ASSESSING THE KNOWLEDGE AND PERCEPTIONS OF SICKLE CELL DISEASE IN HEALTHCARE PROFESSIONALS, BLACK AMERICAN, LATINX AMERICAN, AND OTHER POPULATIONS WITHIN THE MIDWEST

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DEDICATION

This dissertation is dedicated to my guardian angel, my grandmother, siblings, and nieces and nephews. To my guardian angel, even though you are not here your presence has motivated me more than you will ever know, you have been my biggest motivation; I love you mom. To the rest of my family, thank you all for being my biggest supporters. Without your love, support, and belief in me I may not be where I am today. I love you all much more than you will ever know.

This one is for ya’ll.
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ABSTRACT

Sickle cell disease (SCD) is a serious and debilitating disease that primarily affects Black and Latinx populations here in the United States; however, it can affect other racial and ethnic groups as well. In the Midwest, compared to the East and West coast, SCD affects a smaller number, at approximately 15,000. For years, there has been a misconception that SCD is only a “Black” disease. This has influenced the treatment, research, and support of the disease. Given that this disease mostly affects minority populations, it is important to assess not only the knowledge of the groups most commonly affected, but also healthcare professionals who are responsible for providing care for these individuals, and other populations who can be catalysts for raising awareness and knowledge about the disease. Five hundred and seventy-three participants were surveyed and 29 participated in focus groups or interviews. Results showed that healthcare professionals and Black Americans were more knowledgeable about SCD than Latinx Americans and other populations. Perceptions among groups were not statistically different and were similar qualitatively. Stigma was impacted by knowledge level; as knowledge levels increased stigma decreased. There were differences found between healthcare professionals and other populations (both had higher levels of stigma than the other two groups). The findings support that knowledge about SCD is needed across all groups, particularly among Latinx Americans, as well as knowledge concerning treatment of SCD for those in the healthcare field.

Keywords: sickle cell disease, disease knowledge, disease perception, disease stigma
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GLOSSARY OF TERMS

*Perceptions:* The way in which something is regarded, understood, or interpreted.

*Healthcare Professional:* Meaning any medical professional that sees patients with SCD, regardless of discipline. This includes nurses, physicians, residents or medical students, and student nurses.

*Sickle Cell Disease:* A blood disorder characterized by the abnormal shape of red blood cells, caused by abnormal hemoglobin and lack of oxygen in the blood.

*Health-Related Stigma:* Social disqualification on the basis of health conditions and problems
Assessing the Knowledge and Perceptions of Sickle Cell Disease in Healthcare Professionals, Black American, Latinx American, and Other Populations within the Midwest

Introduction

Sickle cell disease (SCD) is a serious debilitating disease that impacts roughly 115,000 individuals in the United States (Hassell, 2010). The disease predominantly affects individuals of African descent but can also affect a broader demographic. The last estimated cost of sickle cell was calculated in 2004 to be approximately $488 million dollars annually in the U.S. (Brousseau, Panepinto, Nimmer, Hoffmann, 2009; CDC, 2019). Much of the research on knowledge and perceptions of SCD primarily comes from researchers and organizations on the east coast and in the south (Huttle, Maestre, Lantigua, & Green, 2015). These areas have higher numbers of African-Americans and thus have a higher prevalence rate of SCD compared to the Midwest (see Figure 1. below for an estimate of prevalence by state) (Hassell, 2010). With this higher prevalence, there are more clinics, hospitals, and healthcare professionals that specialize

![Figure 1. Prevalence by State Reported in 2010.](image-url)
in hematology (blood disorders) and SCD. It is important to understand the knowledge and perceptions of people here in the Midwest so that we can address stigma and overall awareness of SCD here through educating healthcare professionals, communities most at risk, and the general public, in order to improve the overall well-being of youth and adults with SCD in the Midwest.

The purpose of this study was to explore how knowledgeable groups are about sickle cell disease (SCD). A secondary purpose was to understand how individuals perceive the disease and the individuals impacted by the disease. In addition to understanding these areas, stigma was also explored. Within this study, knowledge and perceptions will be assessed within four distinct groups: healthcare professionals, Black American, Latinx American, and the other populations. The relationship between healthcare professionals and patients with SCD has been studied extensively throughout the years, specifically in regard to perceptions and attitudes about SCD patients. This specific subset has the biggest impact on the health of patients with SCD and it is important to gauge their understanding, knowledge, awareness, and stigma towards individuals with SCD as it could have important clinical implications. Black Americans have the highest prevalence rate of SCD and sickle cell trait and Latinx’s have the second highest prevalence rate; it is imperative that these communities are educated about what SCD is, about their trait status, and about their perceptions and attitudes about the disease (CDC, 2019; Siddiqui et al., 2011). Lastly, other populations are being addressed because after a thorough literature review, this group has not been studied. Other populations should have at least a general understanding of SCD since this disease affects a number of people from diverse backgrounds, and because the general public can be the driving force for raising awareness and funding for this disease (Bediako & King-Meadows, 2016).
Sickle Cell Disease

SCD is an inherited blood disorder, that primarily affects people of African descent but can also affect people of Hispanic, Middle Eastern, Asian, and Mediterranean descent. According to the Centers for Disease Control and Prevention (2019), SCD occurs in one in 325 (.003%) Black births. As of July 2013, African Americans make up approximately 12% of the population; one in 13 or 7.69% of African Americans have the trait which equates to roughly 3,288,361.78 people of African descent (American Society of Hematology, 2016). Individuals of Latinx descent have a 1 in 16,000 prevalence of SCD; among the east coast it is reported to affect 1 in 1,100 births (Huttle et al., 2015; Siddiqui et al., 2011). Prevalence amongst the different regions within the United States varies. It is estimated that approximately 47,354 individuals living in the South have SCD compared to 17,023 in the Northeast, 15,096 in the Midwest, and 9,605 in the West (Brousseau, Panepinto, Nimmer, & Hoffmann, 2009).

SCD is characterized by the shape of the red blood cells. Due to an abnormality in the hemoglobin the red blood cells are crescent shaped. Hemoglobin is a protein in the blood that “carries oxygen throughout the body” (National Heart, Lung, and Blood Institute [NHLBI], 2016). The abnormality produces red blood cells with reduced oxygen, which results in the abnormal shape. The shape of normal red blood cells allows them to easily move throughout the blood vessels. The shape of sickled cells does not allow for an easy flow and they “can stick to vessel walls, causing a blockage that slows or stops the flow of blood. When this happens, oxygen can’t reach nearby tissues.

There are several different forms of SCD: Hemoglobin (Hb) SS, SC, Sβ0 thalassemia, Sβ+ thalassemia, SD, SE, and SO (CDC, 2019). Hemoglobin SS is the most common form of SCD, its commonly referred to as Sickle Cell Anemia; this is also the most severe type.
Individuals with Sickle Cell Anemia, have “inherited two sickle genes (S), one from each parent.” The second most common type of SCD is Hemoglobin SC; with this form individuals inherit a sickle gene and an abnormal hemoglobin gene (C). The mixture of the two genes results in a “mild hemolytic anemia” (Nagel, Fabry, & Steinberg, 2003).

**Morbidity and Mortality**

In 1973, the average lifespan of an individual living with SCD was approximately 14 years-old (NHLBI, 2016). In recent years, the lifespan has ranged from 40-60 years of age. The increase has been attributed to “several interventions in early childhood, including widespread newborn screening programs, the use of penicillin prophylaxis, and the use of pneumococcal vaccination” (Lanzkron, Carroll, & Haywood, 2013; p. 111). In contrast, researchers have found a slight increase in mortality rates in adults versus children with SCD from 1979-2005. This may be attributable to the transition of care from adolescence to adulthood. The transition process describes the movement of patients from pediatric care to adult care. This period gradually occurs across the ages of 14-21. This is mostly due to limited access to providers with expertise in sickle cell disease or more generally hematology, fewer health insurance options, and decreased support with health care coordinators (Kayle, Tanabe, Shah, Baker-Ward, & Docherty, 2016). There is no stability in the care of most patients during this time. If an adult provider is not found before the transition is made, patients are left without primary care providers and thus rely on the emergency department for their primary care needs (Blinder et al., 2015).

**Symptomology & Health-Related Quality of Life**

SCD symptoms can cause complications in different areas of an individual’s life, including but not limited to education, employment, and relationships (Thomas & Taylor, 2002). The World Health Organization (WHO) defines quality of life as:
an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. It is a broad ranging concept affected in a complex way by the person’s physical health, psychological state, personal beliefs, social relationships, and their relationship to salient features of their environment. (WHO, 2017)

**Physical and Psychological Factors.**

SCD is primarily characterized by episodes of pain, caused by blood flow blockage that results from the sickled shape of the red blood cells (Clay & Telfair, 2007). A numerous amount of complications can arise as a result of SCD such as, jaundice, seizures, congestive heart failure, bone infarctions (also referred to as avascular necrosis) which is caused by cellular death of parts of the bone caused by the “interruption of the blood supply,” tissue and organ damage, acute chest syndrome, and sometimes early death (Tofferi, 2016; Wilson-Schaeffer et al., 1999; Matthie, Hamilton, Wells, & Jenerette, 2015; Ashley-Koch, Yang, & Olney, 2000).

Physical symptoms of SCD have an immense impact on the daily lives and activities of people living with SCD. Thomas and Taylor (2002) found difficulty controlling pain was most influential in determining an individual’s quality of life. Experiencing the physical symptoms of SCD can affect educational and employment attainment, and social relationships. Individuals with SCD often miss a lot of school because of painful crises; students experience on average between 30%-40% grade retention (King et al., 2014). The pain SCD causes can influence an individual’s vitality as well, causing interference with rest and sleep, and everyday life activities (Thomas & Taylor, 2002).

The moods of individuals living with SCD can impact pain symptoms they experience. Researchers have found increases in stress or negative moods were related to increases in pain
(Gil et al., 2004). Positive moods have been associated with decreases in pain following initial pain days and are also associated with reduced contact with health professionals via, “fewer hospitalizations, ER visits, and telephone calls to doctors” (p. 272). People living with SCD who experience pain and hospitalization more frequently are also more likely to experience depression (Wilson-Schaeffer et al., 1999). In adolescence, depression and anxiety symptoms, can significantly impact their quality of life, particularly in relation to school functioning (Graves, Hodge, & Jacob, 2016).

**Social Influences.**

Social functioning, regarding education, employment, and relationships, is an area that can potentially be impacted due to the incessant nature of SCD. Complications in school settings arise from higher school absences among students with SCD; this can interfere with a student’s ability to identify with their peers (Graves, Hodge, & Jacob, 2016). Peer relationships play an important role in adolescent development; however, since SCD is present from birth it can interfere with the relationships at the most critical stages (King et al., 2014). It can be difficult to develop and maintain relationships with friends as children or adults (Matthie, Hamilton, Wells, & Jenerette, 2016). Some individuals have reported feeling as though their parents were restrictive or overprotective of them as children, especially when it came to their level of activity (Thomas & Taylor, 2002). Overexertion or extreme temperatures can cause pain and fatigue, and are things that many individuals living with SCD must be aware of and monitor. This can lead to missing quality time with friends (Matthie, Hamilton, Wells, & Jenerette, 2016).

The issue of disclosing a diagnosis can also be seen when individuals with SCD embark on personal or intimate relationships; this issue emerged in focus group discussions in the Thomas and Taylor (2002) study. The unpredictability of SCD can be difficult for partners of
those with the disease. Participants in the study spoke about their partner’s anger at the pain or the fact that they have SCD, during crises; also mentioned was their partner’s sense of helplessness. SCD can also impact securing and maintaining employment. Some individuals find themselves conflicted on whether they should disclose their diagnosis with employers (Thomas & Taylor, 2002). Often employers are not attuned to how the disease occurs and the limitations it can cause.

Sickle cell-related pain can affect individuals not only physically, but also mentally and socially as well, affecting their mood and relationships with others. SCD impacts individuals in multiple aspects of their lives, and can influence their interactions with family, friends, healthcare providers, and others. It is important for those that may interact with individuals with the disease to be knowledgeable about how it affects them. SCD is a highly variable disease; this could also contribute to the lack of awareness, negative perceptions and attitudes, and stigma others may have (Pack-Mabien, Herbert, & Haynes).

Knowledge of SCD

Among Healthcare Professionals

General knowledge of disabilities and chronic illnesses within the health profession has important implications for the care that individuals receive and the way that these individuals are perceived and interacted with. In some cases, knowledge or lack thereof can lead to stigma experienced from family, friends, health professionals, and generally society. A study conducted amongst 146 college students in health profession majors assessed the knowledge, attitudes, and self-efficacy about disability using a 90-item survey. Results showed that overall the students’ knowledge of disability was low (53.9%) rather than high (46.1%) (Culp, Rojas-Guyler, Vidourek, & King, 2017). When health professionals are factually knowledgeable about
disabilities their confidence in working with individuals with disabilities also increases (Mesa & Tsakanikos, 2014; Lehman, 2009). Most physicians rely on knowledge they learned during residency when providing care to individuals with SCD (Whiteman et al., 2015). However, in some instances this information learned within the medical program can be outdated if healthcare professionals are not keeping up with current literature and new findings related to SCD. Insufficient knowledge and experience result in decreased comfort in taking care of patients with SCD; research has shown that experience coupled with more knowledge leads to higher levels of comfort.

Among Black and Latinx Americans

There have been contradictory results within the literature regarding knowledge of SCD among Black and Latinx Americans, with most studies concluding that both groups have relatively low knowledge regarding SCD prevalence, awareness, and symptomology (Obed et al., 2017; Boyd, Watkins, Price, Fleming, & DeBaun, 2005; Harrison, Walcott, & Warner, 2017; Treadwell, McClough, & Vichinsky, 2006). However, Siddiqui et al. (2011) surveyed teens and adults (considered of reproductive age) of Dominican and Black American descent in New York City about their knowledge regarding SCD. More Black Americans (76%) were able to properly define SCD than Dominicans (27%). A larger portion of Dominicans (45%) reported that they did not know what SCD was compared to Black Americans (14%). In the parent group more Dominican parents (43%) reported not knowing their trait status than Black parents (7%). A larger proportion of individuals who indicated having a family member with the trait were able to correctly define SCD compared to those without a family member with the trait. Dominicans who indicated having a family member with the trait were just as knowledgeable about the disease as their Black American counterparts. Black Americans who did not indicate having a
family member with the trait were still more knowledgeable about the disease compared to Dominicans. The researchers posit that this may be the case because of the difference in prevalence among these two groups. Treadwell, McClough, and Vichinsky (2006) had slightly differing results, with only 15.9% of their Black American respondents reporting that they know their trait status. Similar to the previous study however, 53% of the participants reported that they learned about their trait status through family members; these individuals were three times more likely to know their trait status. Within this study, participants were involved in focus groups; several of the participants were able to describe the differences between the disease and trait symptomology and characteristics. Although some participants expressed an understanding of the difference in disease and trait, a large majority expressed uncertainty and misconceptions about how inheritance of the disease works.

Knowledge of trait status has a significant impact on knowledge of sickle cell disease, with those having the trait scoring higher on knowledge items than those that do not have the trait or indicate an uncertainty about their status (Harrison, Walcott, & Warner, 2017). Sources of information about SCD is also an indicator of increased knowledge, as is gender. Those that get their information from family members have a higher sickle cell trait knowledge score than those that do not. Women, compared to men, score higher in sickle cell trait knowledge. Participants of Treadwell et al. (2006) identified where they get information about genetics from; mentioned was coursework, on the job, as a research participant, physicians, media, family, and friends.

**Perceptions of SCD**

SCD is commonly portrayed as being a “Black disease,” this portrayal can lead individuals to surmise generally about sickle cell disease or individuals with SCD, based on their prior perceptions of Black people. (Bediako & Moffitt, 2011). It is posited that social attitudes
influence a number of both “preventive and palliative behaviors” of patients, which in turn influences how they seek or choose not to seek medical services. These race-based views could potentially affect many health-related efforts and outcomes.

**Among Healthcare Professionals**

Researchers surveyed hematologists and emergency department physicians in the U.S. Questions were related to perceived characteristics of patients and their pain, pain management with pharmaceuticals, perceptions of addiction, protocols, and other concerns (Shapiro, Benjamin, Payne, & Heidrich, 1997). Emergency department (ED) physicians thought of pain episodes as being shorter than what they are. The researchers posit that this is due to ED physicians being exposed to patients less than doctors that see them regularly and follow-up with them; they only see them “at the time of acute presentation...[and] may not have the opportunity to understand the evolution of pain” (p. 171). This finding has implications for clinical practice; physicians that perceive pain episodes as being short, may provide inadequate services. Specifically, they may not provide the proper amount of medications and treatment, which could contribute to return visits of patients.

Research has shown that healthcare professionals hold differing views about patients based on numerous factors. In regard to race, healthcare professionals have been shown to have more negative attitudes towards Black patients than White patients (Haywood et al., 2015; Van Ryn & Burke, 2000). Black patients are often seen as being less educated, less likely to follow professional medical advice, and are more likely to misuse substances. Haywood et al., assessed attitudes towards patients with SCD based on the characteristics of healthcare professionals (race, professional discipline, and degree of exposure to SCD patients in pain) and found noteworthy differences. In their sample, they found that Asian healthcare professionals held
more negative attitudes; however, they noted that this may not be generalizable given the small number of Asian healthcare professionals included in their study. Black healthcare professionals in the study held more positive attitudes than their White and Asian counterparts. The results of nurse and physician attitudes were compared; nurses displayed more negative attitudes towards SCD patients than physicians, and physicians that saw a greater number of patients with SCD reported more negative attitudes than physicians that saw fewer SCD patients. The researchers posit that a possible contributing factor to the negative attitudes of nurses, could be explained by their interactions with patients. Specifically, nurses have more interactions and potentially are more exposed to “anger, frustration, or concern expressed by the patient...” while they may be in acute pain; therefore, altering their perceptions and attitudes towards the patient. Physicians may display more negative attitudes when patients are seen more often for complications and have more complications than other SCD patients (Ratanawongsa et al., 2009).

Specific negative attitudes have been reported by both patients and healthcare professionals. Some of these attitudes include, associating patients with being drug-seekers, a general lack of sympathy, and having doubts about patients’ experience of pain episodes (Haywood et al., 2010; Wright & Adeosum, 2009). A perception of adult patients as being addicted to pain medication was found to be higher amongst ED physicians (Shapiro et al., 1997). This perception coupled with a misperception about the length of pain episodes can contribute to a cycle often seen in patients with chronic pain conditions. A cycle of undertreatment which forces patients to “complain” more about their symptoms or treatment, visit multiple emergency departments, or ask for more pain medication; which can continue to reinforce the negative perceptions of physicians.
Among Black Americans, Latinx Americans, and General Population

Bediako and King-Meadows (2016) surveyed 298 participants of various backgrounds (including Black, Hispanic, White, and other races) about public support and funding for SCD and its association with race. They measured race using the reported race of the participants and the constructed race of their fictitious sickle cell advocates. Overall perceptions of SCD were positive, and those that reported a perception of SCD as a “Black” disease reported a more positive perception of the disease, regardless of the respondent’s race, than others that perceived it as a disease affecting other races or groups.

Knowledge and Stigma Among the General Population

Public knowledge and perceptions have been assessed for diseases such as peripheral arterial disease (PAD) and (COPD). Findings of public knowledge of these diseases will be used to provide a general background of disease knowledge, perceptions, and stigma within the general population (Hirsch et al., 2007; Smerecnik, Mesters, Vries, & Vries, 2008).

PAD is more common than SCD, with an estimated 8 million Americans having the disease (Hirsch et al., 2007). Even with this disease being more common, the general population is not very informed about PAD. The researchers found that the general population lacks knowledge of the definition of PAD, risk factors for developing PAD, risks associated with limbs and amputation, and its short-term risk factors. Those that were knowledgeable about the disease got their information from sources such as, friends/family, television, and magazines. Researchers identified five articles within the United States (U.S.) and 15 articles from other countries that examined the knowledge of the general population regarding genetic risk factors of certain diseases (Smerecnik, Mesters, Vries, & Vries, 2008); the most common disease being breast cancer. Across these studies, they found that on average, about half of the sample had
awareness knowledge about the existence of different genetic risk factors of diseases. With diseases that are more common than SCD, knowledge in the general population is relatively low; which is why it is important to assess the knowledge, perceptions, and stigma of the general population.

