities without experiencing a relapse, participants still carry an underlying uncertainty about whether SCD will come back. Living with a disease like SCD, individuals often brace themselves for their next crisis, which necessitates vigilance and constant monitoring. Participants recount certain activities (i.e like swimming, taking a bubble bath, etc) that took them months or even years to attempt. Meanwhile, others remain hesitant to try these once restricted activities, as painful memories of past crises resurface, or specific time periods trigger recollections of significantly traumatizing hospitalizations from SCD.

Literature indicates fear of recurrence is often a psychological reaction to stem cell transplant (El-Jawhari, Vandusen, Traeger et al., 2016; Amonoo et al., 2019; Dovern et al., 2023), also identifying symptoms of this fear as a post-traumatic stress symptom of re-experiencing for individuals who have a history of medical trauma (Edmonson, 2014; Janicsak et al., 2021). There are mixed viewpoints that classify it as a post-traumatic stress reaction (El-

Jawhari et al, 2016; Janicsak et al., 2021), and one study that found a small association between fear of recurrence and symptoms of post-traumatic growth (McErlean et al., 2023; Gu, Shen, Zhao, 2024). Further confirming the journey in this process as non-linear, but the survivorship stage after transplant is part of a meaning-making process.

Taking Matters Into My Own Hands - Navigating healthcare post-transplant

Participants reflect on their experiences within the healthcare system after their transplant and observe the changes in the quality of care they have received. They indicate improvements in care, such as no longer being referred to another provider for care and receiving positive verbal and non-verbal feedback when providers learn they no longer have SCD. They emphasize how much smoother and more pleasant the process is to navigate doctors' appointments and visit the emergency department, as they feel prioritized and notice a greater sense of urgency from providers to see them, compared to their experiences in the same hospitals when they had sickle cell disease. They express frustration with the difference in care because it confirms that they were not believed when they had SCD. At the same time, they feel some ambivalence, unsure whether they can validate these negative feelings or if they should be grateful for improved care.

Other participants highlight the changes in the quality of services they receive now that they have commercial insurance and no longer rely on state insurance. One participant has taken community healthcare education courses focused on sickle cell to gain a better understanding of the disparities in care and their impacts on the sickle cell community. Literature on structural racism emphasizes the effects of racial inequities on increased mortality, decreased quality of life, and worsened health outcomes for affected sickle cell patients (Robinson, Daniel, O'Hara et al., 2014; Smith, Valrie, & Sisler, 2022).

In medical decision-making, participants report being intentional about the providers they choose and the qualities they seek. This stems from pervasive medical and cultural mistrust experienced by participants who live with SCD. Most participants now express a preference for Black doctors and/or those who understand sickle cell disease, describe a higher level of racial salience and centrality, meaning that within healthcare settings, they are more aware of the differences they experience racially due to discrimination and experiencing racial bias. Equally, they decide that racial concordance among the providers they choose after transplant is a crucial factor in their informed healthcare decision-making. They recognize that even though they no longer have SCD, this part of their racial identity remains a significant aspect of their health history, which is essential for providers to consider when delivering medical care post-transplant. Understanding this factor is crucial for patients to feel understood and supported by their provider.

Participants emphasize the importance of compassionate care similar to what they received from their transplant team. They want to be seen as individuals who wish to maintain a quality of life, requiring individualized patient care rather than being defined by overarching stereotypes based solely on diagnosis or demographic factors.

Despite participants reclaiming personal autonomy over their health choices, their experiences in healthcare settings generally lead them to avoid hospitals. Participants recognize that past experiences in hospitals and with healthcare providers discourage them from visiting medical facilities. They associate hospitals with sick people and now, following the transplant, they no longer see themselves as ‘sick.’ Equally, participants no longer want to be defined stereotypically by their providers. Participants describe feeling uncomfortable in hospitals, dreading certain follow-up appointments, and postponing medical care even when they are ill.

