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Sickle Cell Disease (SCD) Knowledge, Perceptions, and Attitudes of Undergraduate Students at a Historically Black College or University

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Abstract

Background: Sickle cell disease (SCD), a global health problem despite advances in screening and management, has remained a challenge due to deficient knowledge of sickle cell trait status (SCT) which perpetuates the disease. This study aims to add to the literature of primary prevention strategies through a more feasible and cost-effective approach towards facilitating young black adults' awareness of their hemoglobin genotype.

Methods: Using self-administered questionnaire via Survey Monkey, quantitative descriptive data were collected on the knowledge, perceptions, and attitudes towards SCD from a convenience sample of 111 undergraduate students at a Historical Black College and University (HBCU). The data were analyzed with descriptive statistics, t-tests for independent samples, as well as regression and clustering analysis for further descriptive and tested relationships.

Results: 92.4% of the subjects have moderate knowledge of SCD. However, only 18.9% knew their genotype. Knowledge and attitude of SCD were significantly related to subject's choice of a life partner ($p<0.05$). Knowing genotype status was the only significant predictor of knowledge of SCD ($p=0.033$), with 17.24% of students having higher knowledge and attitude toward the SCD cluster compared to only 8.38% of students with lower knowledge and attitude toward the SCD cluster.

Conclusion: The study results reaffirm findings of previous research studies regarding deficient knowledge of hemoglobin genotype status and need for grassroot SCD education among affected groups. Recommendations include hemoglobin genotype status in the applicable groups' admission criteria into high school and higher education. Knowledge of one's SCT and genotype inheritance patterns are essential steps in the prevention of SCD.

Keywords: Hemoglobin genotype, sickle cell trait, sickle cell disease, reproductive decisions, primary prevention.

Introduction

Sickle cell disease (SCD), with its myriad physiological and psychosocial global health problems, is better prevented than managed through knowledge of one's sickle cell trait status. Related literature abundantly noted that knowledge deficit of Sickle cell trait (SCT) and inheritance issues are implicated in the continued prevalence of SCD and the need for the most impactful use of resources to increase awareness of sickle cell trait status [1-5]. This study affirms Arhin's [2] assertion that, being on the front line of health care, nurses, with their tools and experiences to effectively handle case management and patient education, can champion the primary prevention of SCD. In addition, the study provides a new approach for nurses to reach the susceptible population through timely, targeted, empowering educational interventions in high schools, higher education, and black community faith-based organizations.

SCD, initially prevalent in Africa and parts of the Mediterranean, is currently a global health problem due to immigration [6, 7]. An autosomal recessive inherited disorder such as SCD requires two copies of the sickle hemoglobin gene to develop the disorder. The main types of sickle cell disease with varying degrees of vaso-occlusive crisis include hemoglobin SS (HbSS), hemoglobin SC (HbSC), and hemoglobin S beta-thalassemia. HbSS also known as sickle cell anemia, is the most severe and common form and occurs when a person inherits two hemoglobin S genes (one from each parent). HbSC which causes a milder form of anemia and fewer complications than HbSS occurs when a person inherits one hemoglobin S gene and one abnormal hemoglobin C gene. Hemoglobin S beta-thalassemia occurs when a person inherits one hemoglobin S gene and one gene for beta-thalassemia [8].

In the United States, SCD continues to be perpetuated due to a knowledge deficit of Sickle cell trait (SCT) status and inheritance issues despite the implementation of Universal newborn screening for SCD and SCT in all hospitals nationwide since the 1970s [2]. People with SCT (carriers of the sickle hemoglobin gene) usually are asymptomatic, which offers minimal opportunity for diagnosis and genetic counseling before pregnancy and childbirth, hence perpetuating the passing on of the trait or SCD to their offspring [2]. In 2019, of the 33,404 sickle cell trait births in Michigan, 80.2% of SCT cases were among children who were Black [4]. Generally, SCD occurs in about 1 out of every 365 Black or African American births and about 1 out of every 16,300 Hispanic American births. Thus, after African Americans, Latinx is the second-largest population affected by SCD in the U.S., and the Latinx number is expected to grow, thus the need for intervention [9, 10]. About 1 in 13 Black or African American babies is born with sickle cell trait.