**Stigmatization**

Weiss, Ramakrishna, & Somma (2006) define health-related stigma as being “typically characterized by social disqualification of individuals and populations who are identified with particular health problems. A health stigma and discrimination framework was created to understand health-related stigma at different socio-ecological levels; it provides a holistic view of understanding and approaching stigma interventions and research, this is shown in Figure 2. (Stangl et al., 2019). Stangl and associate’s definition of stigma is based off the work of Goffman (1963) and is defined as experiences of discrimination that can ultimately deny the individual opportunities and fuel social inequalities related to health conditions (Stangl et al., 2019). Family, the general population, and health providers have been identified as the most common sources of one’s health-related stigma (Bulgin, Tanabe, & Jenerette, 2018).
Figure 2. Social Ecological Impact of Health-Related Stigma

Stigma can impact one’s health both physically and mentally, and stigmatizing experiences can also contribute to chronic stress (Link & Phelan, 2006). Experiencing stigma and having a chronic disease like SCD that already reduces health-related quality of life could essentially create unnecessary added tension. Participants in a study assessing stigma illness and uncertainty outlined their perceptions of enacted stigma enforced by society (Blake et al., 2018). After conducting a factor analysis, the researchers identified eighteen factors associated with patients’ perceptions of societies beliefs about them and SCD. Factors included items related to rejection, feelings of uncomfortableness, misperceptions about not being able to keep a job, being lazy, being a burden, treated like an outcast, as fragile, and as a drug-seeker. These factors can contribute to the experience of stressed-related illnesses that, coupled with SCD complications, could present worse in this population (Link & Phelan, 2006). The perceptions of enacted stigma can contribute to patients not seeking treatment, and not disclosing their status to close friends and employers (Blake et al., 2018). High levels of associated stigma can lead to
some diseases receiving less overall attention, meaning that these diseases are lagging in areas such as funding, research, and treatment options (Link & Phelan, 2006).

Historically, the way in which SCD is publicized is very much affected by the racial makeup of the disease. SCD patients are primarily of African descent and here in the United States SCD-related materials have, previously, showcased individuals of deeper complexions which can reinforce the narrative that SCD is a “Black” disease (Bediako & Moffitt, 2011). Perceptions of stigma in the sickle cell community have also been shown to impact the health-related quality of life in a sample of adolescents with SCD (Adeyemo, Ojewunmi, Diaku-Akinwumi, Ayinde, & Akanmu, 2015). Patients with SCD often describe feeling as though some healthcare professionals categorize them as being “drug-seeking,” or faking pain (Wright & Adeosum, 2009; Maxwell, Streetly, & Bevan, 1999; Blake et al., 2018).

Social Ecological Model

Care for patients with SCD occurs “within a complicated and extensive sociocultural system that is shaped by the beliefs and attitudes of the patient, family, community, and health care professionals” (Pack-Mabien, Herbert, & Haynes, 2001, p. 187; Shapiro, Benjamin, Payne, & Heidrich, 1997). Understanding how knowledge, perceptions, attitudes, and stigma impacts SCD through policies, healthcare utilization, and how it impacts individuals with the disease requires research and interventions at multiple levels (Blake et al., 2018). The social-ecological model (SEM) addresses this need for a multi-faceted approach. Stokols (1996) describes SEM as an approach that is useful in framing a diverse range of personal and environmental factors that may be influencing health whether that influence is positive or negative. It is understood, within this model, that the individual is at the center of a large social environment. This environment consists of close relationships, community, institutions/society, and public policy (Salihu,
Wilson, King, Marty, & Whiteman, 2015). The individual level is an amalgamation of an individual’s “knowledge, awareness, attitudes, beliefs, and perceptions” (p. 88). When using the SEM from a health perspective, the close relationships level, also referred to at the intrapersonal level, can be comprised of family, friends, health care providers, and other close relationships. At the community/institution level lies schools, healthcare institutions, and other community features. More specific to health, these other features can include things related to attitudes and acceptance amongst others, for example, “convenience and acceptance of prenatal care, local cultural attitudes about smoking, the availability of public transportation and safety of the neighborhood” (p. 89). Lastly the public policy level is determined by laws as the local, state, and national level; these laws can impact funding and health-related research. Utilization of SEM has had significant implications for health promotion interventions (Giles-Corti & Donovan, 2002). The Social Ecological Model is used within this study to emphasis the importance of understanding knowledge, perceptions, and stigma across all levels. This understanding has the potential to impact societal and policy change.

**Research Questions**

1. Is there a difference in:
   a. Knowledge level across groups (healthcare professionals, Black and Latinx communities, and the general population)?
   b. Perceptions across groups (healthcare professionals, Black and Latinx communities, and the general population)?
   c. Stigma across groups (healthcare professionals, Black and Latinx communities, and the general population)?

2. Can knowledge of SCD predict positive or negative perceptions and stigma?
3. Where do people get their information about SCD from? Is there an association between information source (personal vs. non-personal) and knowledge, perceptions, and stigma?

Method

This study was approved by the Institutional Review Board (IRB) at a midwestern university. The aim of this study was to examine the knowledge, perceptions, and attitudes held by each group (healthcare professionals, Black Americans, Latinx Americans, General Population), while also aiming to understand how and why these perceptions and attitudes were formed.

Recruitment Strategies

Multiple recruitment strategies were used to assess information from healthcare providers and medical students. Healthcare providers and students were recruited through a local medical school and local medical society. Numerous strategies were also used to gain access to Black Americans, Latinx Americans, and individuals in the General Population, including a local university, and community organizations. The recruitment process lasted over nine months. Letters of support and flyers used can be seen in Appendix C.

To be an eligible participant, individuals had to be 18 or older, fluent in English, and live in the United States, more specifically the Midwest. For the purposes of this study the Midwest includes Kansas, Oklahoma, Nebraska, North and South Dakota, Minnesota, Iowa, Missouri, Illinois, Indiana, Ohio, and Michigan.

Participants and Settings

Survey

Initially there were 667 participants who completed the quantitative survey. Ninety-four cases were excluded for the following reasons: answering no to consent (n = 3), answering no
when asked “are you over 18 years of age” (n = 2), no data (n = 17), reporting an age below 18 years (n = 1), and missing a large proportion or all of scale questions (n = 77). Participants were categorized into four groups (Healthcare Professionals, Black American, Hispanic/Latinx American, and Other Populations). Participants were first categorized into the Healthcare Professional group regardless of race or ethnicity. After identifying Healthcare Professionals, participants were then categorized into the Black American group. Participants that identified being Black Hispanic or Biracial with Black descent were also included in this group. Next, Hispanic/Latinx Americans were categorized; participants who identified being mixed race with Hispanic or Latinx populations were also included in this group. Lastly, anyone that did not fit any of the previous groups were categorized as Other Populations; this includes individuals that stated that they were biracial or mixed but did not specify specific races. No participants were included in more than one group.

Most participants in this sample were females (69.8%) from Kansas (86.9%), between 18-24 years old (63.5%). A large percentage of participants were considered “Other Populations” (41.5%), meaning that they were not considered or identified as a Healthcare Professional (39.4%), Black/African American (8.4%), or Hispanic/Latinx American (10.6%), see Table 1. Healthcare Professionals were mostly students (n = 198, 87.6%) rather than professionals in the field (n = 28, 12.4%). For additional demographic information see Table 2.

<table>
<thead>
<tr>
<th>Survey Participant Categories</th>
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<tbody>
<tr>
<td>Healthcare Professionals</td>
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<tr>
<td>Black Americans</td>
<td>56</td>
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</tr>
<tr>
<td>Hispanic/Latinx Americans</td>
<td>61</td>
<td>10.6</td>
</tr>
<tr>
<td>Other Populations</td>
<td>230</td>
<td>40.1</td>
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</tbody>
</table>
Table 2

Demographic Characteristics of Participants

<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
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<tr>
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<td>400</td>
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<tr>
<td>Male</td>
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<tr>
<td>Non-Binary</td>
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</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-24</td>
<td>364</td>
<td>63.5</td>
</tr>
<tr>
<td>25-34</td>
<td>146</td>
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<td>35-44</td>
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<td>5.8</td>
</tr>
<tr>
<td>45-54</td>
<td>12</td>
<td>2.1</td>
</tr>
<tr>
<td>55-64</td>
<td>15</td>
<td>2.6</td>
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<td>65+</td>
<td>3</td>
<td>0.5</td>
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<td>State of Residence</td>
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<td></td>
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<tr>
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<td>13.1</td>
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<td></td>
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<tr>
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<td>233</td>
<td>40.7</td>
</tr>
<tr>
<td>$10,000-$50,000</td>
<td>169</td>
<td>29.5</td>
</tr>
<tr>
<td>$50,001 and above</td>
<td>75</td>
<td>13.0</td>
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<td>Prefer not to answer</td>
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<td>Bachelor’s Degree</td>
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<td>Master’s Degree</td>
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<tr>
<td>Doctorate/Professional Degree</td>
<td>53</td>
<td>9.2</td>
</tr>
</tbody>
</table>

Interviews and Focus Groups

Across all focus groups there were 29 participants, most were women (69.0%), with an average age of 27, single (62.1%), with a Bachelor’s degree (34.5%). Table 3 shows additional demographic characteristics of the focus group participants.

Five Healthcare Professionals or Medical Students participated in interviews. Three focus groups were conducted with Black Americans. There were 11 participants total; four in the first focus group, two in the second focus group, and five in the third focus group. There was one
focus group conducted with Hispanic/Latinx Americans with 4 participants. One of the participants self-identified as White and not Hispanic on their demographics sheet; however, her information was kept because it influenced parts of the discussion. Lastly, there were two focus groups for Other Populations with 9 participants in total, three in the first focus group session and six in the second focus group. One participant in the first focus group self-identified as Hispanic during the focus group discussion; again, their information was kept in this group because it influenced parts of the discussion.

### Table 3
*Focus Group and Interview Demographics*

<table>
<thead>
<tr>
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<tbody>
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<td>Biracial</td>
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<td>$50,001 and above</td>
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</tr>
<tr>
<td>Prefer not to answer</td>
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<td>10.3</td>
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<td><strong>Marital Status</strong></td>
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<td>Living with a Steady Partner</td>
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<td><strong>Education</strong></td>
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<tr>
<td>High School Diploma, GED</td>
<td>1</td>
<td>3.4</td>
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<tr>
<td>Some College, No Degree</td>
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<td>Associate Degree</td>
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<td>10.3</td>
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<tr>
<td></td>
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<td>Master’s Degree</td>
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<tr>
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</table>

**Procedure**

This study consisted of two major phases; first a questionnaire was administered, the survey took approximately 15 minutes to complete. After survey administration, focus groups were conducted across all groups, each focus group was approximately 30-40 minutes long.

**Materials**

**Survey.**

The survey consisted of 28 questions that addressed areas such as perceived stigma and disease severity, knowledge of genetics, newborn screenings, perceived risks of sickle cell disease (SCD), general understanding of SCD, susceptibility to the condition, demographics, and information to be contacted for a focus group or interview (see Appendix A). In addition to these areas, healthcare professionals and medical students were asked about whether or not they have experience caring for SCD patients (an additional 8 questions). Survey questions were developed utilizing many questions and items from SCD literature.

Knowledge questions were modified and adapted from questions used in the following studies Acharya, Lang, & Ross (2009), Treadwell, McClough, & Vichinsky (2006), and Boyd, Watkins, Price, Fleming, & DeBaun (2005). This portion of the survey consisted of 14-items, 5-items were specific to knowledge of trait status and sources of knowledge about SCD. For example, one question asks, “Do you know whether you have sickle cell trait? Answer options include “yes, I have the trait,” “Yes, I do not have the trait,” and “No, I don’t know my status.”
The remaining 9-items are disease-specific multiple-choice questions. For example, one question participants were asked to complete was “Sickle cell disease is a(n)…” Answer options included “infection or virus,” “blood disease,” and “heart disease.” Disease-specific questions that were correct were scored as 1 point, with 9 possible points. Scores between 0–3 were considered “inadequate knowledge,” a range of 4–6 were considered “moderate knowledge,” and scores between 7–9 were considered “adequate knowledge.” The 9 knowledge multiple questions were coded as correct or incorrect and had a low internal consistency, Cronbach’s α = .326.

Perception questions were answered using a five-point Likert scales of likeliness and agreeableness. These questions were modified and adapted from Gustafon, Gettig, Watt-Morse, & Krishnamurti (2007) and van Ryn & Burke (2000); it consisted of 21-items. For example, one question asks, “how likely patients with sickle cell are to ‘abuse drugs and alcohol,’” using a Likert scale (1 = very unlikely to 5 = very likely). Scores range from 5–25. Another question asks, “how strongly you agree or disagree [that] sickle cell disease can impact a child’s school performance,” again using a Likert scale from 1 (strongly agree) to 5 (strongly disagree). Scores range from 15–75. Scores from the likeliness and agreeableness questions will be combined to produce a continuous perception score ranging from 20–100. Scores between 20–46 indicate a positive perception, 47–73 indicates a neutral perception, and 74–100 indicates a negative perception. This scale had a moderate internal consistency, Cronbach’s α = .625.

Stigma was assessed using the Cancer Stigma Scale; this scale was developed and validated for use with the general population (Marlow & Wardle, 2014). The original survey consisted of 25-items and six subscales “awkwardness, severity, avoidance, policy opposition, personal responsibility, and financial discrimination” (p. 1). The subscales ranged from adequate to good on internal reliability, Cronbach’s α = 0.76-0.91 (p. 8). However, the survey was
modified for this study to be shorter and include SCD terminology. One question asked agreeableness towards the following statement, “people with sickle cell cannot live normal lives,” response options were on a Likert scale from 1 (strongly agree) to 5 (strongly disagree). Continuous scores were categorized into the following groups: 13–30 indicates low stigma, 31–48 moderate stigma, and 49–65 high stigma. Refer to Appendix A for additional survey questions. This modified scale had a moderate internal consistency, Cronbach’s α = .636.

**Focus Groups.**

After surveys have been administered, focus groups were held with a sample from each group (healthcare professionals, Black Americans, Latinx Americans, and the general population). Participants will be asked about their general knowledge of sickle cell disease, where they get their knowledge, and their perceptions related to the disease. For example, all groups will be asked “What first comes to mind when you think of sickle cell?” In addition, healthcare professionals are asked about their experience caring for patients with SCD. For example, they are asked, “What do you think is the biggest challenge to taking care of someone with sickle cell disease and why?” For more focus group questions see Appendix B.

Overall seven focus group sessions were conducted. Three focus groups were conducted with Black Americans, one with Hispanic Americans, and two with individuals considered Other Populations. Instead of focus groups, interviews were conducted with Healthcare Professionals for convenience; there were five interviews in total.

Focus groups were audio-recorded and lasted approximately 30–40 minutes. Each recording was transcribed and coded for emerging themes. Focus group transcripts were analyzed using thematic analysis, outlined by Braun and Clarke (2006), and coded into themes. The primary researcher and second coders first independently coded transcripts. After
independently coding, the two coders met to discuss the independent codes and come to a consensus on emerging themes. Inter-rater reliability was used to determine the agreement between the two coders.

**Results**

**Quantitative Data**

**Research Question 1**

**Knowledge.**

Knowledge questions were coded into correct and incorrect responses, scores generated were then grouped based on level of knowledge. Sixty-five participants scored in the Inadequate Knowledge range (11.4%), compared to Moderate Knowledge (n = 397, 69.4%) and Adequate Knowledge (n = 110, 19.2%). Most participants scored in the middle on Knowledge questions (\(M = 5.23, SD = 1.38\)). Continuous Knowledge scores were used to conduct analyses.

A one-way ANOVA was conducted to assess knowledge differences between groups. There was a statistical difference between groups, \(F(3, 568) = 35.086, p < .001\). A Tukey post hoc test revealed that Healthcare Professional’s knowledge level (\(M = 5.87\)) was statistically significantly higher than Black Americans (\(M = 5.32, p = .020\)), Hispanic/Latinx American (\(M = 4.65, p < .001\)), and Other Populations (\(M = 4.73, p < .001\)). Black Americans knowledge level was statistically significantly higher than Hispanic/Latinx Americans (\(p = .024\)) and Other Populations (\(p = .011\)). There was no statistically significant difference between Hispanic/Latinx knowledge levels and Other Populations (\(p = .968\)). The majority of participants, regardless of group had a moderate level of knowledge, for within groups descriptive statistics see Table 4.
Table 4  
Knowledge Scale Categories by Group

<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Healthcare Professionals</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inadequate Knowledge</td>
<td>12</td>
<td>5.3</td>
</tr>
<tr>
<td>Moderate Knowledge</td>
<td>137</td>
<td>60.6</td>
</tr>
<tr>
<td>Adequate Knowledge</td>
<td>77</td>
<td>34.1</td>
</tr>
<tr>
<td><strong>Black Americans</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inadequate Knowledge</td>
<td>6</td>
<td>10.7</td>
</tr>
<tr>
<td>Moderate Knowledge</td>
<td>37</td>
<td>66.1</td>
</tr>
<tr>
<td>Adequate Knowledge</td>
<td>13</td>
<td>23.2</td>
</tr>
<tr>
<td><strong>Hispanic/Latinx Americans</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inadequate Knowledge</td>
<td>10</td>
<td>16.1</td>
</tr>
<tr>
<td>Moderate Knowledge</td>
<td>48</td>
<td>80.0</td>
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<td>Adequate Knowledge</td>
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<td>3.3</td>
</tr>
<tr>
<td><strong>Other Populations</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inadequate Knowledge</td>
<td>37</td>
<td>16.1</td>
</tr>
<tr>
<td>Moderate Knowledge</td>
<td>175</td>
<td>76.1</td>
</tr>
<tr>
<td>Adequate Knowledge</td>
<td>18</td>
<td>7.8</td>
</tr>
</tbody>
</table>

*Note.* Scores between 0-3 considered inadequate, 4-6 considered moderate, and 7-9 considered adequate.

**Trait Knowledge.**

Most participants did not know their trait status (66.0%). Of those who reported that they did know their trait status, most reported knowing due to Childhood Testing (n = 85, 50.9%). Additional categories can be seen in Table 5, “Other” options were themed and added. New answer categories are identified with an asterisk.

Table 5  
Trait Knowledge Descriptives

<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Do you know whether you have SCT</strong>?<strong>?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes, I have the trait</td>
<td>14</td>
<td>2.4</td>
</tr>
<tr>
<td>Yes, I do not have the trait</td>
<td>181</td>
<td>31.6</td>
</tr>
<tr>
<td>No, I don’t know my status</td>
<td>378</td>
<td>66.0</td>
</tr>
<tr>
<td><strong>When/How did you become aware of your trait status?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pregnancy screen</td>
<td>22</td>
<td>13.17</td>
</tr>
<tr>
<td>After my child had a positive newborn screening</td>
<td>7</td>
<td>4.19</td>
</tr>
<tr>
<td>Childhood testing, age unknown (“my parent told me”)</td>
<td>85</td>
<td>50.90</td>
</tr>
<tr>
<td>Other genetic testing (military, athletic, adult testing)*</td>
<td>21</td>
<td>12.57</td>
</tr>
<tr>
<td>Assumption (White, no family history)*</td>
<td>26</td>
<td>15.57</td>
</tr>
</tbody>
</table>
Trait knowledge by grouping (Healthcare Professionals, Black Americans, Latinx American, and Other Populations) can be found in Figures 1–3.

**Figure 1**

*Knowledge of Sickle Cell Trait Knowledge by Grouping*
Perception.

Perception scores \((M = 45.73, SD = 6.32)\) were collapsed into three categories, Negative Perceptions, Neutral Perceptions, and Positive Perceptions. Fifty-seven percent of participants
(n = 319) had more positive perceptions of individuals with SCD and the SCD experience. Fewer participants reported Neutral Perceptions (n = 240, 42.9%), and one participant reported more negative perceptions (n = 1, 0.2%). Continuous Perception scores were used to conduct analyses.