The literature on medical trauma reinforces these reactions as post-traumatic stress symptoms. Avoidance of hospitals serves as a trauma-related safety behavior (Edmonson, 2014; Padova, Grassi, Vagheggini et al., 2021; McBain & Cordova, 2024). The hospital is noted as an environment-related trauma trigger where patients may re-experience arousal symptoms associated with their previous experiences in medical settings (e.g., distress, fear, tension, restlessness). Additionally, since participants' experiences in hospitals were not only linked to the physical management of SCD (e.g., medical procedures), but also to pervasive experiences of racial discrimination and bias, which can further exacerbate the fear response (Edmonson, 2014; Bird, Webb, Schramm et al., 2021).

A natural recovery from trauma is a consistent outcome in trauma research, indicating that some individuals affected by medical trauma will experience a reduction in symptoms over time. Others may undergo post-traumatic growth, forming new relationships with their environment that promote growth and provide benefits. However, some individuals continue to be affected over time, potentially leading to lasting impacts on their mental and physical health (McBain & Cordova, 2024).

Evolution of Self-Identity After Transplant

The evolution of identity among those with sickle cell disease who underwent transplant is characterized by a consistent progression, intertwined with reminders of the past that many participants have grown from, while some aspects continue to persist**.**

I'm A Survivor: The Gift and the Grief

Participants overwhelmingly identify as survivors, reflecting the strength, resilience, and mental toughness needed to endure such a debilitating disease while navigating various systems and social environments. This facet of their strength is closely tied to their identity as Black individuals who not only developed resilience from living with the disease since birth but also felt compelled to be strong in order to withstand the discrimination, trauma, and life-threatening realities of frequent medical complications. These nuances in experience highlighted a difference in how participants defined themselves as either cured or not. Five participants regarded themselves as cured, noting that the improvements in their functioning and pain-free state made their struggles worthwhile during the transplant process. However, one participant viewed the transplant as taking away more than it provided, leaving them disease-free but also leading to losses related to social development, grief, and mental health.

The concepts of the Strong Black Woman Schema (SBW) (Woods-Giscombe, 2016) and John Henryism (James, 1994; Perez et al., 2023) provide a perspective on the trajectories of displaying strength, even in highly challenging life and health circumstances. Literature identifies the role of Black racial socialization in exhibiting strength when faced with multiple hardships and struggles. The tenets of SBW comprise five dimensions, including an obligation to appear strong even when one doesn’t feel that way, the necessity to suppress emotions, resistance to vulnerability, intense motivation to succeed despite limitations, and a sense of obligation to help others (Woods-Giscombe, 2016). The literature highlights the tenets of this schema, which indicate decreased adaptive coping and worsened mental health outcomes such as depression, anxiety, and post-traumatic stress (Woods-Giscombe, 2016). In the context of trauma, particularly in the lives of participants living with SCD and medical trauma, resilience is viewed as a strength necessary for recovering from multiple compounding stressors and traumas (Watson-Singleton, Spivey, & Harrison, 2024), a mainstay defined throughout participants’ narratives. Furthermore, the literature has found this schema to be both protective and a cultural adaptation for enduring trauma and distress (Parks and Hayman, 2024), highlighting its role in self-preservation and its normalization within the broader context of their culture and identity across their lifespan (Watson-Singleton, Spivey, & Harrison, 2024). The identity as a survivor represents a metaphorical ‘sigh of relief’ on a season of participants’ lives filled with living in a state of daily survival and limited quality of life. Kim, Patterson, and White define identity integration for individuals with a chronic illness in adulthood as integrating their past, present, and future (2018), thereby securing a greater sense of autonomy over their body, health, and future (Erikson, 1968; Kim, Patterson, & White, 2018).

As participants see themselves as survivors of the impossible, they also recognize the social implications for their identity as members of the SCD community. Participants experience varying levels of survivor’s remorse as they reflect on the friends and community members who continue to live with SCD. They encounter challenges in defining themselves after transplant, particularly concerning their connection to the sickle cell community, now that they ‘technically’ no longer have SCD. There is very limited literature on survivor’s guilt and stem cell transplant, or survivor’s guilt and SCD. However, there is medical literature on survivor’s remorse related to survivors of solid organ transplants and those transitioning into survivorship from cancer, corroborating our findings that survivor’s remorse is linked to the implications of this occurrence on patients’ organization and reorganization of their self-identity (Glaser, Knowles, Damaskos, 2019; Bistas & Grewal, 2024). Survivor’s guilt manifests as comparing their lives to those who are still living with the disease, feeling helpless, grief, or loss of control, which can lead to psychological outcomes of anxiety, depression, and post-traumatic stress (Glaser, Knowles, Damaskos, 2019; Bistas & Grewal, 2024).