In recent years, significant advancements have been made in developing new therapies and curative treatments for SCD. These include gene therapy approaches and novel medications aimed at reducing symptoms and improving the quality of life for patients [11, 12]. However, these treatments are often expensive and not widely accessible, especially in developing countries with limited resources and funding. Knowledge of SCD and one's genotype status through the school system and other strategic places is an essential route to the way of preventing and controlling SCD, as susceptible young adults will be better equipped to make informed decisions concerning their partners [3, 13, 14]. Choices to prevent potential offspring from a life with SCD stem from knowledge of one's genotype. Knowledge, perception, and attitudes toward SCD among Historically Black Colleges or Universities (HBCUs) undergraduate students are crucial because these students are not only future leaders, healthcare professionals, and community advocates but also have the potential to significantly influence public health outcomes and drive support initiatives through their understanding of SCD.

SCD is a debilitating chronic disease with economic, social, physical, and psychological burdens on individuals, their families, healthcare institutions, and society at large. In a study on the burden of sickle cell disease in Saudi Arabia, Bin Zuair et al. [15] noted substantial observations regarding the catastrophic effect of SCD on patients' lives, with significant financial strains and academic underachievement. Continuing, the authors reported that the nature of the disease, with recurrent vaso-occlusive crises, complications, admissions, and lengthy hospital stays, has a tremendous impact on patients living with SCD. This burden affects the patient's family members' financial, social, and psychological lives. Similarly, findings from the International Sickle Cell World Assessment Survey (SWAY) reaffirm that a substantial proportion of patients with SCD experience a significant effect on their daily life activities, emotional well-being, employment, education, social life, and relationships [16]. Cardiopulmonary and renal end-organ (CPR) complications are associated with early mortality among individuals with SCD [17]. Pain, the hallmark sign and symptom of SCD, results from the constant sickled red cell membrane disruption leading to hemolytic anemia, vaso-occlusion, and tissue ischemia or infarction with a significant impact on morbidity and mortality [7, 18]. The pain intensity is very excruciating, described by participants as unimaginable, agonizing, continuous, inescapable, and limitless pain, which was almost impossible to describe [19].

Adequate knowledge, perceptions, and attitudes of susceptible young adults toward SCD can enhance genetic counseling for efficient marital relationships and safe reproductive decisions. Currently, SCD has few cost-effective treatment options. Stem cell transplant remains the only approved curative treatment for SCD, but new clinical trials are being initiated using gene therapy to add a new healthy gene, gene editing to upregulate fetal hemoglobin, or gene editing to correct the point mutation [12]. In a study by the authors on Treatment decision-making in sickle cell disease patients, participants generally agreed that the four treatment options are beneficial but were more mixed in their thoughts on whether the options are dangerous.

In a similar study assessing knowledge and beliefs toward SCD and reproductive decisions, Alsalman et al. [11] noted that participants' decisions about choosing future partners were more likely to be affected among those with prior knowledge about the disease (p=0.008). In addition, 152 (91.6%) male participants with prior knowledge would change their decision about selecting a future partner compared to 225 (92.4%) female participants. The authors concluded that prevention is the key to reducing the economic, physical, and psychological burdens of the costly management and curative options of SCD. They highlighted the importance of premarital counseling for individuals with the disease and carriers, including alternative reproduction options. Similarly, in a study on reproductive intentions in mothers of young children with sickle cell disease, Schultz et al. [5] found that with the variable acceptability of alternative reproductive options available to decrease the risk of a future child having SCD, participants universally endorsed the need for education regarding hemoglobinopathy status, SCD, and reproductive options before pregnancy. Many participants reflected that the risk of having a child with SCD affected their reproductive intentions. Eight parents chose to have no further children because of fear of SCD in another child, leading the authors to conclude that educational interventions to ensure informed reproductive decision-making should be sensitive to desires for a biological child with ethical and financial considerations.