A one-way ANOVA was conducted to assess perception differences between groups.

There was not a statistical significant difference between groups, $F(3, 556) = 2.031, p < .109$, see Table 6.

**Table 6**

*Perception Scale Categories by Group*

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<tr>
<th></th>
<th>n (%)</th>
<th>Mean</th>
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<tbody>
<tr>
<td>Healthcare Professionals</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Positive Perception</td>
<td>117 (53.7)</td>
<td>46.19</td>
<td>5.82</td>
</tr>
<tr>
<td>Neutral Perception</td>
<td>100 (45.9)</td>
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<td></td>
</tr>
<tr>
<td>Negative Perception</td>
<td>1 (0.5)</td>
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<td></td>
</tr>
<tr>
<td>Black Americans</td>
<td></td>
<td>43.94</td>
<td>7.53</td>
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<tr>
<td>Positive Perception</td>
<td>36 (66.7)</td>
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<tr>
<td>Neutral Perception</td>
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<td>Negative Perception</td>
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<td>Hispanic/Latinx Americans</td>
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<td>7.00</td>
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<td>Positive Perception</td>
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<tr>
<td>Neutral Perception</td>
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<tr>
<td>Negative Perception</td>
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<tr>
<td>Other Populations</td>
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<td>Positive Perception</td>
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<tr>
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<tr>
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</table>

*Note.* Scores between 20-46 considered positive, 47-73 considered neutral, and 74-100 considered negative.

**Stigma.**

Most participants scored moderately on stigma (n = 512, 89.4%) compared to those with low stigma (n = 15, 2.6%) and those with high stigma levels (n = 32, 5.6%). On average the stigma scale score was 43.87 ($SD = 5.73$). Continuous Stigma scores were used to conduct analyses.
A one-way ANOVA was conducted to assess differences in stigma between groups. There was a statistical difference found between groups $F(3, 556) = 4.011, p = .008$. A Tukey post hoc test revealed a difference between Healthcare Professionals ($M = 44.89$) and Other Populations ($M = 43.35$), $p = .022$, Table 7.

<table>
<thead>
<tr>
<th></th>
<th>n (%)</th>
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<th>SD</th>
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<tbody>
<tr>
<td><strong>Healthcare Professionals</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low Stigma</td>
<td>4 (1.8)</td>
<td>44.89</td>
<td>5.62</td>
</tr>
<tr>
<td>Moderate Stigma</td>
<td>155 (71.1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High Stigma</td>
<td>59 (27.1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Black Americans</strong></td>
<td></td>
<td>42.96</td>
<td>5.52</td>
</tr>
<tr>
<td>Low Stigma</td>
<td>3 (5.6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderate Stigma</td>
<td>44 (81.5)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High Stigma</td>
<td>7 (13.0)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Hispanic/Latinx Americans</strong></td>
<td></td>
<td>42.92</td>
<td>6.24</td>
</tr>
<tr>
<td>Low Stigma</td>
<td>2 (3.4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderate Stigma</td>
<td>48 (81.4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High Stigma</td>
<td>9 (15.3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Other Populations</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low Stigma</td>
<td>4 (1.7)</td>
<td>43.35</td>
<td>5.64</td>
</tr>
<tr>
<td>Moderate Stigma</td>
<td>184 (80.3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High Stigma</td>
<td>41 (17.9)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note. Scores between 13-30 considered low, 31-48 considered moderate, and 49-65 considered high.*

Overall, results for this section showed statistically significant differences for knowledge, specifically between Healthcare Professionals and Black Americans compared to the other two groups. Between Healthcare Professionals and Other Populations for stigma levels, and no significance was found between groups for perception levels.

**Research Question 2**

A multinomial linear regression was conducted to assess whether knowledge level was associated with perception and stigma. The final model statistically significantly predicts the dependent variable better than the intercept-only model alone, $\chi^2(10) = 95.281, p < .001$. For
Inadequate Knowledge relative to Adequate Knowledge, the Wald test statistic was 15.956, with a \( p < .001 \). Inadequate Knowledge is statistically different from Adequate Knowledge given the Stigma scale score, for every increase in knowledge stigma decreases by \(-.121 (\beta)\), see Table 8. Healthcare Professionals and Black Americans Knowledge Scores are significantly different from Hispanic/Latinx Americans and Other Populations at Inadequate and Moderate Knowledge Levels.

**Table 8**

*Multinomial Logistic Regression Parameter Estimates*

<table>
<thead>
<tr>
<th>Perception Scale</th>
<th>B</th>
<th>Std. Error</th>
<th>Wald</th>
<th>df</th>
<th>Sig.</th>
<th>Exp(B)</th>
<th>Lower Bound</th>
<th>Upper Bound</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inadequate Knowledge</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perception Scale</td>
<td>.011</td>
<td>.026</td>
<td>.171</td>
<td>1</td>
<td>.679</td>
<td>1.011</td>
<td>.961</td>
<td>1.063</td>
</tr>
<tr>
<td>Stigma Scale</td>
<td>-.121</td>
<td>.030</td>
<td>15.956</td>
<td>1</td>
<td>.000</td>
<td>.886</td>
<td>.834</td>
<td>.940</td>
</tr>
<tr>
<td>Healthcare Professional</td>
<td>2.421</td>
<td>.432</td>
<td>31.398</td>
<td>1</td>
<td>.000</td>
<td>.089</td>
<td>.038</td>
<td>.207</td>
</tr>
<tr>
<td>Black American</td>
<td></td>
<td>.584</td>
<td>7.265</td>
<td>1</td>
<td>.007</td>
<td>.207</td>
<td>.066</td>
<td>.651</td>
</tr>
<tr>
<td>Hispanic American</td>
<td>1.529</td>
<td>1.093</td>
<td>1.956</td>
<td>1</td>
<td>.162</td>
<td>4.613</td>
<td>.541</td>
<td>39.306</td>
</tr>
<tr>
<td>Other Populations</td>
<td>0_b</td>
<td></td>
<td>0</td>
<td></td>
<td>.741</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderate Knowledge</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perception Scale</td>
<td>-.010</td>
<td>.018</td>
<td>.316</td>
<td>1</td>
<td>.574</td>
<td>.990</td>
<td>.955</td>
<td>1.026</td>
</tr>
<tr>
<td>Stigma Scale</td>
<td>-.028</td>
<td>.023</td>
<td>1.443</td>
<td>1</td>
<td>.230</td>
<td>.973</td>
<td>.930</td>
<td>1.018</td>
</tr>
<tr>
<td>Healthcare Professional</td>
<td>1.671</td>
<td>.289</td>
<td>33.337</td>
<td>1</td>
<td>.000</td>
<td>.188</td>
<td>.107</td>
<td>.332</td>
</tr>
<tr>
<td>Black American</td>
<td>1.311</td>
<td>.410</td>
<td>10.211</td>
<td>1</td>
<td>.001</td>
<td>.270</td>
<td>.121</td>
<td>.602</td>
</tr>
<tr>
<td>Hispanic American</td>
<td>1.578</td>
<td>1.041</td>
<td>2.297</td>
<td>1</td>
<td>.130</td>
<td>4.846</td>
<td>.630</td>
<td>37.302</td>
</tr>
<tr>
<td>Other Populations</td>
<td>0_b</td>
<td></td>
<td>0</td>
<td></td>
<td>.741</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note:* a. The reference category is: Adequate Knowledge  
b. This parameter is set to zero because it is redundant.
In summary, a statistically significant difference was found between knowledge levels and stigma across these populations. As knowledge levels increased stigma level decreased. No differences were found between knowledge levels and perception levels.

**Research Question 3**

In order to assess whether personal sources of knowledge (family, friends, and healthcare providers) determine differences between knowledge, perceptions, and stigma a logistic regression was be conducted, if significance was found at the univariate level first. To test for significance at a univariate level a one-way ANOVA was conducted. No significance was found for any of the scaled variables (knowledge, perception, stigma) see Table 9, therefore a multivariate analysis was not conducted.

**Table 9**

*Personal versus Non-Personal Sources of Information, ANOVA*

<table>
<thead>
<tr>
<th>Scale</th>
<th>Sum of Squares</th>
<th>df</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge Scale</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between Groups</td>
<td>2.634</td>
<td>1</td>
<td>2.634</td>
<td>1.413</td>
<td>.235</td>
</tr>
<tr>
<td>Within Groups</td>
<td>878.161</td>
<td>471</td>
<td>1.864</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>880.795</td>
<td>472</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perception Scale</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between Groups</td>
<td>92.448</td>
<td>1</td>
<td>92.448</td>
<td>2.148</td>
<td>.143</td>
</tr>
<tr>
<td>Within Groups</td>
<td>19845.081</td>
<td>461</td>
<td>43.048</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>19937.529</td>
<td>462</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stigma Scale</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between Groups</td>
<td>4.151</td>
<td>1</td>
<td>4.151</td>
<td>.125</td>
<td>.724</td>
</tr>
<tr>
<td>Within Groups</td>
<td>15274.389</td>
<td>461</td>
<td>33.133</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>15278.540</td>
<td>462</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 10 shows where the differences in Knowledge Source (Crosstabs) were for participants based on collapsed scale scores, as well as differences in Knowledge Source based on Grouping Category (i.e. Healthcare Professionals, Black Americans, Hispanic/Latinx
Americans, and Other Populations), see Table 11. Healthcare Professionals, who had the highest knowledge scores, had more non-personal knowledge sources (91.4%). Comparatively, Black Americans, who had the second highest knowledge scores, had more personal knowledge sources (62.0%).

**Table 10**

*Knowledge Source by Collapsed Scale Scores*

<table>
<thead>
<tr>
<th>Collapsed Knowledge Scale</th>
<th>Collapsed Perception Scale</th>
<th>Collapsed Stigma Scale</th>
<th>Non-Personal</th>
<th>Personal</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inadequate Knowledge</td>
<td>Negative Perception</td>
<td>Low Stigma</td>
<td>43</td>
<td>3</td>
<td>46</td>
</tr>
<tr>
<td>% within Collapsed Knowledge Scale</td>
<td>% within Collapsed Perception Scale</td>
<td>% within Collapsed Stigma Scale</td>
<td>93.5%</td>
<td>6.5%</td>
<td>100.0%</td>
</tr>
<tr>
<td>Moderate Knowledge</td>
<td>Neutral Perception</td>
<td>Moderate Stigma</td>
<td>263</td>
<td>62</td>
<td>325</td>
</tr>
<tr>
<td>% within Collapsed Knowledge Scale</td>
<td>% within Collapsed Perception Scale</td>
<td>% within Collapsed Stigma Scale</td>
<td>80.9%</td>
<td>19.1%</td>
<td>100.0%</td>
</tr>
<tr>
<td>Adequate Knowledge</td>
<td></td>
<td></td>
<td>89</td>
<td>13</td>
<td>102</td>
</tr>
<tr>
<td>% within Collapsed Knowledge Scale</td>
<td></td>
<td>% within Collapsed Stigma Scale</td>
<td>87.3%</td>
<td>12.7%</td>
<td>100.0%</td>
</tr>
<tr>
<td>Adequate Knowledge</td>
<td></td>
<td></td>
<td>89</td>
<td>13</td>
<td>102</td>
</tr>
<tr>
<td>% within Collapsed Knowledge Scale</td>
<td></td>
<td>% within Collapsed Stigma Scale</td>
<td>87.3%</td>
<td>12.7%</td>
<td>100.0%</td>
</tr>
<tr>
<td>Adequate Knowledge</td>
<td></td>
<td></td>
<td>89</td>
<td>13</td>
<td>102</td>
</tr>
<tr>
<td>% within Collapsed Knowledge Scale</td>
<td></td>
<td>% within Collapsed Stigma Scale</td>
<td>87.3%</td>
<td>12.7%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

32
<table>
<thead>
<tr>
<th>High Stigma</th>
<th>Count</th>
<th>82</th>
<th>16</th>
<th>98</th>
</tr>
</thead>
<tbody>
<tr>
<td>% withinCollapsed Stigma Scale</td>
<td>83.7%</td>
<td>16.3%</td>
<td>100.0%</td>
<td></td>
</tr>
</tbody>
</table>

*Note:* There was only one participant who had a “positive perception,” knowledge source was missing and is therefore not included here.

**Table 11**

*Knowledge Source by Grouping Category*

<table>
<thead>
<tr>
<th>Grouping Category</th>
<th>Count</th>
<th>Non-Personal</th>
<th>Personal</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Healthcare Professional</td>
<td></td>
<td>191</td>
<td>18</td>
<td>209</td>
</tr>
<tr>
<td>% within Grouping Category</td>
<td></td>
<td>91.4%</td>
<td>8.6%</td>
<td>100.0%</td>
</tr>
<tr>
<td>Black American</td>
<td></td>
<td>19</td>
<td>31</td>
<td>50</td>
</tr>
<tr>
<td>% within Grouping Category</td>
<td></td>
<td>38.0%</td>
<td>62.0%</td>
<td>100.0%</td>
</tr>
<tr>
<td>Hispanic/Latinx American</td>
<td></td>
<td>39</td>
<td>10</td>
<td>49</td>
</tr>
<tr>
<td>% within Grouping Category</td>
<td></td>
<td>79.6%</td>
<td>20.4%</td>
<td>100.0%</td>
</tr>
<tr>
<td>Other Population</td>
<td></td>
<td>146</td>
<td>19</td>
<td>165</td>
</tr>
<tr>
<td>% within Grouping Category</td>
<td></td>
<td>88.5%</td>
<td>11.5%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

**Secondary Findings for Healthcare Professionals and Additional Questions**

Healthcare professionals were asked a number of additional questions that other groups were not asked, to examine their experience with patients with SCD. Simple frequencies were conducted; this information can be seen in Table 12 below.

**Table 12**

*Healthcare Experience Variables*

<table>
<thead>
<tr>
<th>Question</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did your medical education program include sickle cell disease?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>140</td>
<td>83.8</td>
</tr>
<tr>
<td>No</td>
<td>27</td>
<td>16.2</td>
</tr>
<tr>
<td>Does your panel currently include any patients with SCD?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>33</td>
<td>16.8</td>
</tr>
<tr>
<td>No</td>
<td>164</td>
<td>83.2</td>
</tr>
</tbody>
</table>
If yes, how many individuals with SCD would you estimate are receiving regular care from you?

- 0-25: 25 (75.8%)
- 26-50: 2 (6.1%)
- 51-75: 1 (3.0%)
- 76-100: 5 (15.2%)

Do your sickle cell patients’ other physicians communicate about their medical issues with you?

- Yes: 20 (60.6%)
- No: 13 (39.4%)

Do you feel that your sickle cell patients’ medical needs are being met?

- Yes: 29 (87.9%)
- No: 4 (12.1%)

All participants were also asked if SCD affects their racial group. Responses were very similar, most participants reported that SCD did not affect their racial group (n = 290, 51.8%) compared to those that said it does (n = 270, 48.2%). Figure 4 shows the breakdown of responses by racial category.

**Figure 4**

*Perception of Susceptibility by Race & Ethnic Category*
Qualitative Data

Qualitative focus groups and interviews provided substantial detail to the study, particularly in regards to the first research question: *Is there a difference in knowledge, perceptions, and stigma across groups (healthcare professionals, Black and Latinx communities, and the general population)?*

**Overall**

Across all focus groups, excluding Healthcare Professionals, six major themes emerged: *Knowledge, Personal Experience, Perceptions, Perceptions of Healthcare, Adversity, and Increasing Education and Awareness*; see Table 13 for sub-themes and descriptions.

<table>
<thead>
<tr>
<th>Table 13</th>
<th>Qualitative Themes and Descriptions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Themes</strong></td>
<td><strong>Sub-Themes</strong></td>
</tr>
<tr>
<td>Knowledge</td>
<td>Attributes of SCD</td>
</tr>
<tr>
<td>Knowledge</td>
<td>Populations Affected</td>
</tr>
<tr>
<td>Knowledge</td>
<td>Sources of Knowledge</td>
</tr>
<tr>
<td>Knowledge</td>
<td>Lack of Knowledge or Uncertainty</td>
</tr>
<tr>
<td>Personal Experience</td>
<td></td>
</tr>
<tr>
<td>Perceptions</td>
<td>Perception of Population</td>
</tr>
<tr>
<td>Perceptions</td>
<td>Interpersonal Conflict</td>
</tr>
<tr>
<td>Perceptions</td>
<td>Managing Responsibilities</td>
</tr>
<tr>
<td>Perceptions</td>
<td>Cultural Perspectives</td>
</tr>
</tbody>
</table>
• Health Maintenance

Adversity

• General Adversity
• Racial Adversity in Healthcare
• Perceptions of Healthcare
• Stigma and Bias
• Systemic Inequality

“Cause the pop-, black population here in America is very tiny and so maybe it affects the black population the most, then I, it’s not really that big of a deal because you have so many more people that don’t have it. It’s what, eleven percent of the population at the best, uh, so yeah, that’s not. To people who hold the microphones, it’s not really that big of an epidemic or problem so, no need to waste air time t- in their opinion, that’s my words but I would think that they would think that it’s not worth discussing because it’s not that big of a deal.”

Increasing Education and Awareness

• Social Exposure
• Educational Factors
• Barriers to Education

“Dialoguing. People can’t know what they don’t know.”

Knowledge

Attributes of SCD & Populations Affected.

The participants identified the sickle shaped blood cells, anemia, malaria, joint pain, and fatigue, as well as depression and anxiety. Participants were able to identify numerous attributes related to SCD including physical symptoms, emotional symptoms, etc. Pain and fatigue were mentioned frequently, jaundice and muscle soreness were also reported. Participants also reported genetic factors related to SCD. Specifically, that it is a hereditary disease that can be passed down. Black Americans were the most commonly reported population affected by SCD. Participant also mentioned individuals of Hispanic or Latinx descent, as well as Asian groups. However, it was also reported that other groups were susceptible as well.

Sources of Knowledge & Lack of Knowledge.

Participants reported learning about SCD through science-based courses such as Biology or Anatomy. Learning from individuals that have SCD was also mentioned, this was mentioned
most frequently in the Black American focus groups but was also mentioned in the Latinx focus
group and by some individuals in the Other Populations group. Lack of knowledge was apparent
to some extent throughout all focus groups. This was most common in the Latinx and Other
Populations groups. Almost all focus group participants mentioned varying degrees of
uncertainty when answering questions about SCD.

**Personal Experience**

Personal experiences included knowing someone who has or had SCD, being tested for
the trait or disease, and medical experiences. Across all focus groups participants reported
knowing someone with the disease or trait, again, most commonly this was reported in the Black
American groups. Two participants reported having some experience in the medical field (non-
provider) and learning a little through that experience. Three participants reported that they were
tested for the trait. One mentioned testing during basic military training, another mentioned
athletic testing, and lastly, one participant mentioned being tested for the disease as a child.

**Perceptions**

Across all focus groups the general consensus was that individuals with sickle cell
disease look “normal” and that you wouldn’t be able to tell that someone has the disease, simply
by looking at them. Participants perceived that for the most part individuals with SCD lived
normal lives outside of their “flare ups” or crises. However, they did discuss that individuals
with this disease would have to go to the doctor or hospital more frequently than someone
without the disease, and that they would have to be cautious and in tune with their own bodies in
order to maintain their symptoms. Participants also perceived that this disease causes frustration,
fear, and depression or anxiety. Compared to their peers Black Americans did not discuss
depression and anxiety.
Interpersonal or professional conflict was also mentioned, with participants sharing that having SCD must impact relationships, work, and school. Differences in cultural perceptions emerged in one of the Black American focus groups with two participants indicating they were from Nigeria. They spoke about how SCD is treated in their home country. Notably, of those that indicated they knew someone with the disease, Black Americans more commonly talked about the individuals as being strong or resilient, compared to other groups.