Unveiling a New Reflection and Casting a Brighter Light

This subtheme reflects the qualities that participants described as defining their self-esteem in the years following their transplant. Participants reported increased confidence, self-love, a sense of wholeness, and freedom. They identified how SCD had left them feeling isolated and lacking a sense of belonging; however, they now experience a more profound sense of self-worth, freedom, and social connection (Zebrack and Isaacson, 2012). This comfort with themselves has transformed into a greater willingness to share their stories with others (Johnson Vickberg et al., 2001). Many noted feeling insecure about discussing their past due to the sensitivity and vulnerabilities associated with living with SCD. However, participants now find purpose and profound meaning in seeing themselves as advocates for those living with SCD, seizing every opportunity to candidly share their journey through sickle cell and stem cell transplant. Yao et al. defines this deeper relationship to others and social connection as one of the core tenets of post-traumatic growth (2023). Participants describe finding purpose in bestowing upon others the things they received along their journey (e.g., health care information, social support from those who understand, encouragement, prayer, financial resources) and advocating for certain things they did not receive (mental health resources), continuing to walk alongside them—still healing from the mental and emotional scars of their past—to keep fighting for this community — their community.

Implications

Implications of the Findings

The findings and associated literature synthesize evidence of SCD and stem cell transplant as forms of medical trauma, as they are both life-threatening, body-based threats of death or serious injury, with psychological implications for stress reactions over time that increase psychological burden for Post-traumatic stress reactions or meet criteria for Post-traumatic stress disorder.

Clinical

The clinical implications of this study are essential for providing comprehensive care to this community. Considering the psychological, social, emotional, and financial impacts of undergoing a stem cell transplant for sickle cell disease, numerous opportunities exist for an integrated care model to incorporate health psychology during the pre-, intra-, and post-transplant phases. Literature supports the need for assessment and intervention throughout this period to facilitate early mental health evaluations and psychosocial support during pre-transplant assessments, enhance health outcomes, and support adaptation during the transplant and survivorship phases (Amonoo et al., 2019). Another opportunity for integrating psychology during the transplant process is the utilization of the Consultation-Liaison for Psychology/Psychiatry service to assist patients with acute psychiatric needs during their inpatient stay. Psychologists and mental health providers should prioritize establishing relationships, demonstrating genuine curiosity, building trust, and seeking self-education about the sickle cell community to foster a strong patient-provider relationship and provide culturally-relevant care. This is crucial and ideally should commence as early as possible before the transplant to promote continuity of care and lessen the burden on patients during the acute phase of treatment. It is also vital for psychologists and mental health providers to understand the psychosocial implications of transplantation for individuals with sickle cell, given the complex, traumatic histories associated with disease management and negative healthcare experiences, including behavioral and emotional manifestations of stress reactions. A culturally informed qualitative assessment of psychosocial concerns in the context of stem cell transplantation is crucial, as is delivering culturally relevant psychoeducation on the diverse factors that not only integrate the identity-affirming strengths of this community but also identify symptoms [somatic, affective, and idioms of distress (Campbell, 2020)] that could implicate negative psychosocial outcomes (SAHMSA, 2014). Given the role of discrimination and racial bias pervasive in the medical system, coupled with the impact of SCD on their self-concept and racial identity salience in medical systems for Black identifying patients, it is vital to conceptualize and assess mental health prior to transplant, in order to implement patient-centric resources and recommendations such as peer-support groups, psychological follow-up, referrals to psychiatry, leveraging social supports/networks to reduce psychological decompensation and support positive health outcomes.