The above review affirmed related literature positions on the high prevalence and occurrence of SCD in Black communities, the costly and limited accessible management and treatment options, and most importantly, the persistent gap in deficient knowledge of SCT status among susceptible adults. However, despite these studies and advanced management strategies, little has been documented around primary prevention of SCD, especially among young adults. In grassroots prevention strategies, young adults' knowledge of their genotype and SCD inheritance pattern is a necessary first step in prevention and a good entry point for disease prevention interventions [14].

This cross-sectional descriptive study explores the knowledge, perception, and attitude of SCD among undergraduate students in HBCU in the USA. In addition, the study hypothesized that young adults' knowledge, perception, and attitude toward SCD will influence their choice of a life partner. The study's claim of significance is literature, subject, findings and implementation based.

Materials and Methods

Research design and participants

The design is cross-sectional descriptive research. With the permission of the primary author, data were collected with slight modifications of Boadu & Addoah's [13] undergraduate students SCD knowledge and perceptions' self-administered survey questionnaire. The survey instrument was a 35 binary and Likert scale SCD self-administered questionnaire items on knowledge, perception, and attitude toward SCD through SurveyMonkey online and in-person formats.

Participants were undergraduate students aged 18 years and above who were either participating in the Summer Undergraduate Research Institute (SURI) program or enrolled in Summer Sessions I, II, and III courses at the University. In the University SURI program, faculty members conduct research projects that provide hands-on research experience or creative work participation to students. SURI supports undergraduates enrolled at the university to engage in original research or creative work under the guidance of a faculty mentor, to support faculty- based research. The nine consecutive week summer

program requires participation in program orientation/training, bi-weekly research forums and a culminating research symposium for students and faculty to present their research in the form of a poster or creative product resulting from the original research.

SURI program eligibility for faculty entails completing an application that outlines the planned research project and demonstrates involvement of one or more students from any major that aligns with the faculty's research. In addition, faculty mentor formally accepts students to carry out the summer research activity and provides one letter of recommendation per student, which will evaluate the student's performance to date, and their capacity to complete the proposed activities. Faculty must be available to participate in all required program components throughout the summer. Students must be degree-seeking undergraduates at the university at the time of application. Each student receives a stipend of up to $3,500 and faculty mentors up to $1,500 per student mentored (no more than 3 students). Faculty mentors receive a funding allocation of $250 per student mentored for supplies and to support each proposed project. Three undergraduate students working with the primary faculty researcher during the 2019 SURI program collected the SCD data from the target population of 1,109 undergraduate students enrolled in summer classes as well as participants in the SURI program. A convenience sample of 111 students was surveyed to provide insights into the student body's current understanding and attitudes toward SCD.

Ethical Considerations

The study was approved by the University Human Research Ethics Committee (IRB Number 019-0112) on March 30, 2019. Following IRB approval and before completing the survey, participants were directed to sign the written informed consent and complete the survey questionnaire if they were at least 18 years of age and voluntarily agreed to participate.

Data cleaning and analysis

The study used SPSS (Statistical Package for Social Sciences) version 25 and R Studio to conduct descriptive and inferential statistics of the study research questions and hypotheses. In addition, advanced statistical analyses, including regression and clustering analysis, were used to further test relationships. Before analysis, to improve the quality of the dataset for better results, participants' responses were cleaned by filtering responses for completeness, identifying and removing incomplete responses, and removing others not aligned with the aim of the study. The cleaned data were categorized and coded.

To compute the SPSS, descriptive responses were given a numeric value scored between 1 and 5 based on the 5-point Likert scale. Scores for the variables of the study were for the 16 knowledge questions with scores ranging from 16-80, three perception questions with scores ranging from 3-15, and six attitude questions with scores ranging from 6-30. Knowledge of subjects was ranked on a scale of low, moderate and high related to the understanding of genotype, inheritance pattern, treatment and diagnosis of SCD. Perception was determined by beliefs of nonscientific influences of SCD such as religious notions versus scientific causes of SCD. Lastly, attitudes towards SCD were measured by their level of concern for SCD when making reproductive decisions.