**Stigma and Adversity**

Interestingly perceptions of healthcare were mentioned more frequently in the Black and Latinx focus groups. The difference in treatment options and the lack of knowledge that some health providers may have was mentioned. Racial adversity in healthcare was more commonly reported, specifically in regards to how Black and Latinx Americans are treated in the health system, as well as health disparities that these communities already face.

Additionally, the systemic inequalities already faced in these communities was used as reasoning for why SCD is not being discussed or researched. More specifically participants in the Black and Latinx groups reported that because this is a disease that commonly affects minorities and at a lower prevalence, people don’t pay attention to it. These issues were not raised in the Other Populations group.

**Increasing Education and Awareness**

Majority of the participants agreed that awareness needs to be raised for SCD and SCT. Most agreed that there is a general lack of awareness across all populations about the disease. Multiple methods were discussed for increasing awareness. Social media was mentioned often as a means to do so. Participants stated that campaigns, walks, or fundraisers similar to other
diseases, such as cancer or ALS, would be beneficial in educating the public and increasing awareness. Pamphlets were also mentioned, as was celebrity sponsors and advocates.

Table 14 shows demographics for each of the non-healthcare professional focus group sessions.

**Table 14**  
*Focus Group Demographics*

<table>
<thead>
<tr>
<th></th>
<th>Black American</th>
<th>Hispanic American</th>
<th>Other Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population</td>
<td>N=11</td>
<td>N=4</td>
<td>N=9</td>
</tr>
<tr>
<td>Age Range</td>
<td>24-26</td>
<td>21-31</td>
<td>19-51</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>5</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>Male</td>
<td>6</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Education</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>High School Diploma, GED</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Some College, No Degree</td>
<td>3</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Associate Degree</td>
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**Black Americans**

**Knowledge.**

Most participants described SCD as a blood disease, they mentioned cells, genetics, and the immune system as well. For example, one participant asked, “Uh, yeah, I mean, as far as what I think I know, I just, doesn’t it have something to do with your blood cells? (P2, FG 1)” Participant 2 (FG 2) stated

“...I know it affects the immune system, as well. So like, it’s hard for you to fight off, like, certain, you know, stuff, like the common cold, you know, it can be worse. Um, so I know it just like affects how you fight off, you know, sickness and stuff like that as well.”
Additionally, Participant 4 (FG 3) mentioned blood transfusions as a treatment option, saying, “…blood transfusions are the best I guess, curative um, treatment….” In regards to genetics, participants mentioned hereditary characteristics of the disease, one participant mentioned that “…you can have the trait but not exhibit, um, like, manifestation of the disease… (P4, FG 3).” Other participants reported that the disease and trait could skip generations saying, “…I did see that it was hereditary and that it did, like, skip generations and stuff (P2, FG 2), while another stated, “even if you don’t get it, can’t you still pass it on to like your kids and stuff like that? I feel like that’s what I think (P2, FG 1).”

Physical symptoms mentioned by participants included pain, fatigue, and occasional immobility. Participant 4 (FG 1) reported, “Um, pain, like it can be painful.” Both participants in the second focus group reported that people with SCD experience “joint pain,” Participant 1 in the third focus group also mentioned “joint pain.” “Fatigue” was also mentioned (P1, FG 3), as was movement Participant 2 (FG 1) stated “I know like, that it can affect, like, movement or walking and stuff like that, I didn’t know that prior.”

Participants identified these populations as either being affected by SCD or having the potential to be affected by SCD. Some participants mentioned that only Black people get it, or that it is a disease that affects Black people primarily. Participant 2 (FG 1) reported, “…only black people get it…,” while Participant 1 (FG 2) reported “…I think it’s majority African American that has been uh, in the forefront of it that I’ve ever heard and I’m forty years old so, my experience has been mostly black.” Some participants also reported that individuals of Hispanic/Latinx descent can get SCD as well. For example, one participant stated “I think it’s common amongst Hispanics as well (P1, FG 3).” Another stated, “Uh, but mainly, you know, like, I’ve heard stuff, I’ve heard of like, black and then like Mexican and Latinos as well
(P2, FG 2).” When discussing populations affected participants also mentioned that Caucasian individuals weren’t as affected, if at all, they mentioned that it primarily affected minority groups. Participant 2 (FG 3) stated “so I think just like that minority group gets affected from it because I don’t hear about many, like, white people being affected by it, but you do hear that you know, some are affected by it…,” while Participant 1 (FG 3) reported that “[they] feel like mostly it affects um, more of the minority groups like African Americans, Latinas, and just, all those other things and some people just really don’t care about that.”

The participants across all three focus groups identified sources of knowledge or the lack thereof. Sources included most commonly reported was a science-based course in high school or college. Participant 4 (FG 3) reported that they learned about SCD from “School, umm, probably a biology two class when I was in high school…We did like, the [1 second, pause] phenotype…[inaudible] like, so yeah, learning about um, probability.” Some participants posed questions instead of statements, suggesting that there was uncertainty about their answers. Participant 1 (FG 2) mentioned that they “…took some college courses as well…,” while another participant discussed specific material from a course they had taken, saying

I think of, um, there was this movie that I watched in like, science class in grade school, with this girl, she was like 2, and it was like so sad. She ended up like, passing away. And like, that’s the only like, time I was really taught about it in school or anything. So that's what I think of whenever um, like I hear that is that movie. (P4, FG 1)

While there were some participants that reported hearing about SCD in school, others stated that they had not, one participant stated “I hadn’t heard about it in school or anything…(P2, FG 1),” while another stated that “it’s just nothing that is brought up… (P3, FG 1),” and another reported “I haven’t actually learned about sickle cell in class (P3, FG 3).” Some participant’s did mention
learning about SCD from the individuals that they know with the disease (discussed more later), for example Participant 3 (FG 3) reported, “cause I, the only thing I know about sickle cell uh, is what my friend tells me or what I find out from other people.”

There were a few instances where participant expressed not knowing about SCD, or not being certain about questions asked. For example, Participant 3 (FG 1) stated, “I don’t, I don’t even know what it is.” Another participant discussed not knowing about genetic testing for the trait saying,

I guess, no it’s good, I just never, espec-, like maybe I hear about sickle cell disease but like especially getting tested for the trait, I’ve never heard about that. You would think that like, if it was common, it would be something that doctors were like, ‘you should get tested for this’…Or whatever. I just never really heard anything about like testing for the trait or really anything about the trait in general so I f-, like, because like I haven’t heard as much. That makes me think that it’s not as common… (P1, FG 1)

Another participant stated, “I, I don’t have a, a vast knowledge of it, but I am aware of it, and some of the effects of it (P1, FG 2),” another said “So like, I know, like, a little about it, but like, I wanna know more (P2, FG 2).” In addition, some participants compared SCD to other illnesses such as asthma and multiple sclerosis. Participant 2 (FG 3) stated

It’s almost related to an asthma attack. Yeah. It’s just…Okay. Um, first you start with like, from what I’ve seen, first you start with cold…Uh, sudden drop in temperature, just you physically feeling it. Then, uh, I think blood also helps in flow of air through the body, like oxygen and carbon dioxide so it moves into like, this asthma related stage of wheezing. Then passing out and next thing you waking up in the hospital.

Another participant asked if it was similar to MS, stating,
'Cause it like affects the body in a certain way to where your body kind of breaks down and like it’s hard for you to walk and, different stuff like that and like, the person that I know, hers goes in and out, so like, she said that, like, part of the day she’ll be able to walk and do certain things and then just at a instant, like her body’ll just be like, nope, and it’s just like she has to sit and, like go through, like her body goes through those motions again. (P3, FG 1).

**Personal Experience.**

Some participants reported personal experiences with SCD, be it knowing someone who has it, military testing, brief medical experience, or cultural experiences. One participant mentioned that their parent had to have them tested for SCD as a child. They stated

Uh, she told me, um, mmm, I don’t remember. She told me specifically, um, but I guess they tested? I don’t I don’t know what they did um, but she had to take me to the hospital to do whatever they did…Done so I guess it wasn’t one of those things where they just like waited it out they were like “oh when she’s two you’ll know” or whatever, um kind of how like autism is sometimes like oh we have to wait ‘til they get older or whatever. Um but that’s it’s just like in passing heard about it, that’s really it. (P4, FG 1)

Military testing was mentioned by one participant in the first focus group, they stated that “in some training that [they] have been to, uh, certain individuals have to be identified for…the trait…[at] basic training” (P1, FG 1). Another participant talked about learning about SCD through their experience as an EMT, they stated “…I was an EMT for a little while and so that came up then as something that you heard of but never—rarely ever see (P1, FG 2).”

Additionally, Participant 1 (FG 3) mentioned that their “…mom’s a doctor.”
Multiple participants mentioned knowing someone with SCD. Participant 2 (FG 1) mentioned knowing about some symptoms “…since meeting people that have it…,” Participant 1 (FG 1) stated something similar saying, “I think it was um, people that I met, um, I’ve had friends….” Two participants specifically mentioned having family members with the disease, that are deceased. Participant 1 (FG 2) reported “…I had, um, a family member pass away from it. Uh, so it, that kinda hit home. Uh, I know some people currently affected by it…” another participant mentioned “I do have like, friends who are affected by, you know… this disease and stuff like that. And I also did have a family member who passed away from this disease as well” (P2, FG 2). Two participants mentioned their experiences living in Nigeria and knowing people there that have SCD, one of these participants stated “Uh, Nigeria for me. I have several friends in Nigeria with sickle cell, so.”

Perceptions.

Most of the participants reported that individuals with SCD look normal and lead relatively normal lives, despite having this disease. In regards to perceptions of appearance, one participant stated “I feel like there’s not a, like, a look to it. Like I feel like you couldn’t like look to somebody and know (P4, FG 1),” another participant said “uh, they normal looking (P1, FG 2).” Participant 2 (FG 2) stated “um, as far as my friends go, it’s uh, I think like, pretty much they’re demeanor is normal like…They’re pretty normal, and they don’t really, it’s not really something that you show that you have,” while Participant 6 (FG 3) mentioned “I think probably, [2 second pause] seemingly normal, if they’re outside of like, a flareup.”

Perceptions varied in terms of what people with SCD experience (both physically and emotionally) as well as how they may have to change different areas of their lifestyle. The everyday life experiences of an individual living with SCD was discussed amongst participants.
When asked about how SCD may impact an individual’s life participants mentioned planning, being more cautious, doctor’s visits, and treatment options. Participant 2 (FG 1) mentioned that people with SCD are “…always planning…” and that “…maybe [they] can’t go places by [themselves], if, in case something happens.” Similarly, Participant 3 (FG 1) mentioned that they “[have] to be more cautious.” Hospital visits were mentioned by Participant 1 (FG 2) who briefly mentioned them saying, “…frequent hospital visits…” Participant 2 (FG 2), elaborated on this and stated,

...the frequent hospital visits. I know I don’t have to go to the hospital, like frequently, and I know that’s something that they have to do…Um, they have to get those checkups, they have to get everything they need basically…

Participants discussed how SCD may be inconvenient due to how come and go symptoms may be. For example, one participant stated “…some days there’s not as many symptoms, I guess and then some days there are so, I feel like they would look like anybody else, especially on those days that there’s no symptoms (P4, FG 1).” Additionally, participants mentioned the circumspection that individuals with SCD experience in daily life. One participant said,

I think you have to take into account how physically stressed, depending on their body. So um, I don’t know. Maybe a usually easy walk or run, or jog, or workout for someone could be uh, extremely taxing on somebody with sickle cell… it’s an everyday thing depending. (P1, FG 1)

Another participant said, “I mean, I would say you’d probably do well to understand you know, your own condition…and cope with it, and then just try and live your life, I guess, quote normally” (P6, FG 3).
Some participants identified perceptions about emotional experiences of individuals with sickle cell disease, specifically about how “…frustrating… (P5, FG 3)” it can be and how mood may vary. For example, one participant stated

“Um, there are some like, mood changes with them every now and then but—I don’t know of that has something to do with the disease or not but uh…It just really depends in the person actually, ‘cause you know, the mood swings do happen, you know, you do have your ups and your downs and your bad days. It just depends on how you take it and how you run with it (P2, FG 2).”

Additionally, one participant mentioned how the disease may make individuals feel lonely as well. They said “Um, and not having the support that they always need. So, I bet you there’s some aloneness around this. Loneliness. Somewhere (P6, FG 3).”

Interestingly, one participant mentioned how a movie altered their perception of the disease saying

...from that movie they were like people who have sickle cell don’t live past like 16 is what, yeah, is what I like, learned from that movie so I was like, well, I’m probably not gonna meet someone with it. ‘Cause they woulda like passed away at a young age or whatever um so I like, I thought it was like you really don’t meet people with it, or you wouldn’t, like it’s super rare I guess... (P4, FG 1).

However, upon meeting someone with the disease their perception changed, saying

“...it doesn’t affect them as much as maybe you would think that a disease like that would affect someone…You’re like, oh this might like, take over their whole life and the way they do everything, but I haven’t seen that with sickle cell (P4, FG 1).”
They then go on to say discuss how the individual they know views SCD, speaking from their perspective they say that it has

...nothing to do with my goals or my, like, it’s not going to stop me from reaching anything. It has nothing to do with like, how I’m going to get to where I want to get in life. If I want to do something I'ma do it despite this it doesn’t matter um… (P4, FG 1)

Other participants also spoke to the strength and resilience that individual’s that they know with disease have. For example, one participant said “I feel like people are pretty strong with that disease, some days can knock them off worse than other. So, it just depends on the day (P2, FG 2),” and another stated “I mean, even though we said it’s an inconvenience…a lot of people can also still, like, achieve everything that they would whether they had it or not (P2, FG 1).”

Lastly, there were two participants who reported being from Nigeria and one of the participants briefly discussed their cultural perceptions related to SCD, specifically in regards to age and death saying

That’s, that’s what it seems like at least in Nigeria. They let you know when you get to a certain age, you’re gonna die. Like they actually tell you that you’re not gonna make it through. And if you do, it’s a miracle, so… they say in Nigeria it could happen any time. They usually say eighteen and he’s well past eighteen so. It’s just…That’s what they say, yeah. Yeah, then if you get past that, they tell you, “okay, you’re not gonna make it past twenty-two or something,” and if you get past, you’re like, okay.

**Adversity.**

Specific perceptions of healthcare providers, services, or lack thereof was not discussed a lot in these focus groups. One participant mentioned that healthcare professionals may not be as
familiar with the disease because it is not something that they see all the time. The participant specifically stated,

I look at two different ways, you know, I’m a doctor in the ER or just a regular practice doctor, uh and my population is majority of one thing, it’s kinda hard to kinda, get out of that norm to where nine times out of ten, people come in, they would never get this from [inaudible], you never had any patients not in the practice of fifty years… I’ve never had that so if some of that things, er, they come up, are just way back on the back burner and will never be addressed because it’s just not that common for them as a doctor. (P1, FG 2)

The same participant also discussed that treatment options for the disease looked different back in the nineties saying,

…it was not as well diagnosed and or treated as it is probably today…that was late nineties. Now, I know of s-still similar issues but I think it’s the, it’s been some progress made slightly, I guess. I can’t speak [inaudible] any confidence but a slightly been some improvement in the way they treat it. (P1, FG 1)

Stigma surrounding SCD was discussed by participants in terms of why people may not know about the disease. Specifically, participants mentioned that since the disease does not affect the majority or a larger group of individuals it does get enough recognition. One participant stated

‘Cause the pop-, black population here in America is very tiny and so maybe it affects the black population the most, then I, it’s not really that big of a deal because you have so many more people that don’t have it. It’s what, eleven percent of the population at the best, uh, so yeah, that’s not. To people who hold the microphones, it’s not really that big
of an epidemic or problem so, no need to waste air time in their opinion, that’s my words but I would think that they would think that it’s not worth discussing because it’s not that big of a deal. (P1, FG 2)

Another participant agreed with this statement saying

I’d say yeah, the majority hold the uh, holds the, holds the microphone so I feel like it’s, if it’s not affecting them, then it’s not, it, they don’t really care. So, since they don’t care, they’re not gonna, you know, waste their time or whatever um, but I feel like it’s not really i-, it’s not really cared about because not a lot of people suffer from it, so. (P2, FG 2)

Additionally, another participant talked about societal barriers, cultural bias, and prevalence all leading to people not knowing more. The participant stated

I think there’s like, a lot of cultural bias when it comes to, talking about [pause, 1 second] chronic illnesses and who it affects and from that, who talks about it. So if you have minority groups who are in the minority in a societal way as well not just like, racial minority or, you know, LGBTQ+ minority, um, not just that but literal population minority…If the people who are affected by it don’t have the same platforms as people who look different than them then you’re not probably going to talk about the things that are affecting, you know, those groups, so I don’t know that there’s very much a voice of the people who are affected by sickle cell anemia the same way there are to you know, cancers, Multiple sclerosis, ALS, things like that, so you’re not gonna have those voices that are prominent in, in the same way. Um, and then like, understanding it, I don’t know that, you know, people talk very much about, you know, men getting breast cancer even though they can…Um, since it’s not that know, you know a lot of people just don’t think
about it. Um, [pause, 1 second] so yeah. I think there’s a lot of societal barriers to that conversion. (P4, FG 3)

Majority influence was also talked about in regards to radio talk shows as well, one participant stated “I listen to Republican talk radio, which we will never hear it on there… (P1, FG 2).”

**Increasing Education and Awareness.**

When discussing efforts to increase awareness and knowledge about SCD in the Midwest, one participant stated that we “gotta remove stigma… (P6, FG 3).” Another participant also mentioned stigma, but spoke of it in terms of something that may be preventing people from participating in education and awareness efforts saying,

one I think would be the stigma and I think that goes across the board for anything people have or you know, like you know if you have sickle cell that’s—you don’t want to be perceived as having it…people might look at you differently…and people don’t want to be labelled…especially Black people do not want to be labelled. (P1, FG 2)

Participants mentioned that early education for caregivers would be important for those that have children with the trait and disease. One participant stated

…I feel like early education would be good or something like that…early education, with um, I don’t know there’s a lot to educate with pregnancy, but I feel like that would be um, and gen-genetic testing, I feel like, that would be good ‘cause if it’s something genetic like you’d wanna know…. (P4, FG 1)

Another participant mentioned a specific type of event that would provide an ease of access to parents that may potentially have a child with the trait or disease saying,

...you can even just go to like some of the events that they have for like the baby, the the big baby event …Where they give out different stuff for people having a child and like,
letting them know like, this could be a possibility, like, You don’t want to scare them but you still want them to be aware because, I feel like, when something happens to your child and you don’t know anything about it, but then you find out that there was a community who coulda told you…From the jump, you know, like, I feel like that you know, is like a responsibility that the community has to…Educate people on everything…(P3, FG 1)

A lack of social exposure was mentioned by participants, as a reason that more awareness is needed. Specifically, participants mentioned not hearing much about SCD across different media. One participant reported,

…it’s not like, um, hepatitis, you see those commercials for that all the time. Hepatitis C and then you got your AIDS prevention medicine, you know, you can see all that types of stuff all the time on TV, but I’ve never seen anything for sickle cell. (P1, FG 2)

Most participants reported not hearing about SCD or any campaigns regarding SCD, in the media at all, one participant state “I’ve not, I don’t think I’ve really ever heard it discussed in the media, or rarely, rarely (P4, FG 1),” another reported seeing things in the media “rarely, vary rarely (P1, FG 2).” Social media was, however, reported as being one of the ways that education and awareness could be increased. One participant stated “Uh I mean, I think the fastest way [inaudible] social media yeah, and as far as like, adults, and everything that’s probably the easiest way to get them to be talking about it (P2, FG 1).”

Campaigns, similar to other diseases, was mentioned as an additional way to raise awareness and education as well. Participant 5 (FG 3) stated
I feel like it can be raised the same way we raise awareness for like, cancer and stuff like that. Um, for my dad, what we did is we made T-shirts and we went on walks, marathons…And just that type of stuff to raise awareness.