Provision of mental health clinical services throughout survivorship after transplant provides an important opportunity to support the new phase of adjustment and recovery in the first year following acute medical recovery from the transplant. This support addresses systemic stressors such as potential financial strain, encourages resources for vocational rehabilitation for individuals looking to return to work, and aids in psychological adjustment while managing possible stress reactions that may arise from the stress of the stem cell transplant. The second important phase of follow-up encompasses the years following the initial adjustment period, during which patients navigate survivorship into the later years post-transplant. In this phase, more existential reflection and meaning-making may occur as patients resettle into their new normal (Yao et al, 2023, Dovern et al., 2023). This period is also significant as patients may experience recurring mental health symptoms, stress reactions like fear of recurrence, identity and role confusion, and face new life stages that present different challenges or opportunities. As patients transition into this new life stage, where they are no longer living with SCD, they have the chance to participate in life review and reflect on the impact of SCD on their lives. Many patients have not identified the prevailing impact of living with SCD, and the subsequent ways it can be impacting their self-identity and ways they have learned to cope with the multiple forms of medical trauma they have experienced. Creating opportunities to assess, educate, and address the role of trauma and subsequent symptomology is crucial, as is implementing trauma treatment, narrative work, and/or meaning-making centered therapy (McBain et al., 2022; McBain, 2024).

Providing opportunities to build community throughout the transplant process would support patients considering or undergoing transplant by allowing them to give back and share their stories. Currently, there are bone marrow transplant and hematopoietic stem cell transplant groups operating at local and national levels, primarily encompassing patients diagnosed with other hematological malignancies that differ from the lifelong chronicity and disease progression of sickle cell disease (i.e. Leukemia, Lymphoma, Multiple Myeloma, Myelodysplastic Syndromes, etc). Opportunities for one-on-one peer support programs, patient-driven reading materials, and options for virtual and in-person support groups can foster community building, reduce some of the isolation and associated with the transplant process, and facilitate psychological adjustment (Doull et al., 2017). A secondary effect of these groups is to address the survivor's guilt that may persist after transplant. A group setting can help patients explore and manage these feelings (Joo et al., 2022). The findings indicated that participants struggled to identify with a specific group or location now that they no longer had SCD, further highlighting the need for a support group dedicated to community building and sharing their experiences.

Implementing these clinical programs is necessary for the sickle cell community to provide patient-centered, culturally relevant care and to promote positive health outcomes. For healthcare systems with embedded bone marrow/stem cell transplant (BMT/SCT) programs, changes in assessment can begin at the initial bone marrow transplant psychosocial assessments conducted by mental health providers. Culturally-relevant resources and recommendations can be outlined in assessment reports prior to transplant and discussed in case conferences among the interdisciplinary team who will be providing care for the patient. BMT programs should ideally include a psychologist or mental health provider who can also provide inpatient follow-up with SCD patients who are identified with a moderate to high incidence of psychosocial risk factors or utilize a consult model when discussing patients' progress in interdisciplinary BMT team meetings to identify patients who may need additional support (Amonoo et al., 2019). It is important that psychological resources and access to a mental health provider are made available prior to and following transplant, despite the outcome (Amonoo et al., 2019; Dovern et al., 2023).

Training

This study highlights the impact of living with SCD and transplant on participants' mental health outcomes and their desire to seek therapy. Improving training for psychologists and medical professionals is essential. Due to the prevalence of racial discrimination and medical mistrust experienced by patients with SCD, along with implicit bias from providers, proper training in assessment and conceptualization is crucial to close care gaps, reduce misdiagnoses, and enhance health outcomes for this community (McBain, Stoycos, & Doenges, 2022). Assessments that consider cultural background, such as Hays' ADDRESSING model (2008), and the effects of culture on mental health, like the Cultural Formulation Interview (APA, Lewis-Fernandez et al., 2016), are useful tools for initiating conversations about culture, understanding its influence on mental health, identity, help-seeking behaviors, and the patient-provider relationship among Black SCD patients undergoing stem cell transplants. Additionally, using an open-ended approach in qualitative research is vital to understand patients' racial and illness identity factors, and individual healthcare experiences, including pain management, coping strategies, and the impact of living with SCD on quality of life. This information supports a comprehensive understanding of patients' culture, their history with SCD, and their healthcare experiences, enabling the development of more intentional and personalized treatment plans to support psychosocial adjustment. It also helps to understand how living with a lifelong chronic condition affects individuals' self-concept, healthcare navigation, and coping mechanisms. Findings from this study indicate that patients' lives improved significantly, and despite many patients being resilient or potentially emotionally numb from years of disease management, it is easy to overlook important insights and miss opportunities to assess and address psychosocial impacts. This level of assessment and multifaceted understanding promotes more accurate mental health diagnoses, psychoeducation, treatment, and resource access for this community.