Table 1 presents the demographic characteristics of the study participants. A total of 111 individuals participated in the study. Regarding relationship status, most subjects reported being single (57.3%), followed by those in a relationship (25.4%), while 17.3% were married. In terms of ethnicity, most participants identified as African American (87.4%), representing the largest proportion of the sample. Smaller percentages of participants identified as Asian American (6.4%), Hispanic American (3.6%), and Caucasian (1.8%). Overall, the sample was predominantly African American and largely comprised of individuals who were single. For the study hypothesis, with a Significance level of $p<0.05$, the independent-samples t-test statistical method was used due to different people providing scores for each variable to determine if the young adults' knowledge, perception, and attitude influenced their choice of a life partner. In the second stage of the analysis, regression analysis was considered to identify significant predictors of knowledge and attitudes toward SCD. In addition, to complement the regression findings, K-means clustering analysis was used to reveal patterns in knowledge and attitudes toward SCD.

Characteristics	All
Number	111
Relationship Status, n (%)	
Single	57.3%
In a Relationship	25.4%
Married	17.3%
Ethnicity, n (%)	
African American	87.4%
Asian American	6.4%
Hispanic American	3.6%
Caucasian	1.8%

Table. 1: Demographic Characteristics of Study Participants

First, the relationship between knowledge of SCD and known genotype status and inheritance patterns was analyzed using an independent t-test. The result, presented in Table 2, with a significance level of 0.000 (less than the 0.05 threshold), supported a significant relationship. This suggested that individuals' knowledge of SCD was meaningfully related to their understanding of genotype status and inheritance patterns.

Next, the study examined the perception of SCD in relation to known genotype status and inheritance patterns. Again, an independent t-test was conducted and presented in Table 2, but the significance level was 0.063 (greater than 0.05) this time. The lack of significance led to the conclusion that perception did not show a meaningful relationship with genotype status and inheritance patterns.

The attitude towards SCD was also explored in relation to known genotype status and inheritance patterns. The statistical test revealed a significance level of 0.000, indicating a strong, significant relationship. This suggested that individuals' attitudes towards SCD were significantly related to their knowledge of genotype status and inheritance patterns. When considering the combined effects of knowledge, perception, and attitude towards SCD in relation to known genotype status and inheritance patterns, the analysis presented in Table 2, showed a significance level of 0.051, which is slightly above the 0.05 threshold. As a result, this combination of factors was not found to have a significant relationship with genotype status and inheritance patterns.

In summary, data analysis revealed that while knowledge and attitude towards SCD were significantly related to known genotype status and inheritance patterns, perception alone was not. The research suggests that understanding and attitudes toward SCD are more closely linked to genotype knowledge than perceptions of the disease.

Variables	Statistical Test	Significance Level <0.05%	Conclusions
Knowledge of SCD in relation to known genome status and inheritance pattern	Independent T-test	.000	Supported
Perception of SCD in relation to known genome status and inheritance pattern	Independent T-test	.063	Not Supported
Attitude towards SCD in relation to known genome status and inheritance pattern	Independent T-test	.000	Supported
Together, knowledge, perception, and attitude towards SCD in relation to known genome status and inheritance pattern	Independent T-test	.051	Not Supported

Table 2. Research Hypothesis

To control for the potential inflation of Type I error due to multiple comparisons, Bonferroni correction for the four t-tests was conducted. The adjusted significance threshold was $p < 0.0125$. Results indicated that the knowledge of SCD was significantly related to the awareness of genotype and inheritance patterns ($p<0.000$), which is well below the adjusted threshold. Attitudes towards SCD also showed a significant relationship with genotype knowledge ($p<0.000$), maintaining significance well below the adjusted threshold. However, the relationship between perception of SCD and genotype knowledge was not significant after correction ($p=1.000$). Additionally, the combined measure of knowledge, perception, and attitude towards SCD in relation to known genotype status and inheritance pattern was not significant after the Bonferroni correction ($p=0.204$). To further explore these tested relationships, regression analysis was conducted to identify significant predictors of knowledge and attitudes of SCD because both were found to be significant, and a clustering analysis to uncover distinct patterns in data. The regression analysis revealed that the Knows Genotype variable was the only significant predictor of Knowledge of SCD ($\beta= 8.6157$, $p=0.0349$), while other demographic variables such as gender, marital status, and religion were not significant predictors ($p>0.05$). The model explained 9.6% of the variance ($R^2= 0.09563$). This suggests that awareness of genotypes could play a vital role in determining knowledge of SCD outcomes.