Participant 4 (FG 1) also suggested campaigns similar to other diseases, saying

I dunno but a lotta the things that you see campaigns for you may not know what it does but you know that it exists…Like when ALS got really big. I have no clue what AL, wait is it, ALS? ALS? I have no clue what AL- (P1) The ice bucket challenge. (Other) But yeah I have no clue what ALS i-is or like does to the body but like I know it exits but I feel like that’s not the same with sickle cell, like. People are like, yeah I’ve heard of it, or like, I know MS is like a thing, I don’t know what it does to the body…I feel like even just like starting out a campaign could be good.

Simple dialoguing was also mentioned, a participant reported “dialoguing, people can’t know what they don’t know (P6, FG 3), in contrast however another participant stated “…there can’t be conversations about something that people don’t understand, or are even aware that ‘hey’ this can impact you (P5, FG 3).” Focus groups were suggested as a way to facilitate conversation participants stated “uh, focus groups like this. Pretty much (P3, FG 3), another said “have more focus groups (P3, FG 1),” and one other participant said “…we can act-actually try to spread the word about it more and like, try to actually, you know, try to get people to come to events and these studies and stuff but they don’t really show up and turn out… (P2, FG 2).”

Celebrity advocates were also mentioned as a strategy that could be beneficial in raising awareness, for example one participant said “I feel so too. I feel like, I don’t know a lot of, maybe famous people that have it…I feel like more people are gonna be talking about it if more famous people had it, in my opinion (P3, FG 3).” Another participant mentioned how a member
of a pop group raised awareness about the disease saying, “…. Chili from TLC put, like, a light on it, like, in the public (P1, FG 3).”

In summary, Black Americans reported knowing some details about SCD, however they reported some uncertainty or lack of knowledge as well. A large majority expressed knowing people with SCD, and reported their interactions and knowledge gained from the people that they knew with the disease. They generally perceived individuals to appear “normal” and outside of flare ups, live a relatively normal life, aside from hospital visits, monitoring health, etc. Perceptions of SCD were evident because of knowing someone who had the disease or trait. Disease comparisons were often made, particularly they associated SCD with diseases such as Asthma or ALS. Most knowledge about the disease came from coursework or, again, individuals with the disease. Mentioned often was the systemic inequality or adversity experienced by Black people in daily life and in hospital settings; they were also aware of the challenges faced by those living with SCD. Social media and dialogue were mentioned most often as methods for increasing awareness.

**Hispanic Americans**

**Knowledge.**

Participants in this focus group were able to identify some attributes about SCD, but not many and there was a level of uncertainty throughout the discussion. Participants were able to identify some characteristics related to the shape of the cells. One participant, when asked about the first thing they thought of when they heard sickle cell disease stated, “I think of the shape, like a crescent (P1)” that same participant later went one to mention that “it makes it harder for those cells to move, um, throughout the body so that causes pain, I think.” Another participant mentioned, “maybe not being able to create new cells (P4),” but didn’t mention anything specific
in terms of what that might cause. Participants also mentioned symptoms such as fatigue, shortness of breath, pain, and muscle soreness. One participant reported “the first thing that I think is people not feeling well. Like people feeling tired (P3),” another stated that “it can cause fatigue in certain people (P2).” Another participant stated, “I feel like, muscle soreness (P1),” Participant 3 stated “shortness of breath. If your cells aren’t doing what they’re supposed to at their normal rate. Shortness of breath might be one (P3). Lastly, participants mentioned genetics when asked about how people get SCD, saying “I don’t remember the correct terminology for this, but like it can be active or dormant. So, like, even if you don’t have it, you can still pass it on, um, to your children (P1),” others said “Yeah, through DNA (P2, P3).”

When describing the population affected by SCD participants mentioned race and ethnicity as well as gender. Participant 2 reported,

Um, predominantly like in African American communities…Um, is it, um, I think it’s predominantly, is it men? So, I’m gonna say predominantly, um Latino and Africa—African American men…I know it’s predominately in African Americans but my friend was Hispanic so that’s how I, like that’s why I figure it’s um African Americans and Hispanic people.

One participant mentioned, “I’d say minorities, but I think females (P3).” Two other participants reported on knowing African Americans as the affected population. Participant 1 said “I thought it was mostly, just, uh, African American community. Um, but even then, I thought it was low percentage as well,” while another participant reported “I would, I would’ve just thought predominately African American men.”

When discussing prevalence, again participants were uncertain. One participant reported “I think amongst Latinos it’s very common but it’s not diagnosed (P3),” while another stated “I
think I know one person that has it? I—just from my personal experience I would think it’s rare [inaudible] and rare at least within my community (P1).” Another participant gave a specific number saying, “I’d say 1 in 200,000. I don’t know if that’s right. I’m just throwing a number out there (P2).” Additionally, media references were also used to gauge prevalence, one participant stated

I’d have to imagine it’s fairly common if it’s like, referenced as often as it is, especially even in like comedies and- and it’s like, almost like a typecast in comedy characters that have sickle cell [inaudible]. I imagine it has to be fairly high amount of people for that to land as often as it does. (P4)

Two participants mentioned learning about SCD at school. One participant mentioned their “psychology textbook (P1),” another stated that they learned about it from a biology course saying, “like ten years ago, so that’s why I can’t remember anything about it. Yeah, it was like a biology class I think (P4).” Only two participants mentioned knowing someone that has SCD, one reported.

Some people don’t know they have it, like, um, I’m in the military and, uh, one of my friends he was trying to go, like, special operations in the military. And he went 30 years with no idea that he had it whatsoever. Like they did all this bloodwork and then disqualified him from it because of it, um, but like he had no idea. (P2)

However, when asked if the friend had the disease or the trait, the participant was unsure saying,

Um, I’m not- okay, I’m not sure of the top. Uh, I thought he had like the actual disease ‘cause, like, um, his wife was a nutritionist and so he was telling me how his wife was like, gonna modify his diet to help, uh, with that. And then um, yeah. (P2)
While another participant reported learning about SCD, “My friend, my friend that had it-or has it (P4).” Another informal source included articles, Participant 3 specifically reported “I think, I, uh read a few articles here and there, nothing too formal like a textbook but things here and there.”

As mentioned previously, participant reported general lack of knowledge as well. When asked what first comes to mind when they think of SCD, one participant reported “I tend to think of how little I actually do know (P3)” this same participant also posed a question saying “from the title it makes you think, is it a cell that’s sick?”

**Perceptions.**

One participant mentioned perceptions related to physical characteristics and lifestyle, specifically saying

Like he’s been extremely active his entire life, like, by the looks of him like he’s ripped like you could never think, that like, there was anything like holding him back so I like really, like, look at it as something that like holds people back I guess, ‘cause even some people it doesn’t at all. (P2)

Another participant reported that you wouldn’t be able to look at someone and identify whether or not they have SCD, they stated

...it’s something that you would only get through your, like, physician, it’s not something they can tell you have just by me looking at him. Like, oh you have sickle cell, no. It’s something you have to get, go through your doctor. (P3)

Others agreed saying that individuals look normal, for example, Participant 4 stated “I would say normal” when asked what an individual with SCD looks like.
Participants discussed methods of maintaining health that they perceived that individuals with SCD would have to do. For example, one participant reported

I would think that, and I don’t know a lot of it, but my assumption is that there’s sometimes where it gets worse, where um the symptoms are really bad, or they might be, um like even hospitalized for short periods of time. Um, but it’s something that doesn’t affect everything they do but can like sprout up, um [pause, 2 sec] sometimes…They might have to take a day off work or school, um, to kind of recover. (P1)

Another participant reported similar thoughts saying

I would say rest. Um, they probably would just, um, need to like take it easy or something like that. Maybe like um again I don’t know but I, uh, guess that maybe, um, it sprouts up like whenever maybe during a high stress situation or um they have a lot going on so maybe just like sitting back and resting for a little bit…Maybe try not to stress yourself out or something like that. (P2)

Participants also reported that they may have to take prescription medication or have specific diet restrictions. Participant 3 mentioned “…different diet restrictions,” and Participant 2 stated “maybe take medication” when asked about how and individuals’ life with SCD may be different. Another participant mentioned hospital visits as well reporting “And, the one thing I was thinking of is hospital visits. Like, I-, I-, I haven’t been to the hospital since I was a kid, so. Like it might become more familiar with that type of thing (P1).”

Additionally, limitations and being aware of limitations via circumspection, such as not being able to be too physically active, were also identified. Participant 3 stated “precautions that they have to take that maybe we don’t have to, people who don’t have that… I was thinking more like running a marathon or something, like running a 5k.”
Interestingly, another perception mentioned lack of visibility, specifically, that people may not be aware that they have the disease. One participant stated “I haven’t ran into that many people or with maybe, again, another systemic interpretation might be that: does people that do have it don’t know? And so, how could I know if they didn’t know (P4)?”

**Adversity.**

Within this focus group participants mentioned that SCD may not be as known about or as researched as other diseases because of systemic inequality already in existence. Participant 2 reported about lack of funding and research saying,

I know there’s like a lot of, um, of those like small little things and like minorities and like women that like there’s just a lot of stuff that we don’t know and it’s just not researched and it’s not funded. Um, because there’s not, like, a need to figure out, like, er, there’s not a want. There’s the need but not a want to like figure out what, uh, like how it’s affecting people and stuff like that.

Additionally, research was mentioned by two other participants, one stated “research. There hasn’t been much research done of it. Maybe it’s just come up to, like, within that last few decades (P3),” the other said “At least now, there’s more but, um, that’s an issue for them and for white, um, men, it’s not usually, um it’s not really an issue, um, so they don’t research it (P1).”

Access to care was also highlighted but participants. Participant 3 stated

And this makes me wonder if it comes down to healthcare situation, where people don’t have access to, like, the health resources; they don’t have insurance therefore they can’t get tested…and then what happens if we do educate people but then they don’t have access to go to the doctor and get treated or get diagnosed? What good is it going to be if they know what it is but they can’t get treatment for it?
Participant 4 reported similar thoughts saying,

...maybe it’s a larger systemic issue revolving around probably healthcare and availability to healthcare and just general education about certain things and traditionally speaking those haven’t been the most available to Latinos and our community…

**Increasing Education and Awareness.**

When asked about how often participants have heard about SCD in their communities and in media, participants mentioned celebrities, news, and comedy shows. Participant 3 stated “I don’t even know, I think I’ve heard like of a celebrity who has it. That’s usually when you see it in the media." While Participant 4 stated “Yeah maybe like once in like a good morning America piece, and I wouldn’t be able to tell you which one that was.” The same participant also reported

Well, I would imagine like I’ve probably heard it in like a Tyler Perry movie. I would’ve heard it through like Dave Chappelle, or through a number of other black comedians that reference that or in like other minority-based movies. Like, I think I heard it as a joke in “Nothing Like The Holidays” which is a movie about Black Americans, so. (P4)

Participants used these means of dissemination as a way to propose how SCD awareness and education can be increased. One participant discussed more media coverage stating “...maybe if like if the media covered it a little bit more because I think I mean that kind of hits all races, all communities and stuff like that. Um so maybe like more coverage in the media…(P2),” while another mentioned using celebrity advocates “…so even just like, it’s cheesy but like having like even just like celebrity sponsors be like, hey I have sickle cell (P4).”

Additionally, one participant mentioned incorporating education into college orientations saying,
...maybe like in college, like if they incorporate something in like orientation, or maybe something like that to make people more aware. ‘Cause I know like in orientation, just a couple weeks ago, I think they talked about like mental health and stuff like that, maybe like um like they talked about mental health and like if you have any, um, if you have any issues you can go to this place so maybe if they like incorporate that then more college students would uh have like a resource of something they could maybe get tested to see if they have it or something like that. (P2)

Another suggested more incorporation into school biology courses “...to teach kids in school like during health or biology class (P1).”

Lastly, pamphlets were also discussed as ways to increase knowledge and awareness, specifically pamphlets available in Spanish. One participant reported

I think one thing that really would help out, for example the Hispanic community, is if that info was out in Spanish. For example, if they’re not- they’re not gonna know whether they have it if they don’t even know what it is. So maybe if you have like a small flyer or a pamphlet and it tells you, “hey do you know what this is?” and then it kind of explains. Maybe that would kind of encourage people to kind of ponder on it a little bit, like, hey what is this maybe I have it, do I need to talk to my doctor? (P3)

Additionally, one participant mentioned a potential barrier to education, specifically discussing other health issues and topics that are of importance to the Hispanic community that SCD information may have to compete with. The participant stated

...so even just the idea of like, well we need to educate these people but we’re already behind on educating them with everything else up to that point so it’s like what- what’s
on the docket? Do we want our kids to read or do we want them to know about sickle cell? (P4)

In summary, Latinx Americans more readily expressed a lack of knowledge or uncertainty regarding SCD. They were able to identify the shape of the blood cells, pain and fatigue as symptoms, and prevalence within the Black community. They identified that SCD happened in their community but were unaware of the prevalence. It was perceived that SCD was not as known about in this community because of lack of access to care, low prevalence of knowledge, and perceived low prevalence or visibility within the community. Pamphlets offered in Spanish were reported as a potential method to increase awareness within this community.

Other Populations

Knowledge.

Participants were able to identify attributes related to the SCD cell shape, anemia it causes, as well as hereditary aspects such as the relationship to malaria. One participant mentioned “C-shaped blood cells (P1, FG 1),” another stated “I just actually picture the cell, the shape (P4, FG 2).” One participant mentioned “anemia (P1, FG 2),” and another stated “Malaria. I had heard—and I don’t know if it’s true—but I had heard that sickle cell could be a evolutionary adaptation because people with sickle cell are less likely to catch malaria (P2, FG 2).” Additionally, participants mentioned that sickle cell disease was “genetic (P2, FG 1),” and “hereditary (P3, FG 2).” One participant provided more detail saying,

Umm, from what I understand it’s genetic, so it can be transferred, um, you know, to children, and it’s like, based on, ah, certain traits—you can or can’t get it depending on what parents, if both parents have it. The gene. (P3, FG 1)
Another stated, “I think it’s from both parents. Like it’s—I don’t think you can get it from just one parent, I think both parents, and then, um, but if you get it from one parent you’re a carrier for it (P4, FG 2).”

When discussing physical and emotional symptoms related to the disease participants identified pain, jaundice, fatigue, depression, and anxiety. One participant stated “umm, I’m pretty sure it can be painful, to some degree (P1, FG 1),” another mentioned “…massive sort of systemic pain… (P2, FG 2),” while another stated “I know it’s very painful (P4, FG 2).” Three participants mentioned “fatigue” (P2, P1, P5; FG 2). Participant 4 (FG 2) additionally mentioned “jaundice, and feet and hands are swollen, I think.” Three participants mentioned depression or anxiety, one stated “I would guess, like, there would be a lot of anxiety with it (P4, FG 2),” another participant mentioned “…it would probably make me rather depressed to be honest (P5, FG 2).” Lastly, one participant mentioned comorbidities saying, “[I] know that it causes a whole bunch of different health problems… (P2, FG 2).” One participant also mentioned prevalence of a specific form of SCD, saying “…sickle cell anemia is the most common, I think (P4, FG 2).”

Participants reported Latinx, Black Americans, and Asian individuals as the populations affected by SCD. One participant reported “…I’ve heard that there are stereotypes that African American, uh populations or African populations experience it more (P3, FG 1),” while other stated “yeah, it impacts [the] African American community more (P1, FG 2),” and “Black Americans (P1, FG 1).” Participant 1 (FG 1) indicated “Latino” populations, as did Participant 3 (FG 2) who stated “I’m pretty sure it impacts, uh, Black and Latinx populations more.” Participant 2 (FG 1) reported that individuals of Asian descent get the disease saying, “I think I was told Asian as well, but I’m not positive on that.” Other participants mentioned that other
groups could get it as well, but did not discuss any particular race or ethnicity, for example Participant 3 (FG 1) stated “I would imagine, like, any ethnicity can…”

In regards to the prevalence of SCD and SCT, participants reported that it was common. Participant 1 (FG 1) stated “I think it might be pretty common actually,” while Participant 3 (FG 1) reported “I’m not sure. I would say it’s probably more common than I think, but otherwise I’m not sure.” Lastly, Participant 4 (FG 2) reported “I bet there are a lot of carriers, and a lot less who have it. If I had to guess.”

Treatment and new curative methods were also discussed. One participant recalled hearing about a new cure being study, via NPR, “…where they used CRISPR to try and redo her DNA in order to treat her sickle cell, but it’s going to be years before they know whether or not it’s effective (P2, FG 2).” Another participant mentioned that “it can be treated with penicillin, I think, if I remember right. I think the only cure is the bone marrow transplant (P4, FG 2).” Additionally, Participant 1 (FG 2) stated

…well on the questionnaire online it said about treatment. I think it can be managed, but for that it said blood transfusion, but that’s wrong, I think—I think that the only true treatment is, um, bone marrow replacement. That’s my understanding of it.

Some participants reported lack of knowledge or uncertainty related to prevalence, physical symptoms, and the disease and trait. Participants often reported “I don’t really know (P2, FG 1),” or “that may not be true (P3).” In one instance a participant reported “that’s new news for me too (P3, FG 2),” after another participant stated that the disease affected Latinx populations “Yeah, and I, I know where, whether or not those rates are, uh, similar or if Latinxer is ah, is at a lesser, um frequency, I’m not sure. I have no idea (P3, FG 2).” Another participant reported not knowing about commonality as well saying “Yeah, I feel like if it might be as
common, uh I don’t know how common it is, but if it might be as common as cancer, then, uh, there should be something said about it more (P1, FG 1).” While another mentioned the trait, saying “Um, and also the sickle cell trait, I didn’t, didn’t know anything about that, so, yeah (P2, FG 1).”

Typical sources of knowledge included an educational course and podcasts. Participants reported “my biology class (P6, FG 2),” “biology…health class (P1, FG 2),” and “anatomy (P6, FG 2).” Another participant stated “I know I learned about it a little bit in, like, one of my science classes… (P3, FG 1).” Some participants also noted that they knew someone with SCD, specifically, one individual in the first focus group mentioned “…my friend used to have it (P1, FG 1),” and half of the second focus groups answered “yes” when being asked if they knew someone with SCD (P4, P5, and P3).

Some participants discussed that where they group or their communities were places where they wouldn’t have learned about the disease. For example, one participant stated,

I grew up in a very small town up North, and, um you know we just—we had two children in the whole school who were part African American, so, um, you know, that’s just not something I ever would have encountered growing up. (P2, FG 1)

Two others mentioned being from Denver and stated,

So, growing up, as I did live at elevation, so, I probably wouldn’t have had anybody in—(P2) Yeah! I’m from Denver! I bet you— (P3) Wouldn’t have had anybody in my, mean, I’m sure there are people in Denver who are acclimatized, but there weren’t anybody in the mountains that I knew of. (P2)
**Personal Experience.**

One participant indicated having a biracial daughter that had the trait. The participant stated,

I received a letter when my daughter was a few weeks old saying that, um, there was something wrong with her blood and I had to see a specialist. And when we got to the specialist she told us that she had, um, sickle cell trait, and that was the first that I think I’d ever heard about it. (P2, FG 1)

The participant then went on to describe their experience with the physician, they reported

So, uh, it was, um, the doctor told us at the time she’ll never be affected by this, um it’s just she could potentially have a child that’s affected by that…’cause the doctor said that if she has children with a White person, then there’s not any risk. But that if she is with Latin, African American, and maybe Asian was just the Mongolian spot [laughs]. Um, but, they said that she could be at risk for, um, passing something on to her children, or, um, things, but that’s, uh, my extent of my knowledge was just what they told us that they, in the doctor’s office. (P2, FG 1)

Another participant described their experience in the healthcare field, the participant reported learning about SCD “when [they] worked at the hospital (P4, FG 2).”

**Perceptions.**

Participants reported that you would not be able to tell if someone had SCD, for example, one participant stated that an individual would look like “a regular person. I don’t think you’d be able to tell at all (P1, FG 1).” Another stated “I wouldn’t think there’d be—would be much of a visible difference (P3, FG 1).” Additionally, other participants mentioned that they would look
just like “you and I (P1, FG 2),” and that “[they] would argue you wouldn’t be able to tell from
the outside (P2, FG 2).”