Additionally, this study's findings have implications for patients, as participants identified that many medical providers did not understand sickle cell and held biases towards them based on their race and health status. These experiences influenced participants' health-seeking behaviors, their desire to visit the hospital, and their trust in the healthcare system after transplant. These findings underscore the importance of enhancing medical education training to consider sociocultural factors and disease implications for individuals living with SCD, as well as the need to foster positive patient-provider relationships and implement implicit bias training for healthcare providers and staff.

For many years, health psychology and trauma psychology have been siloed. In the years of training for psychologists, integration of medical trauma into the doctoral, residency, and fellowship training is pivotal to addressing community needs and providing holistic treatment for our marginalized and racially minoritized communities (Cook et al., 2017). McBain et al. assert the importance of assessment and psychoeducation on common trauma reactions, how they may present among medically ill patients or those with acute medical needs (2022). Also, the importance of using brief interventions to address potential symptoms like intrusive thoughts, avoidance, or using trauma-informed coping strategies to address symptoms like grief, depression, or treatment adherence is also indicated (McBain et al., 2022). This level of developmentally appropriate training at each level of Psychology training is essential to the ethical provision of mental health care. A parallel benefit to this training for future psychologists is that it well positions our field for interdisciplinary care and training to adjacent medical staff, like providers and nurses, who are likely the first points of contact to observe or assess for these symptoms. This interdisciplinary team approach supports a more holistic patient care experience and can be a step in reducing systemic bias and decreasing negative healthcare interactions for the sickle cell community.

Implications for Future Research

As this study was exploratory, several themes emerged, and several outcomes warrant further exploration in future research.

This study had a very specific inclusion criterion, highlighting patients who were considered to have undergone successful stem cell transplants with minimal physical side effects. However, this is not the case for every sickle cell patient who undergoes a transplant. Some patients continue to experience pain from severe complications of sickle cell disease, such as avascular necrosis. Although they are no longer living with sickle cell disease, it is essential to understand the various domains under study among patients with differing treatment outcomes to identify any variations. Additionally, like one participant in this study who underwent a second transplant after the first failed, exploring self-identity among individuals with SCD who have experienced failed stem cell transplants would also add depth to the literature.

Another important future direction involves further exploration of concepts that intersect with participants' identities, such as sickle cell disease among Black adults and spirituality. Most participants recognized the role of spirituality in their meaning-making, sense of purpose, and coping (Siler, Arora, Doyon et al., 2021). Preliminary patterns emerged from this study's findings, indicating that relationships with spirituality were complex and nuanced, evolving from childhood to adulthood. The cultural significance of spirituality, particularly within the Black community, and the impact of chronic illness on shaping one's identity are vital parallels that could enhance existing literature through further inquiry.

Similarly, there were multiple points of intersectionality that would benefit from future inquiry. Another area of further exploration is the role of living with a chronic illness, like sickle cell disease, and the intersectionality with Black motherhood. This study featured two mothers who identified some of the pivotal challenges they faced in managing sickle cell disease, pregnancy, and child rearing. With maternal mortality for pregnant people living with sickle cell is 26 times higher than in non-Black communities (Early, Eke, Gemmill et al., 2023), expanding research in this area is essential for the health outcomes of this community.

Finally, it would be essential to explore developmental age factors that impact psychosocial adjustment and mental health outcomes among individuals going through stem cell transplant. Our study noted demographic differences in the age of transplant recipients, ranging from 19 to 44 years old. Understanding the stages of life and adjustment experiences among individuals in emerging adulthood, early adulthood, and late adulthood can add depth to research, illuminating generational effects and developmental differences that impact psychosocial outcomes (Cooke, Chung, Grant, 2011).