To complement the regression results, a K-means clustering analysis was used, focusing on knowledge and attitudes of SCD variables. The analysis shown in Figure 3 identifies two clusters. Cluster 2 represents students with higher knowledge of SCD and higher attitudes towards SCD. However, Cluster 1 represents students with lower knowledge of SCD and lower attitudes toward SCD.

Results

Based on the study's research question and hypothesis, 92.6% of subjects have moderate knowledge of SCD. However, only 18.9% knew their genotype. Knowledge and attitudes toward SCD were significantly related to knowledge of genotype and inheritance patterns, subsequently influencing the subjects' choice of a life partner ($p<0.05$).

Figure 1 presents key findings on undergraduate students' knowledge, perception, and attitude toward Sickle Cell Disease (SCD). The data is presented in a bar graph, categorizing the students into high, moderate, and low percentages.

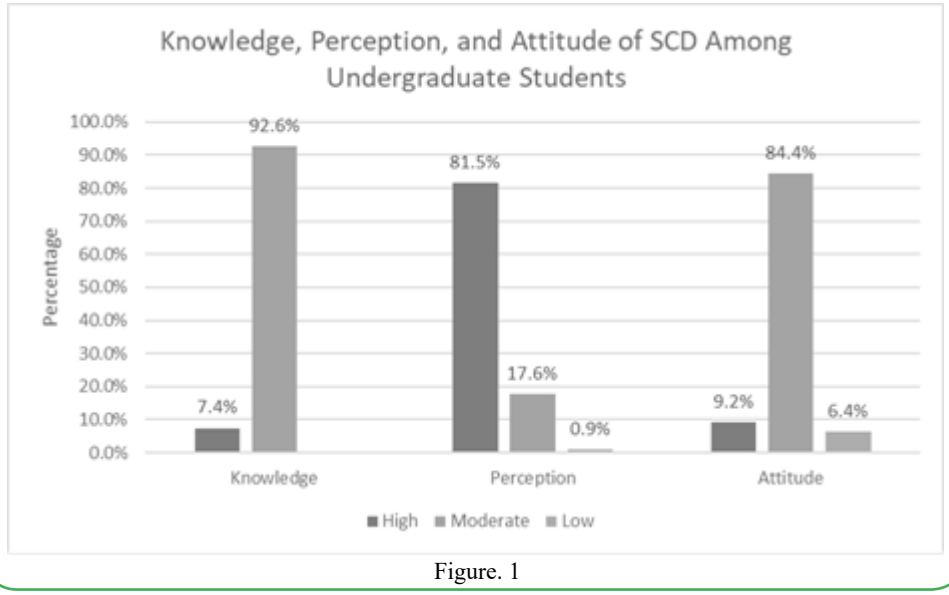


Figure. 1

Knowledge: Most students (92.6%) demonstrate a moderate level of knowledge about SCD. A small portion (7.4%) shows a high level of knowledge, while none fall into the low knowledge category, indicating a generally well-informed student body.

Perception: The perception of SCD among students shows a different trend, with the majority (81.5%) having a high perception. 17.6% of the students have a moderate perception, and a very small percentage (0.9%) have a low perception.

Attitude: The attitudes towards SCD are fairly distributed across the spectrum. Many students (84.4%) exhibit a moderate attitude, indicating a balanced understanding. A small percentage (9.2%) demonstrate a high attitude, and an even smaller group (6.4%) have a low attitude towards the disease.

Findings indicate that undergraduate students generally have moderate knowledge and attitudes toward SCD, reflecting a balanced understanding. However, their perception of the disease tends to be higher, suggesting a need for further education and awareness.