Participants also reported that individuals with SCD may have to take medications, visit
the hospital or doctor, and put some parts of their life on hold. Participant 2 (FG 1) stated “I
would think the same as anybody managing any kind of long-term illness, just doctor’s
appointments, hospital visits, missing out on things sometimes.” Another participant mentioned
planning saying,

   Probably a lot more important, f—um, for people with sickle cell to have a plan in place
in—in case anything happens, but I’m sure with people with sickle cell, you have to have
a plan in place no matter where you are, you have to have, know where the hospital is,
stuff like that. (P3, FG 2)

This same participant talked about how putting plans in place may be more difficult because of
the experience of symptoms, they reported

   You really don’t know, from my knowledge anyways, um, life expectancy if you have
sickle cell, so, uhm making plans must be, which could be a struggle. Um, umm, not
knowing when these symptoms are gonna increase, not knowing, just there’s, there’s just
so many question marks around it in terms of when you’ll be experiencing the height of
the symptoms, when, um, yeah, all that stuff. (P3, FG 2).

Additionally, lack of freedom was also discussed. Participants stated that there is “not much
freedom (P1, FG 2), or “not as much freedom (P2, FG 2), and that it can be “restricted (P1, FG
2).” Travel was discussed as well, one participant stated “you may have to travel long distances,
’specially if you live in a—in a remote area, of course (P1, FG 2).” Other participant agreed with
this statement as well (P2 & P3).
Participants discussed that there may be frustration and fear as well. Participant 6 (FG 2) reported “yeah, I’d say pretty frustrating,” another said that having SCD is “probably a little scary, too, probably a lot scary (P1, FG 2).” Interpersonal conflict was also briefly mentioned by Participant 5 (FG 2) who stated “imagine difficult, any kind of chronic illness is gonna cause strain and probably with somebody’s relationships and their work life, school life, personal life, probably all areas of their life. I would imagine.” Another participant reported

But I can anticipate that because sickle cell disease symptoms tend to be difficult to see from the outside, /that relationships and teachers may have trouble being sympathetic and empathetic when those symptoms flare up. And that dealing with those relationships can potentially be challenging. (P2, FG 2)

Another mentioned that …”it would make it difficult to work and complete school, so yeah it really would impact the—the life in that way (P1, FG 2).”

**Adversity and Increasing Education and Awareness.**

One participant mentioned how it may be difficult to manage symptoms and that this may lead to difficulties in the medical system. This participant reported

And I’m sure it’s challenging as well because there’s so little information out there about sickle cell, so. Um they’re not, shhu—you know, there’s probably a good chance that they’re not sure how to identify those symptoms or, in—you know, like you were saying with a lot of other cases there’s things that are readily de—ibeah—identifiable, but not for this case, and I’m sure that that leads to complications in healthcare as well, um in terms of, um severity of symptoms, um, et cetera, because there’s not—you’re not sure how to gauge it. Um, does that make sense? Like... (P3, FG 2)
One participant discussed the medical fields role in raising awareness saying “...the medical industry has to take it really seriously for communities to start seeing it more, so like they need to take it super seriously and put it on the radar for people (P5, FG 2).”

One participant mentioned biases related to the populations mostly affected by SCD. They stated,

I’m sure that’s very difficult and also kind of, you know, aligns with, um, a lot of other research out there about implicit biases directed towards um Black and uh-uh-uh Latinx populations about, um, oo—oo—how much they perceive pain, whether the severity of pain versus what they’re reporting isn’t taken as seriously as other demographics and I’m sure that that, um, even more difficult for people with sickle cell, because those are already hard to identify. (P3, FG 2)

Other participants also mentioned that the disease may get more attention and people would be more aware if it affected other groups. For example, Participant 3 (FG 1) mentioned

I don’t, I don’t see them like really worrying about it unless it becomes like a huge issue or something that affects certain types of people, maybe if certain, uhm...important groups of people were experiencing it, then it might be a problem, like, say if there is an outbreak somewhere, or something.

Participants recalled the instance that they heard SCD being discussed in media. Again, NPR was mentioned Participant 2 (FG 2) reported

..there was a recent discussion on NPR about it so it was a big deal in sort of the science-reporting world. But I feel like that doesn’t get a whole lotta air anyway, so--I, yeah.

Other than that specific instance, I never, I never see it or hear—hear much about it.
Another participant discussed a football player that was able to play in a particular stadium. Participant 3 (FG 2) stated “Yeah, just that I remember, I think I remember first hearing [what] sickle cell is because there’s a football player that had it, and so he couldn’t play in Mile High Stadium because of the—uh [inaudible] quality of the air!” Others mentioned that they hadn’t really thought about SCD or heard it before the study. For example, participants in the first focus group stated “you’re the first one that I feel like has brought it up (P2),” “yeah (P1),” “mhm (P3),” “if I wouldn’t have seen the uh, survey, I don’t think I would have uh thought much into it (P1).”

When discussing strategies to increase awareness, participants mentioned campaigns similar to other diseases, social media, pamphlets, and guidance when diagnosed with the disease or trait. Participant 3 (FG 1) stated “like maybe there could be even, uh, like they do Relay for Life, they could do relay for, um, sickle cell, you know?” Other participants mentioned “Twitter and Facebook,” Participant 4 (FG 2) stated “I’m thinkin’ like a, like a campaign on Twitter or Facebook like the ice bucket challenge, but something cooler….“ Pamphlets were also mentioned one participant stated “…I think pamphlets, any kind of literature on it, um, any resource here’s where you can go to find more. I think that would be helpful (P2, FG 1).”

Additionally, the parent of a child with the trait mentioned more guidance stating, I think maybe sometimes the way it was presented to me was your daughter has this, but there’s nothing wrong with her and there never will be...So, okay! Bye! You know? Why do I need to look into it more? I don’t know if maybe when you hear that if they have trait, but it’s, it’s fine, there’s nothing wrong, an, you just think oh, okay, nothin’ else to think about. So. Maybe a little bit more guidance on that, like, you know this will affect them when they go to have children—this will. (P2, FG 1)
Additionally, one participant mentioned that being compassionate and understanding about people’s lives in a holistic way would help to increase awareness as well, they reported

Um, I think we could do a much better job of talking about...that kind of, of, um, I think we could do a lot better ta—job of talking about the way people experience life, whether it’s with sickle cell disease, or MS, or ALS… when we talk about history and we talk about people and school and, um, you know, we don’t talk about people’s whole lives, we talk about very specific chunks of them, and I just wonder, you know, how many, um, really important people in, you know the creation of this nation and, and in everyday life deal with sickle cell disease or with other sort of whole-life, holistic issues that we could bring a—bring mor—more awareness to. (P2, FG 2)

Another participant added to this point saying, “yeah, it’s gotta promote understanding overall compassion and awareness (P1, FG 2).”

Having champions and advocates was also mentioned Participant 5 stated

with anything that needs more awareness, like having champions of that. The champions who are gonna go out and, you know, advocate for it and advoc—a, you know create advocacy groups or whatever kinda groups that are gonna, you know, not wait for it to become, um, not wait for people to become aware of it, but, really put it out there like, you know. So. Yeah. (P5, FG 2)

Lastly, two participants talked briefly about why awareness may not be raised within the Midwest. Participant 3 (FG 2) stated

A—as opposed to—especially in the Midwest where the majority of the population’s White, maybe, uh, that’s—there’s a reason that the Midwest is lacking in information
about sickle cell disease. Um, because it impacts Black and Latinx people so specifically.

Um, I don’t know if that’s actually happening I’m just saying could be! You know? So. Participant 1 (FG 2) then stated “the Midwest, in general is kind of lacking in knowledge of all sorts of things. There’s sort of a “suck it up buttercup” kind of mentality about a lot stuff….”

In conclusion, this group was able to identify attributes of SCD as well as some physical symptoms and mental health issues such as depression or anxiety. A large majority of participants identified knowing someone with SCD and one participant has a child with SCT. When discussing populations affected, minority populations were often mentioned including Black and Latinx Americans. Again, perceptions were that individuals with SCD were normal outside of having to manage symptoms and care. Participants expressed that this may be more difficult in regional locations like the Midwest. This was also mentioned a reason that awareness raising is not as prominent. Social media, pamphlets, and advocates were mentioned as methods to increase knowledge and awareness.

**Healthcare Professionals**

Table 14 provides demographics of the healthcare professionals that participated in interviews.

<table>
<thead>
<tr>
<th></th>
<th>Participant 1</th>
<th>Participant 2</th>
<th>Participant 3</th>
<th>Participant 4</th>
<th>Participant 5</th>
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<tbody>
<tr>
<td><strong>Age</strong></td>
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<tr>
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<td>Master’s</td>
<td>Bachelor’s (Current Student)</td>
<td>Bachelor’s (Current Student)</td>
<td>Master’s (Current Student)</td>
</tr>
</tbody>
</table>
Within the healthcare focus groups fives themes emerged two themes were similar to the other groups; however, three themes were specific to this group. Themes, subthemes, and descriptions can be seen in Table 15.

**Table 15**

**Qualitative Themes and Descriptions for Healthcare Professionals**

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-Themes</th>
<th>Exemplar Quote</th>
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</thead>
<tbody>
<tr>
<td>Knowledge</td>
<td>• Attributes of SCD</td>
<td>“low oxygenation as well so, they’re not getting enough blood flow everywhere”</td>
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<tr>
<td></td>
<td>• Lack of Knowledge</td>
<td></td>
</tr>
<tr>
<td>Medical</td>
<td>• Source of Knowledge</td>
<td>“so I actually haven’t like, worked yet, like as a nurse, since I’m going straight to nursing school, but I don’t think we had enough information like, in school. And I didn’t get like get presented, like I don’t feel enough, uhm, with patients that, uhm, had this, had sickle cell disease”</td>
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<tr>
<td>Training</td>
<td>• Treatment/Health Maintenance</td>
<td></td>
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<td></td>
<td>• Insufficient Training</td>
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<td></td>
<td>• Additional Training</td>
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<tr>
<td></td>
<td>• Interaction Frequency</td>
<td></td>
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<tr>
<td></td>
<td>• SCD Expertise</td>
<td></td>
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<tr>
<td></td>
<td>• Lack of SCD Expertise</td>
<td></td>
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<tr>
<td>Perceptions</td>
<td>•</td>
<td>“I think a lot of it is just the location that we are in the nation, too. So, uhm, when you talk about African Americans, people of color, you know, Middle-Eastern people, uhm. You’re just not seeing a lot of those as veterans, honestly. I mean, at this point in the older adult population, uhm, so that’s what I would think anyways, for the type of patients I deal with on a daily basis.”</td>
</tr>
<tr>
<td>Adversity</td>
<td>• Racial Adversity in Healthcare</td>
<td>“Um, it’s hard for a nurse to want to give a narcotic to a patient who says they’re a 10 out of 10 but they’re comfortably watching tv, looking like they’re comfortably watching tv, um.”</td>
</tr>
<tr>
<td></td>
<td>• Stigma and Bias</td>
<td></td>
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</table>
Breathing normally, um, not grimacing, or anything like that. It’s—it’s really hard to see that, but at the same time, we have to look at ourselves and understand that, like, we don’t feel what the patient feels.”

| Increasing Education and Awareness | Public Education
| --- | ---
|  | Familial Education
|  | Patient Education
|  | “I think it’d be really cool if it was associated with community, um, centers or libraries, sometimes the hospitals will host things that are open to the communities.”

**Knowledge.**

*Attributes of SCD.*

When asked about what they know about SCD the healthcare participants reported the abnormal shape of the blood cells, lack of oxygen in the blood, anemia, and the protection it provides against malaria. Participant two mentioned that “the actual blood cells, uhm, or blood cells in the body are abnormal, abnormally shaped, uhm, in like a C-shaped or sickle shaped.” Participant 1 stated that SCD “basically distorts the red blood cells so you can’t carry oxygen efficiently and then they get lodged in your uh, small vessels.” Participant 5 also mentioned the shape of the cells and the complications it can cause, saying, “I know that it is an anemic disease where the cells, um, form a different shape, and don’t carry oxygen properly…low oxygenation as well, so they’re not getting enough blood flow everywhere….“ Participants were also able to identify the complications that the blood shape and low oxygenation, together, can cause. This primarily included pain crises and flare ups. For example, one participant mentioned that the shape of the blood cells could “cause pain, uhm, with the blood flow. With the difference, instead of them being rounded and smooth on the outside, you know, causing tears and things like that to the, to the veins (Participant 3).” Another participant mentioned “I know that there are flare ups and, uhm, pain crises that come along with sickle cell anemia… (Participant 2).”
Participants were additionally able to identify the genetic characteristics of the trait. One participant stated that individuals could “have like sickle cell trait or sickle cell disease depending on the genetics. Whether it’s heterozygous or homozygous—it’s a recessive condition.” Participant 4 similarly stated “that there’s varying, I guess, degrees of sickle cell. So you can have, um, I guess both allele’s and that would be the full disease, but then you can also just have sickle cell trait.” Physical symptoms mentioned include, again, pain, cramping, ischemia, coldness in the finger and limbs, and fatigue. Participants mentioned, “pain, cramping (Participant 1),” “the fingers and the limbs can get really cold which is just another symptom of low oxygenation to us (Participant 5),” “…decreased energy levels just because you can get that with any sort of anemia (Participant 4),” and “…low blood cell count, which could obviously cause fatigue (Participant 3).” Spleen ruptures were also mentioned by one participant; Participant 3 reported, “So you have sickle cell uhm, those cells that you know, are sickled and you know they affect the spleen, you know they cause, a lot of times, ruptures in the spleen, and stuff like that.”

Lack of Knowledge.

Some participants still expressed a lack of knowledge and training (discussed below) and uncertainty when speaking about certain aspects of SCD. Participant 1 stated a few times, “I think I know,” “well, I think yeah,” “I don’t know,” and “I guess.” Participant 2 mentioned “I would think…,” as well as not knowing about SCD “in depth.” The same was true for the remaining three participants, as well; a number of “I don’t know,” or “I think” statements.
Medical Training.

Source of Knowledge.

Most participants were nurses, two were medical students the training that they had or were currently experiencing was very similar. The participants mentioned learning about SCD in brief modules in class. Typically, these models were in their hematology or genetic disease units. Participant 4 reported:

“Yea, so I—it was—mostly we hit on it during our molecular medicine module where we were talking about genetics and genetic diseases. Um, so that’s when we were first introduced to it and we kinda learned about the hemoglobin structure and it was talked about how that changes with sickle cell. Um, and I think it was also brought up again in our hematology unit. So, there were multiple classes that um, multiple hour long class sections that either sickle cell would have been the main focus or a part of it.”

Participant 5 discussed their experiences saying,

“Yea, um, it was part of our, I believe, our—either our hematology or our auto immune, um, unit. I can’t remember which one. And, we kind of just touched base on it and described like the pathophysiology of it, the symptoms, which is what we always do. Um, it was unfortunately looped in with a bunch of other things, I wish I knew more about it.”

Most participants expressed learning about SCD primarily through class, however two participants had personal experience with relatives or friend that have had both the trait and the disease (Participant 2 & 3). Specifically, participant 3 stated that her “sister dated a guy for about seven years who had sickle cell, so I learned a lot from him, and just kinda watched a lot of the stuff that he went through.” One participant also reported that they had received athletic testing
for the trait, Participant 1 stated “so I played, uhm, college soccer and they like tested all the athletes, like they made us get a sickle cell uhm, test or whatever.”

_Treatment/Health Maintenance._

Participants were also able to identify treatment and healthcare maintenance needs of patients with SCD. Mentioned most often, was controlling pain, oxygen saturation, fluid intake, and personal care. One participant mentioned “pain control, uhm, oxygenation, and then like, treating other, other, uhm, other problems that they have I guess (Participant 1).” Participant 3 reported that “focusing on pain would obviously be one of the biggest parts of it because I think once you get pain under control you can kind of address other, other problems that they might be having uhm.” Additionally, Participant 4 stated “Um, pain, oxygenation, and fluid resuscitation is really important when someone is going through the crisis.”

Also mentioned by participants was the difficulty in treating and maintaining pain. One participant reported

“since I haven’t [had a patient with SCD] yet, my assumption would probably again be pain. Um, just cause that’s like the number one thing for us to focus on and it’s going to be the hardest thing to put under control. Cause we’re taught that, you know, pain is what the patient says it is no matter what. But, we also have to be careful with narcotics and things, and not over do it and put someone at risk of their life in danger. Um, and sense they already have low oxygenation, we’re at a little bit higher of a risk with that.”

(Participant 5)

Participant 3 also discussed similar issues saying,

“I would certainly say uhm, managing the pain, uhm. You know and I’m not really sure why that’s such a difficult tasks, uhm, I think of it a lot like nerve pain, you know it’s
very hard to control nerve pain, uhm, because of, of the effects. So you have nerve pain that causes you know, other things to occur. Uhm, and I don’t know why it’s so difficult, uhm, honestly, to manage that pain. But, um, I think a lot of the issue nowadays is probably the, the huge issue that we have with narcotic abuse. Uhm, you know, not wanting to prescribe narcotics because of the potential of abuse.”

**Insufficient Training.**

All participants expressed that the training they received, in regards to SCD was insufficient. When asked about training Participant 4 stated they had no training “outside of the curriculum.” Additionally, Participant 3 reported insufficient training saying,

“you know, honestly, I can’t say that I’ve had a lot of training. Uhm, you know, I think we touched on it in nursing school but obviously, you know, you're, you got a ton of stuff to go over in nursing school, so you know you have a module on it, you learn a little bit about it, and then you’re on to the next. So, I can't say I’ve had a ton of training per say. So, no. I don't think that I would say that I've had enough training on it.”

**Additional Training.**

In addition to insufficient training mentioned by participants, recommendations for additional training was also discussed. Case studies during medical school and one’s professional career was mentioned. As was, cultural responsiveness, continuing education credits (CEU’s), patient panels, and experience. Participant 5 and Participant 3 both mentioned CEU’s Participant 5 stated “we do a lot of continued education at our hospital and it helps me a lot with learning in general so I feel like that would additionally help,” while Participant 3 reported

Uhm, I would really like to see, uhm, more options for, for like conferences and things like that, cause I, I tend to attend a lot of conferences through the year, to get my CEU’s
and stuff like that, and I just don’t, uhm, see a lot of options available for sickle cell. I tend to, uhm, try and get like, 10 CEU’s every two years in an area that I don’t deal in, uhm, while I try and get my other 20 CEU’s in like gerontology, or the older adult or mental health, ‘cause those are typically my main focus, but, uhm. But I would like to see some more focus, some more conferences offered…

Participant 2 mentioned cultural responsiveness saying “I really think it’s like cultural responsiveness and like, humility. And I’m not sure that can be taught, but their needs to be some kind of way to get folks to be able to do it.” While Participant 1 mentioned case reviews saying, I mean for, for doctors who are like actually practicing and working, it probably looks more like case reviews and reading articles, and uhm, stuff like that, and talking through things with their colleagues. For students it could be working through more cases together, including it more, uhm, a couple more times throughout our medical education.

**Interaction Frequency.**

All participants mentioned having little to no interaction with patients with sickle cell disease. This limited experience was due to working in a specific specialty and/or being early medical and nursing students. Participant 5 stated that “It’s probably because I’m at a specialty hospital though, yea. I’m at a heart hospital so, I feel like [inaudible] cross paths with somebody with sickle cell, but I don’t that it’s as common as maybe a main hospital.” Participant 3 discussed having a specialty in gerontology, mentioning

So, my focus is gerontology, like that’s, I deal with a lot of older adults, and I deal with veterans as well. Uhm, and honestly, I don’t know why I wouldn’t see very many, because I think it’s a prevalent disease uhm. But, I also know that, dealing with the older adults, like often times those with sickle cell, they don’t live very very long lives, and
uhm, unfortunately, you know, caring for older adults, you know, I don’t think that that population would, would include very many with this disease, but, uhm.

Participants 1 and 4 expressed similar interaction frequencies saying,

I, I mean I don’t do a lot of patient interaction now, uhm, but we did have a patient panel and they did have someone on the panel with sickle cell disease. Uhm, but that’s my only patient interaction, as of yet… (Participant 1)

and “I don’t believe so, not that, not that they told or knew (Participant 4),” respectively.