Strengths and Limitations of the Study

Strengths

Acknowledge the methodological strengths of the study, such as the in-depth nature of IPA, the rich data collected, and the rigorous analytical process. Several strengths of this study were the method of qualitative inquiry employed through IPA. This methodology enabled an in-depth analysis of not only participants' narrative experiences but also provided the flexibility for participants' feelings, thoughts, and meaning-making processes to emerge. The richness of the data enabled a greater depth of critical analysis and interpretation. The rigorous analysis process for IPA required several weeks of initial reflections, memoing, multiple coding sessions, and exploring themes. The experience of engaging closely with the participants' data was a privilege, allowing me to bear witness to their stories and create a space for them to share some of the most intimate and vulnerable aspects of their lives.

Limitations

Though a mainstay of IPA that enables richer, more in-depth analysis, a small participant pool serves as both a strength and a limitation. A small, purposefully selected sample is crucial to the integrity of the data and enhances the participants' experience (Smith et al., 2009). However, this limited information may negatively impact the dissemination and publication of meaningful research (Charlick, Pincombe, McKellar et al., 2016). Another limitation of this research approach is recall bias. Participants were, on average, 4-7 years post-transplant, which can influence their recall of certain details in retrospect. Improvements for future studies include interviewing participants at various stages following the transplant, starting from the end of treatment and ideally at 6- to 12-month increments to minimize recall bias (Althubaiti, 2016). Finally, this study was conducted at a single clinic in a specific geographic area of the United States. This method may limit the diversity of perspectives and the broader range of experiences of others after stem cell transplant for SCD. Replicating this study across multiple health centers, along with a comparative analysis of the findings, would further enhance the research (Jenkins, Slemon, Haines-Saah, 2018).

Conclusion

As this study served as a qualitative exploration of post-transplant impacts on self-identity and experiences, participants guided the experiential themes and data, showing that their past experiences living with sickle cell disease are highly relevant to the adjustment process and navigating a new health status. Likewise, using a critical lens to approach and understand how participants experiences navigating medical settings post-transplant closely relates to the pervasive healthcare system interactions patients encountered, as both positive and negative interactions influence healthcare decision-making post-transplant. There was an overarching thread of medical trauma that was pervasive throughout several themes, and psychological symptoms, such as post-traumatic stress reactions, were present throughout the post-transplant process. This study contributes a unique perspective on the role of not only medical trauma, but racial trauma impacts the lives and identities of those in this community.

The adjustment period and navigating survivorship in the years following a stem cell transplant highlight the various quality of life improvements and psychosocial challenges individuals encounter, representing a dynamic process after the transplant that can facilitate both concurrent post-traumatic growth and post-traumatic stress reactions (Yao et al., 2023; Amonoo et al., 2019). These outcomes include a wider range of psychosocial outcomes, including normative adjustment reactions such as depressive and anxiety symptoms. However, this study underscores a significant gap in the literature regarding the acknowledgement of medical trauma as a significant contributor to SCD shaping self-identity and mental health outcomes. It also emphasizes perspectives on enhancing patients' empowered healthcare decision-making, mental health advocacy, and adequate access to appropriate resources, both during vital survivorship periods.

Self-identity among Black adults following stem cell transplant was transformative, as the identity of being a survivor of the impossible is salient; the tenets of racial socialization foster a balance between resilience and the need to be strong. Where their racial identity becomes most salient in healthcare settings where they must now negotiate this aspect of their identity to navigate bias and discrimination. Participants indicate the lingering impact of survivor's remorse on their connection to the broader SCD community, especially now that they no longer live with SCD. However, they find deep purpose and meaning in the opportunities to be more vulnerable about their history with SCD, leaning into this new confidence by advocating for those living with SCD. This study represents a comprehensive examination of the narrative life review of patients with sickle cell disease after undergoing a stem cell transplant, exploring the various experiences and choices that shape their identities over time and the importance of the broader medical and mental health community hearing their truths and striving to see them fully with fresh eyes.

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APPENDIX A: CONSENT FORM

UNIVERSITY OF GEORGIA
CONSENT FORM

MORE THAN A CURE: A QUALITATIVE EXPLORATION OF SELF-IDENTITY IN BLACK ADULTS FOLLOWING STEM CELL TRANSPLANT FOR SICKLE CELL DISEASE

Before you decide to participate in this study, it is important that you understand why the research is being done and what it will involve. This form is designed to give you the information about the study, so you can decide whether to be in the study or not. Please take the time to read the following information carefully. Please ask the researcher if there is anything that is not clear or if you need more information. When all your questions have been answered, you can decide if you want to be in the study or not. This process is called "informed consent." A copy of this form will be given to you.