Figure 2: The bar graph visually represents study survey findings on individuals' knowledge of genotype status and family inheritance of Sickle Cell Disease (SCD) and Sickle Cell Trait (SCT). The categories of knowledge are represented by the percentage of individuals who are aware ('Yes') versus unaware ('No') in three distinct areas: knowing genotype status, the presence of SCD in the family, and the presence of SCT in the family.

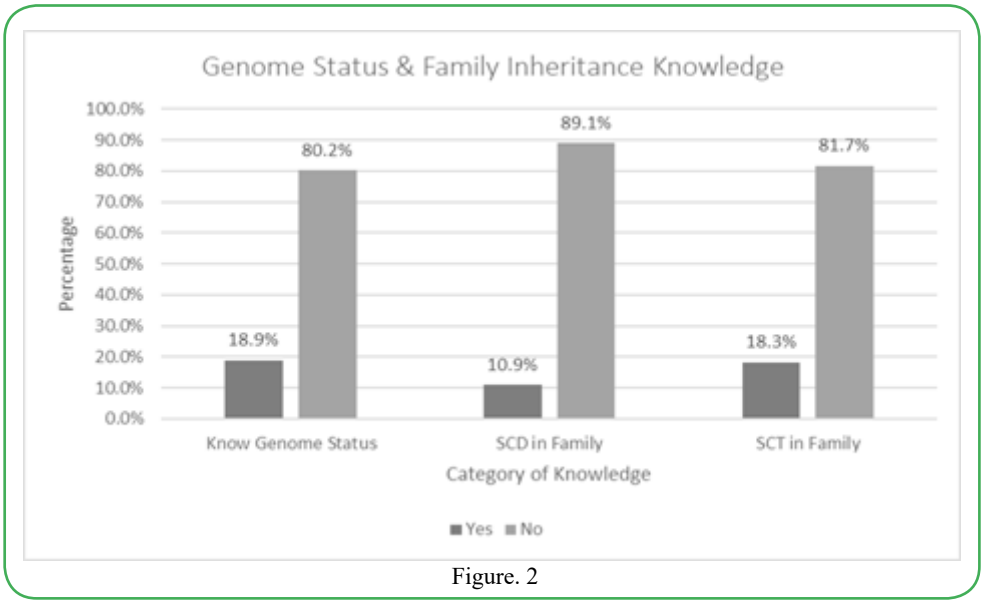


Figure. 2

These findings highlight significant concerns for healthcare professionals, genetic counselors, and policymakers. The data reveal that 80.2% of individuals surveyed are unaware of their genotype status, a crucial aspect of managing genetic health. With only 18.9% possessing this knowledge, there is a clear need for more proactive measures and programs to improve genetic health management. Equally concerning is the fact that only 10.9% of individuals know that SCD is present in their family, while a vast majority (89.1%) are unaware. This significant gap suggests a need for families to increase communication and understanding about these conditions as a vital step in managing genetic health. Regarding the presence of SCT in the family, 18.3% of individuals are aware of SCT, whereas a larger majority (81.7%) are not.

The graph not only underscores the general need for greater awareness among individuals about personal genotype status and family inheritance of SCD and SCT but also presents an opportunity for healthcare professionals, genetic counselors, and policymakers to address this awareness gap and improve healthcare outcomes for individuals living with SCD.

Figure 3: K-means Clustering of SCD Survey Data. Interestingly, Cluster 2 has a slightly higher proportion of students who are aware of their genotype (17.24%) compared to those in Cluster 1 (8.38%). This slight difference in genotype awareness aligns with the regression results. Even a small increase in the proportion of students who are aware of their genotype could contribute to the higher knowledge observed in Cluster 2.