Participant two mentioned their experience in clinical’s mentioning that they

“did see like, when I was in clinicals, uhm, I was on a labor and delivery like clinical unit and actually while I was there through a summer, there were like, at least two or three patients that came in, uhm, and actually a couple of them like miscarried or were dealing with a pain crisis, while their—uhm, delivering, uhm, unfortunately, and they had sickle cell disease.

Immersion and experience are important in being able to manage SCD symptoms, as is explained by Participant 3 who stated that

…you can read all you want about it I think, but when you talk about caring for an individual with sickle cell, you truly don’t know what that is about or what that’s like until you're actually, uhm, immersed in, and just, just doing it hands on.

**SCD Expertise.**

Participants expressed that there are probably health professionals that do have expertise in hematology or SCD, and are more knowledgeable. Participant 5 reported “I mean, it depends on the health professional and where they work…Um, I think in some areas, people are little bit
more—have a little bit more expertise. It really depends on the person and the unit that they’re in.” Participant 4 mentioned that

…it would also depend on what department you’re working in, you know, so if you saw a patient, you know, if you worked on—in a hematology clinic or something you’re definitely going to be knowledgeable about it compared to you know something else they may not [be] as knowledgeable.

Lastly, Participant 3 expressed similar thoughts

So, uhm, and I mean, when you talk about healthcare, I mean, that’s a vast amount of different options, different avenues you can go, so, obviously those that are focusing on, you know, things that, like for example, like HIV, like amino disorders, and things like that, I think would probably have more education and more knowledge when you start talking about sickle cell anemia, so, yeah.

**Lack of SCD Expertise.**

Participants discussed the lack of SCD expertise in the health field, mentioned most often is the lack of experience and specialty. Participant 1 stated that “probably not everybody is knowledgeable about it.” Participant 2 reported “I, I feel like they think they are knowledgeable until they actually have a patient who presents with sickle cell…I can’t confidently say that they know how to—people know how to manage or take care of folks with sickle cell.” Additionally, this participant stated

I don’t know that providers can just do it all, that doesn’t make sense, because they’re not doing it effectively. I’m very shady to my profession, and like all medical professions, but, there’s just a lot like wrong with how we uhm, deal with medicine in general.

Two participants emphasized that specialty could impact this. Participant 5 reported
that’s another reason why I probably don’t know as much just because…other than like COPD and congestive heart failure, um, I don’t deal with a lot of chronic-based patients… Um, like I said, I don’t necessarily feel super comfortable, like if I have a patient with sickle cell, I’m going to look up the disease again to refresh my mind and make sure I know what’s going on.”

While another participant—when asked whether healthcare professionals are knowledgeable about SCD, reported

Uhm, probably not, uhm, you know there's so many different avenues when you talk about healthcare, and uhm, you know like I had mentioned before when you, when you find that focus or find your area of expertise or your specialty that you want to focus on, you know, you kinda just go all in, uhm, on that and so a lot of times you fail to gain further education or knowledge about those diseases or conditions that might affect people that don’t necessarily fall into that specialty that you have your focus on.

**Perceptions.**

Like similar groups, participants expressed that individuals with SCD appear normal and you wouldn’t be able to tell that an individual has it based off of physical characteristics.

Participant 2 stated that

they look like a normal person, they, it’s not something that, most the time that is like, presenting like outwardly, like, you wouldn't like, be able to tell if they had sickle cell or not, until they uhm, like exhibit symptoms.

Participant 3 reported similarly saying that individuals with SCD look like “You and me. Uhm, I don’t know if they have any physical traits, not from my experience, uhm, just like a normal
person, you just wouldn’t know, most times.” Participant 4 expressed that the only thing that would be different are the barriers faced by individuals with SCD. They stated

Um, I mean I don’t think that they would be different any way, except for you know the symptoms that they presented with and maybe, you know, different barriers that they had to what they were able to do in their life in the sense of activity level and stuff like that if they were having a lot of exacerbations of it. Um, other than that there wouldn’t be any real abnormalities or anything like that.

One participant mentioned misconceptions that the she may have due to her circle of influence. More specifically they stated

Uhm, I mean that might be like just a misconception that I have just because, uhm, like in my circle of influence, I’m from like a very small, not very diverse place and so I don’t really, I mean I just haven’t even really been around very many people of African descent like in ya know, that I would really know that many people with the disease if they had it. Uhm, so that might just be like a misconception about like how prevalent it is in the population. (Participant 1)

Adversity.

Racial Adversity in Healthcare.

Adversity in healthcare, particularly racial adversity experienced by minorities, specifically Black Americans was discussed by most participants. Participants 1 and 2 both mentioned the disproportionate health disparities experienced by Black women. Participant 1 stated that

Black women have way higher mortality rates uhm, and infant mortality rates as their giving birth and stuff. And often times, uhm, the way that uh, Black people are treated in
this health care system, is not okay uhm, so I, I, I’m just thinking it’s probably similar for people with sickle cell disease, that they would experience the same kind of biases or discrimination or hardships that other black people would face in the health system.

While Participant 2 reported

I also think that since it’s predominantly, like found, for me, I guess I should speak for myself, like, I see it in a lot of African Americans, uhm, a lot of times, I feel like Black people aren’t listened too, especially if they’re like, a Black woman, their pain concerns are ignored, uhm, so you have not only like, a racial or even like an economic kind of like tone to this, uhm, but then there’s also like a societal view on like, the management of pain.

Participant 3 additionally expressed similar opinions stating,

I might be a little biased here, I just, I don’t really think there is, uhm, a lot of money that is put into the research, for it, uhm, because of the race that it typically affects, uhm, but. I guess you could say that for a number of different things, but I do feel like that, if it affected more of the majority of the population, uhm, that there would probably be more funding allowed for research.

Participant 5 expressed that “there’s potential [that race plays a role] because, while I wish there wasn’t I think that there’s always some kind of racial stigma underlying things.” Another participant discussed the impact that the use of opioids can cause for patients with SCD saying, “now they have like this opioid crisis, and stuff like that, so there’s a lot of like biases that I still go into, trying to treat, or take care of, uhm, deliver care to patients with sickle cell (Participant 2).”
Stigma and Bias.

Some participants expressed that they approached each patient that they see, as people. That they try to be unbiased but aware of differences that may influence care. For example, Participant 5 stated

We're given, you know, disease states and we're said this disease, you know--has--is in--the greatest proportion of people with this disease x, y, z, race. You know, so we kind of already have like predetermined ideas in our head about, like, okay, "you're this race so like you can have this disease and people outside of that race aren't going to have that disease," and I think sickle cell disease is one of the one's that could easily fall into that…I think just being cognizant of no matter what the race is, it can have any disease even if that's maybe not the most common thing.

Participant 3 mentioned

I think for me, when I have a patient I see them as a person, uhm, and I think that’s so important because I don’t think that any disease ever defines anybody. Uhm, so I don’t know that I would see a patient with sickle cell any different than a patient with congestive heart failure, uhm, they both have two very debilitating diseases that, you know, can definitely affect them negatively, and I think that, uhm, my main goal is, always, to make sure I treat people as humans, and make sure they know that, this disease or that disease doesn’t define you or doesn’t dictate how I treat you as a patient, so.

Additionally, methods of decreasing adversity and encouraging professionals to be unbiased was also mentioned by participants. One participant stated,

Uhm, I think instead of like cultural competency, it should be cultural responsiveness, cause competency just says like, this patient, probably in your textbook, a Black patient
presents with these symptoms, what do you think they have? And then they would just say sickle cell, and we know sickle cell like as a case study or something. But cultural responsiveness would allow folks to meet any individual whether their Black or Mediterranean, or presenting with the usual population, but uhm, they would be able to see the symptoms, ask about, and when they tell them, like “I do have sickle cell disease”, to be able to management and like, hopefully move any biases in their mind out of the way, uhm, and be like, responsive and like, interact and interchange between themselves and uhm, their patient. (Participant 2)

**Increasing Education and Awareness.**

Participants provided suggestions for patient education, familial education, and general education of the public. Specifically, for patient education participants talked about asking questions of patients to identify where they may need additional education. Participant 4 stated “I'd probably want to spend the most time talking to the patient to see what their goals are, what they understand about the disease, so you know if there's any educational proportion I would have to go into it.” Participant 1 stated that patient education and, and like empowerment is always a really uhm, good way to improve outcomes, and giving the patients resources that they need to kind of take ownership for their health and like, uhm to, be able to be proactive and take care of themselves.

Participant 2 also mentioned listening to patients because they know about their bodies and pain experiences, they stated being able to give, uhm, like autonomy and managing their pain like, within reason…I think that’s really important and like lacking in care a lot of the time, is like, coming in
with preconceived notions and then not, and then something falls in your face, and it’s not what you got in school and so, you’re confused, and their saying “no it can’t be”, and it’s like yeah it is. Like, follow what you’re supposed to do and like, listen to the patient. Additionally, another participant stated

but yea, I'd probably want to spend the most time talking to the patient to see what their goals are, what they understand about the disease, so you know if there's any educational proportion I would have to go into it. (Patient 4)

**Familial and Public Education.**

As for familial education, one participant discussed this very briefly stating “aside from patient education, also like family member education as well. Public education strategies mentioned by participants included increasing knowledge through education efforts, hosting informational sessions at public libraries or hospitals, and increased exposure. Participant 3 stated “increased knowledge, increased exposure, I think, uhm you know, I think that’s the best way to learn is being exposed, uhm, to those with, uh, to those that are struggling with that disease, and uhm, hands on, really.” While Participant 5 mentioned

Um, and maybe even just general education for the public so people can understand where those patients are coming from. I think it’d be really cool if it was associated with community, um, centers or libraries, sometimes the hospitals will host things that are open to the communities. Additionally, Participant 4 expressed similar ideas stating

Um, I think just awareness to what it looks like and what it's like to have sickle cell disease. Um, just for not only health providers but the general public just because I would assume that there's probably people that have, um, misunderstandings about what sickle
cell disease is and how, you know, if you haven't had a biology background maybe you
don't understand the genetics of it and that sort of thing. Um, so yea I would just say
more awareness.

**Discussion**

This research was conducted to understand the knowledge, perceptions, and stigma
reported by healthcare professionals, Black Americans, Latinx Americans, and other populations.
It was also designed to understand if knowledge levels and sources of knowledge impact
perceptions and stigma among these various populations. Overall, findings showed that these
groups were somewhat knowledgeable about SCD. Health professionals were the most
knowledgeable and Latinx Americans were the least knowledgeable. Findings were consistent
with prior research related to knowledge for Healthcare Professionals, Black Americans, and
Latinx Americans (Siddiqui et al., 2012, Whiteman et al., 2015). Perception findings were also
consistent with previous literature; participants generally had positive perceptions about
individuals with SCD (Bediako & King-Meadows, 2016). However, there is a dearth in the
literature regarding other Populations this current research add to that literature. This study adds
to the literature regarding knowledge, perceptions, and stigma among other Populations. Stigma
findings were also consistent with previous literature about healthcare professionals (Labbé,
Herbert, & Haynes, 2005; Shapiro et al., 1997; Bergman & Diamond, 2013). There is a dearth in
the literature regarding stigma in other groups as it relates to SCD. This is the first study to look
at differences in knowledge, perceptions, and stigma across these four populations.
Quantitative

Knowledge

Findings regarding knowledge levels suggest that there are 1) differences in knowledge across groups, and 2) that knowledge does impact stigmatization of SCD. Knowledge levels were higher among Healthcare Professionals and Black Americans. Health professionals had more non-personal sources of knowledge compared to Black Americans who had more personal sources of knowledge (i.e., family, friends, etc.). Knowledge levels also had an inverse relationship to stigma; as knowledge increased stigma decreased. However, qualitative findings showed that knowledge levels were relatively equal among the Healthcare Professionals, Black Americans, and Other Populations, but were vastly different for Hispanic Americans (Siddiqui et al., 2012).

Findings showed that Black Americans were more likely to know someone with SCD than their counterparts. However, this did not help or hinder their knowledge levels. Across all groups, knowledge was inadequate to moderate, with very few illustrating adequate knowledge. Although knowledge levels were high among two groups and were apparent in qualitative focus groups and interviewing, participants still readily expressed uncertainty about their knowledge. They also expressed wanting or wishing that they knew more about SCD. Previous literature about knowledge among Black women in a Midwestern state, identified that these women while knowledgeable about some basic aspects of SCD (i.e. that it’s a blood disorder) were not as knowledgeable about other things such as the inheritance pattern of SCD (Boyd et al., 2005). Past research has identified differences between Black and Latinx Americans regarding knowledge and awareness of SCD, specifically, that Black Americans are more knowledgeable about SCD and are more aware of their trait status compared to Latinx Americans (Siddiqui et
al., 2012). Previous research has shown that high-risk groups, such as Black and Hispanic Americans, do not know whether they have the trait or not (Treadwell, McClough, & Vichinsky, 2006). However, across all groups, a majority of the participants did not know their own trait status.

**Perceptions**

Participants perceptions of SCD did not vary based on quantitative data between groups. Findings showed that although there were no significant variations between groups most participants did hold positive perceptions of SCD with Black Americans being the most positive on average and healthcare professionals being the least positive. It can be assumed that because of the saliency of SCD to Black Americans, they perceive SCD differently than non-Black groups. While healthcare professionals have perceptual experiences based on their interactions with patients, which may impact their perceptions of individuals with the disease compared to the other groups. Another factor is that a majority of participants assumed that SCD did not impact their racial group. This association of race has been shown, preliminarily, to impact social attitudes negatively (Bediako & Moffitt, 2011), although the differences were not significant this could explain the minimal differences in mean perception score between groups. This is an area that should be examined more.

**Stigma**

In non-health professional groups, Black and Latinx Americans spoke in more detail about stigma and adversity faced by people of color in the healthcare field. They also talked more readily about systemic inequality with the US and how that can play a role in why SCD is not as known about, studied, or funded. On the contrary, Latinx Americans did hold more stigmatizing views of SCD; as briefly mentioned previously, this could be explained by the
overall lack of knowledge about SCD. The same can be said for Other Populations who had the second highest levels of stigma; however, knowledge within the focus group sessions were more apparent than the survey.

**Qualitative**

One theme of particular importance that emerged from the focus groups was this idea of racial adversity experienced generally and within healthcare settings by people of color, specifically among Black people. This was discussed in Black and Latinx groups the most, but was also discussed in a different way in the Healthcare Professional group. This is discussed more below. However, additionally, important differences emerged between groups and explained some difference that were seen quantitatively. Specifically, that Latinx Americans had the lowest knowledge and understanding of SCD among the groups. While Black Americans expressed more positive perceptions of SCD, compared to the other groups.

**Racial Adversity**

Racial adversity was a topic discussed, to varying degrees, across groups. This theme was discussed more in Black and Hispanic groups, but was mentioned throughout the other groups. Previous literature has identified the historical racial connotations of SCD. In its earliest discovery SCD had negative social ramifications (Bergman & Diamond, 2013). These negative ramifications are still prominent in medicine and in people’s perceptions of SCD (Bediako & Moffitt, 2011). This was apparent throughout both the quantitative and qualitative analysis. When participants were asked if SCD affected their racial group or if they knew their trait status, responses included assumptions that individuals do not have the trait because they are “White.”
Stigma in Healthcare Settings.

Healthcare professionals often expressed seeing and treating all of their patients the same; however, healthcare professionals had the highest levels of stigma across all 4 group. Previous research has identified issues regarding perceptions and stigma of patients with SCD in healthcare settings. Specifically, issues involving the subjectivity of pain experiences. Often, individuals with SCD partake in activities that are “inconsistent with the traditional picture of patients in severe pain” (Bergman & Diamond, 2013, p. 4–5). This creates mistrust of patients with SCD, which further impacts the patient experience and overall health. Previous research mentions that Black Healthcare Professionals hold more positive perceptions of minority patients (Haywood et al., 2015). Within this study Black Healthcare Professionals did not necessarily express positive sentiments about SCD and individuals with the disease. They did however discuss cultural responsiveness and highlighted adversity’s faced by Black Americans in the health system, more thoroughly than their counterparts. Cultural awareness and communication skills interventions have been shown to be effective in increasing the confidence of health professionals, reducing mistrust, as well as increasing more empathetic responses (Thomas & Cohn, 2006).

Attitudes and beliefs of healthcare professionals are essential in determining the type of care that patients with SCD receive (Bergman & Diamond, 2013). Participants within this study expressed uncertainty concerning the proper care of patients with SCD. Bergman and Diamond (2013) suggest that “the absence of a cure generates uncertainty as to proper courses of treatment” this could potentially explain why health professionals find it challenging to treat pain and other symptoms (p. 5). Also discussed by participants were concerns related to treating pain and using opioids to do so. This has also been identified in previous research as well (Labbé,
Participants frequently discussed the issue of their not being enough research about SCD; this was discussed in not only the healthcare professional qualitative interviews, but also in the focus group sessions for the other three groups.

**Knowledge Differences**

Participants seem to be more knowledgeable about attributes related to SCD (i.e., pain, genetics, other physical symptoms), than they were more complex issues with SCD and SCT. Latinx Americans were not able to identify these attributes as readily as other groups and often discussed SCD in a manner that identified that they were mostly guessing, uncertainty, or providing answers that they thought were what the researcher wanted to hear. As mentioned in the quantitative section, this lack of knowledge is consistent with prior research (Siddiqui et al., 2011).

Healthcare professionals, however, have more knowledge about health maintenance and treatment of SCD, which is expected because they are able to infer about treatment processes based on their specific medical training and experience. This knowledge is however, limited, and dependent upon experience and expertise or specialty in the medical field. This is consistent with previous research about the perceptions of primary care doctors and nurses. Researchers identified challenges in care of patients with SCD, specifically that the healthcare professionals lacked knowledge about the complexity of the care that patients with SCD require (Gomes et al., 2015; Solomon, 2008). This same research found that healthcare professionals were “not prepared to assist SCD patients” which was related to their “lack of knowledge regarding existing protocols” (p. 249).
Perceptual Differences

Participants primarily talked about perceiving individuals with SCD as normal. Also mentioned were the small differences in their day-to-day life compared to those with SCD or chronic illness. More specifically, that individuals with SCD have more hospital or doctors’ visits, may experience depression or anxiety, and may have to monitor their health in ways that others without this disease do not have to do. Additionally, participants mentioned the impact to interpersonal relationships and work, mostly that it may produce conflict in these areas of life. This is reflective of experiences mentioned by individuals with SCD in past research (Thomas & Taylor, 2002; Matthie, Hamilton, Wells, & Jenerette, 2016).

Black participants used more positive language, specifically referring to individuals with SCD as “strong.” Although participants in other groups did report knowing people with SCD, from the discussions it seemed that Black Americans interacted more intimately with the people that they knew. They described seeing their friends or family in pain and seeing how their friends or family were impacted by SCD, whereas other participants did not describe similar experiences or did not describe them in as much detail.

Implications

Social Ecological Model

Utilizing the social ecological model, developed by Stokols (1996), is beneficial in helping us understand how knowledge can be increased, perceptions changed, and stigma reduced as it applies to SCD in these different populations. The social ecological model identifies how issues are integrative across multiple sectors including at the individual, interpersonal, organizational/community, and societal levels. These levels could also potentially impact public policy as well.
At the individual level it is important to increase knowledge of education; this can be done using a number of educational efforts. Findings from the current study suggest that social media, pamphlets, or community events/forums may be one of the best methods for reaching people. It is especially important for Black and Latinx Americans to be knowledgeable about SCD given that it impacts them at higher rates. Specifically, knowledge of SCD and the genetic characteristics of the disease, particularly how it is passed down is important for 1) decreasing the prevalence of the disease and the trait, 2) increasing the self-efficacy of parents whose newborn may have the disease, and 3) encouraging these communities to learn more about genetic traits and family planning. This is especially important because individuals who identify as non-Black may believe that they are not susceptible to this disease, when in fact they may be (Bediako & Moffitt, 2011). More broadly, increased knowledge across all populations can help to stimulate awareness and saliency, as well as potentially increase funding and research of the disease.