Principal Investigator:	Linda Campbell, PhD *Department of Counseling & Human Development lcampbel@uga.edu, (706)542-8508*
Co-Investigator:	Jasmine McGhee Akoma, M.Ed. *Department of Counseling & Human Development jasmine.mcghee@uga.edu,, (615)628-7061*

Purpose of the Study
You are being invited to participate in a research study that explores the experiences of Black adults who have previously undergone hematopoietic stem cell transplant for sickle cell disease. The purpose of this study is to gain an in-depth understanding of the experiences of Black adults navigating facets of their identity after living with a chronic illness throughout their life. Further, this study seeks to understand how these experiences have impacted participants' wellbeing, mental health, and experience in the medical system. This study is important as little is known about the lived experiences of Black adults' identity after undergoing a curative treatment for sickle cell disease. Findings of this study will be utilized to inform the medical and mental health community about the unique needs of this community, and ways to address these needs for better health outcomes.

Study Procedures and Time Commitment
Participation in this study is voluntary. If you decide to participate, you will be asked to complete a 60-90-minute semi-structured interview with the primary researcher. This dialogue will be

audio-recorded and transcribed. The recording will assist the primary researcher in ensuring accuracy of the information gathered for the data analysis purposes.

During the loose semi-structured interview, the primary researcher will verbally conduct a demographic questionnaire. This will take about 10 minutes. After, the remaining time will be used to ask about your life and medical experiences after undergoing stem cell transplant, its impact on your mental health and the ways you've navigated life no longer having sickle cell disease. After, recordings will be de-identified and assigned a pseudonym (a different name) in order to keep your identity confidential.

These dialogues will be completed via Zoom. The meeting will be conducted via the UGA Zoom portal. All Zoom interviews will occur in a quiet, private location. Please be aware that you do not have to participate in this research, and you may stop your participation at any time without penalty.

Risks and Discomforts

The study involves no risks to your physical health. The possible risks associated with your participation in this study are minimal. You may experience some unpleasant feelings or might remember difficult life memories when asked to reflect on your life. Should this happen, you can decline to answer and/or skip questions. You have the right to disclose topics at your discretion. If you do experience distress, you are encouraged to let the investigator know immediately. If you experience any uncomfortable feelings, we can provide you with referral resources.

To protect the sensitivity of information you may share, the primary researcher is taking precautions to keep your information confidential and prevent anyone from discovering your identity. Therefore, your audio recording will be de-identified and given a pseudonym (a different name) instead of your actual name. Also, all information will be password-protected on a computer.

Benefits

There are no direct benefits to you. However, this study has the purpose and potential to provide Clinical and Counseling Psychology programs with a greater understanding of the experiences of Black adults who previously had sickle cell disease, provides an opportunity for you to share your story, and inform improvements in mental healthcare practices.

Incentives for Participation

You will be compensated with $40 U.S. dollars upon completion of a 60-90-minute interview. For interviews shorter than 90-minutes you will be compensated $13.33 for every 30-minutes. Compensation will be provided in the form of a gift card at the end of the interview.

Confidentiality of Records

Several safeguards will be taken to protect your identity and your names will not appear on any of the data except for this consent form. This consent form, the audio recording, audio-visual items, and the transcript will be kept electronically in a folder on a password-protected computer. Audio recordings will be deleted after transcription. No identifying information will be tied to your responses and interview transcripts will be de-identified. Further, a pseudonym will be assigned to you to protect your confidentiality. Additionally, it is important for you to know that you will be asked to initial a payment log stating you received compensation. This payment log will be shared with accounts payable of the University of Georgia in order to process your compensation. Your full name and any other identifiable information will not appear on this log.