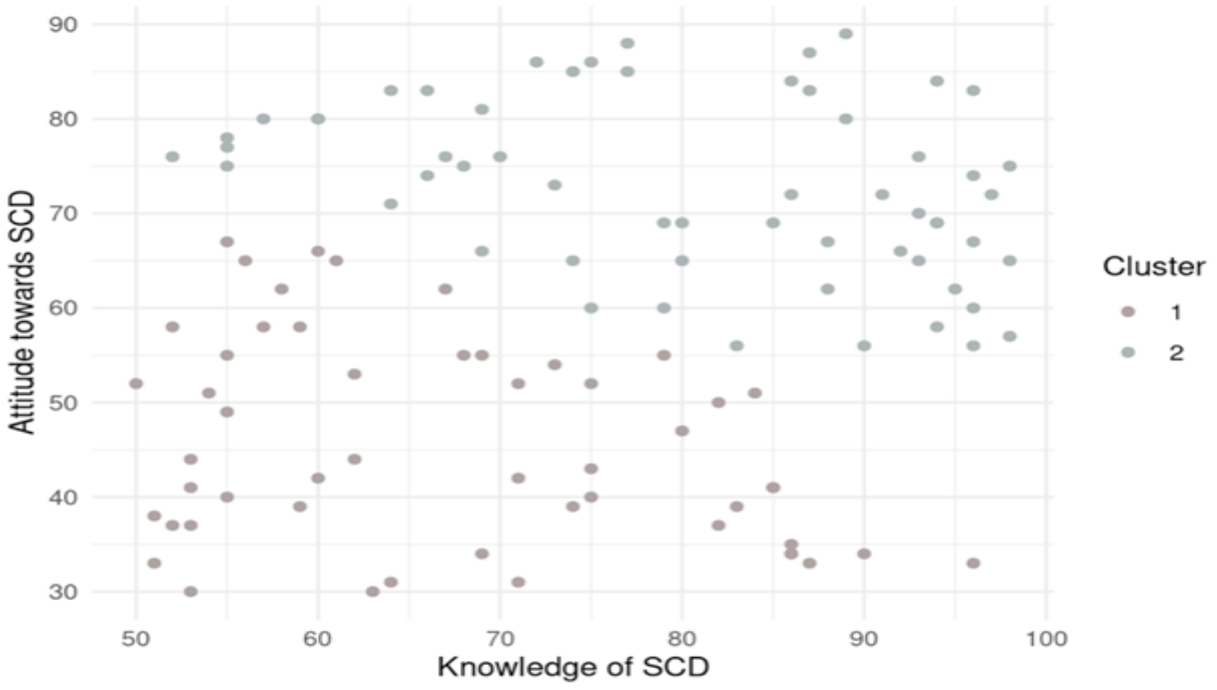


Figure 3: K-means Clustering of SCD Survey Data

Discussion

As the prevalence of SCD grows in the United States, knowledge and awareness become increasingly important in primary prevention, specifically, which actions can be taken to prevent the disease from occurring in the first place. With a higher level of understanding about the disease, individuals can make informed decisions regarding marriage and reproduction, potentially reducing the risk of passing on the disease to their children. The study found a significant correlation between knowledge and attitude toward SCD, genotype, inheritance patterns, and the choice of a life partner ($p<0.05$). Knowledge of genotype was identified as a key significant predictor of knowledge and attitude toward SCD ($p=0.0349$). After further exploration, it was found that two clusters were identified. Cluster 2 has a slightly higher proportion of students who are aware of their genotype (17.24%) than Cluster 1 (8.38%).

Together, these findings underscore the importance of genotype awareness in predicting knowledge and informed relationship decisions. Almost half (45.9%) of the subjects expressed their willingness to continue their relationship even if their genotypes predispose them to have children with SCD. In addition, 46.7% of the subjects said that they would continue to marry their partner even if they discover that their genotypes predispose them to having children with SCD, regardless of the consequences. In addition, as young adults, the subjects' responses imply lack of knowledge of the implication and severity of SCD management, hence the need to create more awareness in schools and communities. Generally, the subjects' thought process could be like those of adults who despite moderate knowledge choose to gamble with the 25% chance of having a child with SCD. Such individuals have misconceived or a lack of understanding about the repercussions of genetic disorder.