Identifying knowledge, perceptions, and stigma can assist in the development of intervention programs. This study identifies gaps in knowledge and the relationship of knowledge level to stigma. These are areas where interventions can be beneficial to those interpersonally impacted by SCD, meaning, family, friends, spouses, caregivers, and children of individuals that have SCD.

At the organizational level, specifically in the health field, knowledge of SCD is especially important to the care of patients with this disease. Having a holistic approach to patient care is more impactful to and beneficial for positive patient outcomes, than a disease-specific or less person-centered approach. Perception and stigma as mentioned previously, can impact care received, especially with diseases where subjective pain is the most common
symptom, and healthcare professionals have a documented history of having negative perceptions and stigma of patients with SCD (Bediako & Moffitt, 2011). Understanding stigma and perceptions of healthcare professionals can help identify areas were more training (be it technical, cultural, etc.) is needed. It is important for increasing comfortability and trust among patients and providers; which can thereby increase the health and well-being of patients with SCD. This is especially important for patients in the Midwest where SCD is not as prevalent.

At the public policy level SCD is widely screened for across all states as part of a national screening effort; it is also tested for in military and athletic settings (Naik & Haywood, 2015). This is consistent with testing measures identified in focus group sessions within the current study. Naik and Haywood identified inconsistencies in follow-up for individuals who test positive for SCT; again, this is consistent with sentiments expressed by one of the parents who reported that their child has SCT. More rigorous protocols need to be developed in an effort to improve knowledge, perceptions, and stigma related to SCD. Researchers stated that there is significant variability in the way that states approach follow-up notifications after a positive SCT testing. “In this context, SCT screening has been labeled a “neglected opportunity” in its failure to deliver early genetic and reproductive counseling, community empowerment, and greater patient involvement in healthcare decisions (p. 7).” More rigorous protocols need to be developed in an effort to improve knowledge, perceptions, and stigma related to SCD and SCT. Knowing trait status not only increases knowledge, but it can potentially decrease the prevalence of SCD if people are more knowledgeable about how inheritance of SCT and SCD work.

The findings of this study also have important implications for the health and well-being of individuals living with SCD. It’s important, not only to their treatment in healthcare settings, but also their interpersonal and work relationships with others. Individuals with SCD have
reported interpersonal conflict in interpersonal, peer, and work settings. Increasing knowledge could help reduce negative stigmas and perceptions, thereby reducing interpersonal and other relationship conflicts. Understanding health stigma and discrimination of SCD has important implications for research endeavors, interventions, and policy development that can impact the lived experiences of individuals with this disease as well (Stangl et al., 2019). This important to the development of public health initiatives to address chronic illnesses.

Limitations

The self-report method of the survey could have also altered participant responses in regard to the perception questions. This may have influenced people to give what they thought were socially desirable answers. Similarly, the use of a multiple-choice survey design to assess knowledge may have impacted participant responses by making it easier for participants to identify correct responses through elimination of choices. This may have not been readily available knowledge, that if asked differently, would have emerged otherwise. Additionally, more robust and succinct scales and questions need to be developed. A number of the scales were adapted from other scales and this may have interfered with the internal reliability of the scale. However, the reliability did not appear to be influenced by the change in the scale scores.

Quantitative sample sizes of Black and Hispanic American groups were relatively small compared to the other survey groups. A more targeted approach to participant recruitment would have been beneficial in increasing response rates of Black and Hispanic American participants. Thus, it is not clear if this study was able to recruit a representative sample of Black and Latinx communities.

Healthcare Professional interviews, primarily were medical students and nurses, their experience thus far is primarily representative of states that have lower occurrences of SCD
compared to the East, West, and South, which may impact their likelihood of being exposed to patients that present with SCD. Therefore, limiting their knowledge and confidence in treating patients. It would be beneficial to try to increase the number of practicing healthcare professionals, as well as specialty healthcare professionals, to see whether knowledge, perceptions, or stigma levels change for this particular group.

**Recommendations**

There is a dearth in the literature regarding knowledge and awareness in non-Black and non-Hispanic groups. This is an area that could benefit from additional research, specifically, research that identifies why this gap exists and remedies for how this gap in knowledge can be reduced. For healthcare professionals, it would be beneficial to consider developing a “continued education credit” intervention to improve knowledge of healthcare professionals who do not work in specialty hematology clinics or fields. This is especially important for areas with significantly smaller communities of color, such as in the Midwest. Additional training and educational opportunities have been beneficial in increasing knowledge, comfort, and confidence of healthcare professionals (Reeves et al., 2015).

This study revealed that there is a significant need for more knowledge and awareness in Hispanic/Latinx populations within the US. As previously mentioned, there is a significant gap in knowledge, perceptions, and stigma between this population and the other populations represented in this study. Future research could continue to explore where these knowledge gaps are, why they exist, and how they could be further remedied. This is especially important with this population having the second highest prevalence rate in the United States. It would also be of interest to examine the differences between genders regarding knowledge, perceptions, and stigma. This would allow for more targeted approaches to increasing knowledge, and reducing
negative perceptions and stigma. Updating policies related to SCD and SCT testing and follow-up is also needed in order to address gaps in knowledge.

Specific strategies for raising awareness included the mention of social media, pamphlets, and community forums, events, or focus groups. Further research could be beneficial, if explored, especially for other rare diseases that predominantly affect populations not considered the “majority.” Previous research has shown that Black Americans prefer to learn about SCD through pamphlets or educational meetings (Boyd et al., 2005). It would be important to assess, in greater detail, whether this translates to other communities and actually increases knowledge.

Conclusion

SCD is a rare disease across the U.S. population, however SCT is more common than the disease. It is important for individuals with an increased possibility of having a child with SCD or SCT to be knowledgeable about disease specifics, and be more understanding of the impacts, both medically and personally, that this disease can have on the lives of those who live with it.

There is a need for healthcare professionals who lack SCD expertise to be knowledgeable about the disease in an effort to increase in health in places where the disease is less common, such as the Midwest. This is especially true in healthcare settings where SCD is often stigmatized. Raising awareness can improve health-related stigma, thereby improving health related outcomes of individuals living with this disease. Additionally, increases in knowledge has important implications for research, funding, and the overall well-being of individuals with SCD (currently and in the future), not just medically, but interpersonally as well. This mixed-methods approach has shed light on the gaps that need to be examined within the community to improve the lives of individuals living with SCD.
REFERENCES
REFERENCES


Appendix A: Survey Questions

Assessing the Knowledge, Perceptions, and Attitudes about Sickle Cell Disease in Healthcare Professionals, Black American, Latinx American, and Other Populations within the Midwest

What is your age? ______________

What do you identify as?

- Male
- Female

What is your race?

- Black/African American
- Indian/Alaskan
- Hawaiian/Pacific Islander
- White
- Other, please specify ________________

Are you Hispanic or Latino?

- Yes
- No

What is your income?

- Less than $10,000
- $10,001-$20,000
- $20,001-$30,000
- $30,001-$40,000
- $40,001-$50,000
- $50,001-$60,000
- $60,001-$70,000
- $70,001-$80,000
- $80,001-$90,000
- $90,001-$100,000
- $100,000 or more
- I don’t know
- Prefer not to answer

What is your marital status?

- Single
- Married
- Divorced
- Living with steady partner
- Widowed
- Prefer not to answer

What is your highest education level achieved?

- Less than high school
- High school diploma, GED
- Some college, No degree
- Trade/Technical school
- Associate Degree
- Bachelor’s Degree
- Master’s Degree
- Doctorate/Professional Degree

Please indicate which of the following states you live in.

- Illinois
- Indiana
- Iowa
- Kansas
- Michigan
- Minnesota
- Missouri
- Nebraska
- North Dakota
- Ohio
- Oklahoma
- South Dakota
KNOWLEDGE

Can people with sickle cell disease be physically active?
☐ Yes
☐ No

Can people with sickle cell disease outgrow the disease?
☐ Yes
☐ No

Sickle cell disease is a(n)
☐ Infection or virus
☐ Blood Disease
☐ Heart Disease

Sickle cell disease can be transmitted through ___.
☐ contact with infected blood
☐ genetics
☐ saliva

Which is true about sickle cell disease?
☐ There are many different forms of the disease
☐ There is only one form of the disease
☐ There are two forms of the disease

People with sickle cell trait ___.
☐ have a mild form of the disease
☐ are not affected at all
☐ can develop the disease if they are not treated

Sickle cell disease makes red blood cells ___.
☐ hard and “C” shaped
☐ sticky and blue
☐ stiff and round

Which of the following statements are NOT true?
☐ Sickle cell causes a lot of pain
☐ Sickle cell disease can skip generations
☐ Both a and b

Which is true about sickle cell disease?
☐ Sickle cell can only be treated through blood transfusions
☐ There are multiple ways to treat sickle cell
☐ Sickle cell cannot be treated
TRAIT-SPECIFIC KNOWLEDGE

Do you know whether you have sickle cell trait?
☐ Yes, I have the trait
☐ Yes, I do not have the trait
☐ No, I do not know my status

When/How did you become aware of your trait status?
☐ Pregnancy screen
☐ After my child had a positive newborn screening
☐ Childhood testing, age unknown (“my parent told me”)
☐ I don’t know my status
☐ Other, please specify ________________________________

Do you have a child with sickle cell disease?
☐ Yes
☐ No

Do you have a child with sickle cell trait?
☐ Yes
☐ No

Where did you learn about sickle cell disease from?
☐ Friends/family
☐ Science course
☐ Social media
☐ Internet
☐ Healthcare professional
☐ Other please specify ________________________________
☐ N/A

PERCEPTIONS

Please answer the questions below about how likely patients with sickle cell are to do the following:

<table>
<thead>
<tr>
<th></th>
<th>Very Likely</th>
<th>Somewhat Likely</th>
<th>Neither Likely nor Unlikely</th>
<th>Somewhat Unlikely</th>
<th>Very Unlikely</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abuse drugs and alcohol</td>
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<tr>
<td>Fail to comply with medical advice</td>
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</tr>
</tbody>
</table>

108
**SICKLE CELL DISEASE IN THE MIDWEST**

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Somewhat Agree</th>
<th>Neither Agree nor Disagree</th>
<th>Somewhat Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly desire a very physical active lifestyle</td>
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<td>Lack social support</td>
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<tr>
<td>Have a lower socioeconomic status</td>
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<td>Rate how strongly you agree or disagree with the following statements:</td>
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<tr>
<td>Sickle cell disease can impact a child’s school performance</td>
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<td>Sickle cell disease can impact an individual’s pain levels, which may require hospitalization</td>
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<tr>
<td>Sickle cell disease can cause life threatening infections</td>
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<tr>
<td>Sickle cell disease is a serious disease</td>
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<tr>
<td>Having a child with sickle cell disease would be very scary</td>
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<tr>
<td>My life would change if I had a child with sickle cell disease</td>
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<tr>
<td>Sickle cell disease could happen in my family</td>
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<tr>
<td>It is useful to know whether I have the sickle cell trait</td>
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<tr>
<td>It is useful to know whether my partner has the sickle cell trait</td>
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</tbody>
</table>
Knowing the risk of having sickle cell disease would change how I plan a pregnancy

My partner would be hard to convince to be tested

I would not want to pay for sickle cell trait testing if it is not paid for by insurance

<table>
<thead>
<tr>
<th>Only African Americans get sickle cell disease</th>
<th>Strongly Agree</th>
<th>Somewhat Agree</th>
<th>Neither Agree nor Disagree</th>
<th>Somewhat Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I can tell when someone has sickle cell disease</td>
<td></td>
<td></td>
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<tr>
<td>People with sickle cell disease can live long healthy lives</td>
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</tbody>
</table>

Does sickle cell disease affect your racial group?
- Yes
- No

Rate how strongly you agree or disagree with the following statements:

<table>
<thead>
<tr>
<th>People with sickle cell disease cannot live normal lives</th>
<th>Strongly Agree</th>
<th>Somewhat Agree</th>
<th>Neither Agree nor Disagree</th>
<th>Somewhat Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>People with sickle cell disease are not able to go to school or work full-time</td>
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<tr>
<td>A person with sickle cell disease is accountable for their condition</td>
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</tr>
<tr>
<td>Statement</td>
<td>Strongly Agree</td>
<td>Somewhat Agree</td>
<td>Neither Agree nor Disagree</td>
<td>Somewhat Disagree</td>
<td>Strongly Disagree</td>
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<tr>
<td>Sickle cell disease usually ruins close personal relationships</td>
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<tr>
<td>Sickle cell disease devastates the lives of those it touches</td>
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<tr>
<td>I would feel comfortable around someone with sickle cell disease</td>
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<tr>
<td>I would try to avoid someone with sickle cell disease</td>
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<tr>
<td>I would find it difficult being around someone with sickle cell disease</td>
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<tr>
<td>I would find it hard to talk with someone with sickle cell disease</td>
<td></td>
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</tr>
<tr>
<td>The needs of people with sickle cell disease should be given top priority</td>
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<tr>
<td>More government funding should be spent on the care and treatment of those with sickle cell disease</td>
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</tr>
<tr>
<td>We have a responsibility to provide the best possible care for people with sickle cell disease</td>
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<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

Rate how strongly you agree or disagree with the following statement:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Somewhat Agree</th>
<th>Neither Agree nor Disagree</th>
<th>Somewhat Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>It is acceptable for insurance companies to reconsider a policy if</td>
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</tbody>
</table>
someone has sickle cell disease

**Would you like to be contacted to participate in a future focus group or interview?**
☐ Yes  ☐ No

**What is the best email/phone to contact you at?**

Email _________________________________
Appendix B: Focus Group Questions

<table>
<thead>
<tr>
<th>Focus Group Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Black, Latino, and Other Populations</strong></td>
</tr>
<tr>
<td>What first comes to mind when you think of sickle cell?</td>
</tr>
<tr>
<td>What do you know about sickle cell disease?</td>
</tr>
<tr>
<td><em>Probe:</em> How do people get it? What are the symptoms of sickle cell disease? What does someone with sickle cell disease look like? Is sickle cell a rare disease? Where did you learn about sickle cell disease?</td>
</tr>
<tr>
<td>Who gets sickle cell disease?</td>
</tr>
<tr>
<td><em>Probe:</em> Are there any other races or ethnicities that experience sickle cell disease?</td>
</tr>
<tr>
<td>Do you know anyone with sickle cell disease?</td>
</tr>
<tr>
<td><em>Probe:</em> What is it like for them living with sickle cell disease? How are their lives different than yours? How are they the same?</td>
</tr>
<tr>
<td>Is sickle cell disease talked about in the media?</td>
</tr>
<tr>
<td><em>Probe:</em> What have you seen in the media about sickle cell disease? Are there any groups or individuals advocating on behalf of individuals with sickle cell disease?</td>
</tr>
<tr>
<td>How can awareness about sickle cell disease be increased in your community?</td>
</tr>
<tr>
<td><strong>Healthcare Professionals</strong></td>
</tr>
<tr>
<td>What first comes to mind when you think of sickle cell?</td>
</tr>
<tr>
<td>What do you know about sickle cell disease?</td>
</tr>
<tr>
<td><em>Probe:</em> How do people get it? What are the symptoms of sickle cell disease? What does someone with sickle cell disease look like? Is sickle cell a rare disease?</td>
</tr>
<tr>
<td>Who gets sickle cell disease?</td>
</tr>
<tr>
<td><em>Probe:</em> Are there any other races or ethnicities that experience sickle cell disease?</td>
</tr>
<tr>
<td>Has anyone ever had patients with sickle cell disease?</td>
</tr>
<tr>
<td><em>Probe:</em> When was the last time you had a patient with sickle cell disease? How frequently do you see or interact with patients with sickle cell disease? How are your patients with sickle cell disease different from the other patients you see? How are they similar? (If no) Why do you believe that you don’t have many patients with sickle cell disease?</td>
</tr>
<tr>
<td><em>Probe:</em> Would you consider taking sickle cell patients in the future?</td>
</tr>
<tr>
<td>What do you think is the biggest challenge to taking care of someone with sickle cell disease and why?</td>
</tr>
<tr>
<td>How does race affect the management and treatment of sickle cell disease? Why or why not?</td>
</tr>
<tr>
<td>Do other health professionals know enough about sickle cell disease? Why or why not?</td>
</tr>
<tr>
<td>Why might the term “sicklers” be used in medical settings?</td>
</tr>
<tr>
<td><em>Probe:</em> Where did that term come from? Why is it used? Is it patient-centered?</td>
</tr>
<tr>
<td>What have you seen in the media about sickle cell disease? Are there any groups or individuals advocating on behalf of individuals with sickle cell disease?</td>
</tr>
<tr>
<td>What can be done to increase the health and well-being of individuals with sickle cell disease in the Midwest?</td>
</tr>
</tbody>
</table>
Appendix C: Flyers and Letters of Support

WICHITA STATE UNIVERSITY

STUDY OF KNOWLEDGE, PERCEPTIONS, AND ATTITUDES ABOUT SICKLE CELL DISEASE

We're looking for individuals who are 18+, fluent in English, and lives in Kansas to participate in our survey.

The survey is available online or in-person on paper. It will take approximately 20 minutes to complete.

If you are interested please contact Paignton Mayes at plmayes@shockers.wichita.edu

Scan this QR code with your smartphone camera to open the survey
SICKLE CELL DISEASE IN THE MIDWEST

WICHITA STATE UNIVERSITY

STUDY OF KNOWLEDGE, PERCEPTIONS, AND ATTITUDES ABOUT SICKLE CELL DISEASE

We're looking for Health Professionals or Students who are 18+, fluent in English, and lives in Kansas to participate in our survey.

The survey is available online or in-person on paper. It will take approximately 20 minutes to complete.

If you are interested please contact Paligton Mayes at plmayes@shockers.wichita.edu

Scan this QR code with your smartphone camera to open the survey
February 25, 2019

To Whom It May Concern,

This letter is in support of Wichita State University doctoral candidate Paigton Mayes’ project titled “Assessing the Knowledge, Perceptions, and Attitudes of Sickle Disease in Healthcare, Black and Latinx American, and General Populations within the Midwest”.

The study aims to assess the knowledge, perceptions, and attitudes related to sickle cell disease. In assessing these areas Ms. Mayes hopes to learn more about individual’s understanding of sickle cell disease and trait, including facts about who the disease affects, how it manifests, its complications, health-related stigma, and overall perceptions. Identifying this information will guide and further research, and will help researchers understand how aware these different populations are about a disease that affects approximately 100,000 individuals in the U.S.

Myself, and the Department of Family and Community Medicine, support Paigton’s efforts regarding the evaluation of medical students’ knowledge, perceptions, and attitudes about sickle cell disease. We will provide support in recruiting students at the University of Kansas School of Medicine to complete this survey, as well as any other instrumental support we can provide in making her project a success.

Thank you,

Kari M. Nilsen, PhD
Education Assistant Professor
Director of Resident and Medical Student Research
Dept. of Family & Community Medicine
KU School of Medicine- Wichita
1010 N. Kansas, Wichita, KS 67214-3199
316.293.1894
knilsen@kumc.edu
February 28, 2019

To Whom it May Concern,

On behalf of the Medical Society of Sedgwick County (MSSC), I want to express my support for doctoral candidate Paignton Mayes’ sickle cell disease project for a community based participatory research survey. As I understand, this project will be surveying healthcare professionals as one of the targeted groups on the knowledge, perceptions and attitudes of this particular disease.

With the community group, and physician input and feedback, Ms. Mayes will learn facts on the sickle cell disease and what patients may endure as symptoms. We hope with her research, perhaps it can assist clinical researchers as this affects a limited population throughout the United States.

As the executive director of the MSSC, which consists of more than 90 percent of physicians in our county, I will be happy to respond to the request to send this survey to physicians who are treating patients with this disease within our population. We are able to assist by sending the survey to family medicine, internal medicine and pediatric physicians within our membership to obtain information regarding this project.

I support this Ms. Mayes’ project and look forward to the MSSC’s involvement.

Sincerely,

[Signature]
Phillip Brownlee
Executive Director
Medical Society of Sedgwick County