The researcher will not release identifiable results of the study to anyone other than individuals working on the project without your written consent unless required by law and in the event that you disclose that there is currently harm to yourself of others, report of suicidal ideation and suspected abuse or neglect of a child or an elder. Disclosure of the aforementioned events may result in reporting to local authorities. The information gathered from this study will be utilized for future publications and scientific conferences in addition to the dissertation of the researcher. The information will be distributed for future research with de-identified information without further consent.

Lastly, if you choose to participate in the loose semi-structured interview via Zoom, is important to note that limitations to confidentiality and data security exist. As such the researcher cannot guarantee that all communication and information will be confidential when using online methods.

Participant Rights

Participation is entirely voluntary. You may change your mind about participating in the study and decide to not continue at any time without negative consequences. If you have any questions or concerns regarding your rights as a research participant in this study, you may contact the Institutional Review Board (IRB) Chairperson at 706.542.3199 or irb@uga.edu.

Questions

If questions arise about this research study, please contact *Jasmine McGhee Akoma, jasmine.mcghee@uga.edu, or (615)628-7061.* Additionally, you may contact the principal investigator *Linda Campbell* at the University of Georgia (706)542-8508 or *lcampbel@uga.edu*

Consent for Audio Recording

Audio recording is part of this research study, and all recordings will be transcribed to ensure for accuracy in the participant's story. You can choose whether to give permission to be recorded. If you decide that you do not wish to be recorded, you will not be able to participate in this research study.

_______I give my consent to be recorded.

_______I do not consent to be recorded.

If you agree to participate in this research study, please sign below:

Name of Researcher	Signature	Date
Name of Participant	Signature	Date

Please keep one copy and return the signed copy to the researcher.

APPENDIX B: INTERVIEW GUIDE

Interview Guide

How has living with sickle cell disease shaped your life?

Probe: How has SCD shaped how you see yourself?

Probe: What has it meant to you to be a Black woman/man living with sickle cell disease?

-how does being a black man/woman impact your life

- how do you feel your experience would have been different if you only had SCD but weren't black?

Probe: As a Black woman/man who lived with sickle cell disease, Tell me about your experiences trusting the healthcare system?

Probe: Its common that people have positive and negative experiences with trusting the healthcare system: What were those like for you?

What made them trustworthy or not?

Did you ever imagine what life would be like without sickle cell disease?

Probe: what led you to seek it out?

Probe: What did you hope for yourself and your life after transplant? Have any of your hopes or expectations come true?

Probe: What did you look forward to most after the transplant?

Tell me about your 1st year after transplant…So at you're one-year follow-up after the transplant and your doctor informed you that you no longer had sickle cell, what was going through your mind? How did you feel?

Probe: Tell me about the first experience you had that solidified to you, "i dont have sickle cell anymore?'

Probe: What has been the biggest adjustment?

**Probe: How did having a SCT impact your life? How did you spend your days?*

Probe: Work/School? Hobbies?

Probe: What did you notice about your body? Did it change? Feel different?

Probe: Describe how your mental health was after the transplant? Did you seek out mental health support? Why or why not?

Probe: What services or support would have helped you best navigate life after transplant?

Noting your experiences with SCD and navigating the health care system. Im curious about what that experience is like now.

Probe: Describe your experiences navigating the health system now as Black woman/man?

Probe: What are the biggest hurdles you navigate now when going to the doctor or ER?

Probe: How would you describe your relationship with your transplant team? Other providers not on your team?

Probe: How have you felt about interactions with providers during/after the transplant process?

Now that you are ___ years out from transplant. How is life now?

Probe: What has been the biggest adjustment?
Probe: What changes have you seen in yourself since transplant? Probe: Mental, Physical, Emotional, Social, Spiritual?
Probe: Describe how your mental health has been since the transplant?
If no - Probe: Looking back, do you think it could have helped at any point in the transplant process? Looking back, do you think it could have helped at any point in the transplant process?
Probe: Do you consider yourself to be cured?
Probe: How has your relationship with your body changed?
Probe: Best things that have come from transplant? Worst things that have come from transplant?
Probe: What have you learned about yourself since undergoing transplant?
Probe: Knowing what you know now, would you go back and change anything about the process?
Probe: What would you tell others who are going through this process?

ENDING: What word would you use to describe what this transplant meant to you? Why?

Thank you so much for your time!