Awareness of the implications of SCD inheritance pattern should also be discussed within religious organizations. According to Dennis-Antwi et al. [20], reliance on a "Supreme Being" is a significant coping mechanism for individuals and families managing SCD, often manifesting in prayer and faith-based support. Furthermore, "The most frequent reference to religion was about the importance of faith and reliance on prayer for coping with SCD and decision-making around potential interventions" (p.7). Faith-based communities play a crucial role in education and support, with churches and mosques identified as effective platforms for public health campaigns (p. 16). The study also notes that religious norms often discourage sickle cell carrier couples from marrying one another, framed as a moral obligation to avoid the birth of children with SCD (p. 12). The study also highlights challenges where religious beliefs hinder effective SCD management. Traditional and religious norms often associate SCD with curses or divine punishment, leading to stigmatization and reluctance to engage with genomic research (p. 15). Concerns about the misuse of biological specimens stemming from cultural fears further complicate research efforts (p. 15). Also, when properly informed, religious leaders can act as liaisons in dispelling misconceptions and promoting community engagement in SCD care (p. 17). These findings emphasize the importance of collaboration between religious institutions and healthcare providers to balance faith with science, ensuring informed decision-making while respecting cultural and spiritual values.

Limitations and Strengths

Given the enormous resources involved in the management of SCD, the importance of prevention cannot be overstated. Educational interventions and the dissemination of knowledge about SCD among young adults help inform them about reproductive decisions and close knowledge gaps regarding sickle cell disease. Therefore, continued assessment and advocacy for premarital genetic screening and other preventive measures are needed to reduce disease incidence and bridge knowledge gaps [21].

Several limitations must be considered when interpreting the findings of this study. First, the use of a convenience sample from a single university restricts the generalizability of the results to broader populations of young adults. Second, reliance on self-reported data may have introduced recall bias, which could affect the accuracy of participants' responses. Third, recruitment from a single-site university further limits the external validity of the findings, as participants may not represent the diversity of young adults across various educational, geographic, and cultural contexts. Fourth, the relatively small sample size, due to limited summer enrollment in the SURI research program, may have reduced the statistical power of the analyses. Future research should address these limitations by recruiting larger samples during the regular academic semester, incorporating multiple recruitment sites, employing more representative sampling strategies, and including a more diverse population to enhance the validity and generalizability of the findings.

Recommendations

Nurses are at the forefront of health care and education initiatives. To facilitate primary educational awareness of hemoglobin genotype, nurses in predominantly African American schools and colleges, as well as Black faith communities, can champion health education of SCD. The health education initiatives could be annually on World Sickle Cell Awareness Day with emphasis on knowledge of genotype and implications of SCT status for reproductive decisions. In addition, hemoglobin genotype status should be required in young Black adults' physical examination admission criteria into high school and higher education. These strategies will provide targeted and cost-effective grassroots primary prevention of SCD. For more generalizable findings and earlier prevention, further research could target regular semester undergraduate students, more than one HBCU and high school students.

Conclusion

This study highlights the critical importance of creating timely awareness of one's hemoglobin genotype status and knowledge of the implications of mismatched genotypes in the choice of a life partner and reproductive decisions. Prevention of SCD is more effective than the management of the disease. Integrating genetic counseling, screening, hemoglobin genotype status among immunization status requirements, and education programs in schools and communities could play a pivotal role in increasing awareness and empowering young Black adults to make informed decisions and reduce the prevalence of SCD in future generations.

All listed authors met the following criteria:

- Made a significant contribution to the concept, design, acquisition, analysis or interpretation of data
- Drafted the article or revised it critically for important intellectual content
- Approved the final version of the article for publication
- Agreed to be accountable for all aspects of the work and resolved any issues related to its accuracy or integrity.

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Ethical approval and informed consent statements

This study was approved by Bowie State University Human Research Ethics Committee (IRB Number 019-0112) on March 30, 2019. Prior to completing the survey, participants were directed to sign the written informed consent and complete the survey questionnaire if they were at least 18 years of age and voluntarily agreed to participate.

Competing interests: The authors declare that they have no competing interests.

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