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Experiences and Management Practices of Individuals Living with Sickle Cell Anemia in Nigeria

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ABSTRACT

Background: Sickle cell anemia (SCA) remains a major public health concern in Nigeria, where it significantly affects the physical, emotional, and social well-being of affected individuals. Despite advancements in medical care, many patients continue to face challenges related to disease management and societal perceptions.

Purpose: This study aimed to explore the experiences and management practices of individuals living with SCA in Nigeria.

Methods: A descriptive cross-sectional study was conducted among individuals living with sickle cell anemia in Nigeria using a structured online questionnaire distributed through WhatsApp support groups. Ethical approval was obtained from the Federal Medical Centre, Abeokuta, Nigeria. A voluntary participant recruitment approach was employed, and data collected included socio-demographic characteristics, disease experiences, pain triggers, and management practices. Data were analyzed using descriptive statistics in SPSS and Microsoft Excel.

Result: Out of 307 individuals contacted, 66 respondents completed the survey (21.5% response rate). Most respondents were female (69.6%), aged 31-40 years (51.5%), and had the HbSS genotype (72.7%). Frequent pain crises were reported by 42.4% of participants, while 69.7% stated that sickle cell disease had negatively affected their life pursuits. Societal discrimination was experienced by 68.1% of respondents. Malaria was the most commonly reported trigger of pain crises (34%), followed by stress and extremely cold weather. Medication was the most common management strategy (47.0%), while hospital visitation was the preferred approach during crises (59%).

Conclusion: The study highlights the complex realities of living with SCA in Nigeria, characterized by frequent clinical complications, diverse management practices, and substantial psychosocial burdens.

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1. Introduction

Sickle cell anemia (SCA) is a hereditary disease of the blood (Elendu *et al.,* 2023). It is caused by a monogenic hemoglobinopathy, which is due to a point mutation in the beta-globin gene, resulting in the abnormal formation of hemoglobin S (HbS) (Meraya *et al.,* 2026). It is a disease that affects millions of people around the world, particularly those of African, Mediterranean, Middle Eastern, or South Asian descent (Elendu *et al.,* 2023). There is limited data reporting the burden of sickle cell anemia in several African settings. SCA is a major health problem in the world with about 300,000 children born with SCA annually (Kilonzi *et al.,* 2022). Although sickle cell anemia has been designated by the UN and WHO as a global public health problem. There are still inadequate strategies for prevention and care in sub-Saharan Africa (Adeloye *et al.,* 2026).

Patients with SCA may experience a multitude of clinical presentations, some more severe than others. Frequent severe pain attacks (vaso-occlusive crises) are the hallmark sign. Anemia, increased susceptibility to infections, and exhaustion are additional typical symptoms. The

physical and psychological well-being of people with SCA is greatly impacted by these symptoms (Essien *et al.,* 2023). Healthcare providers, patients, and their families must have a thorough grasp of the causes, symptoms, and available treatments for sickle cell disease (SCD). This information enhances the quality of life for people with this chronic illness and promotes early identification and symptom treatment (Gazta *et al.,* 2026). SCA affects patients' mental health, social life, education, and employment in addition to their physical health (Kilonzi *et al.,* 2022).

The goal of SCA treatment is to improve quality of life while managing symptoms and complications (McGann *et al.,* 2013). The clinical results and quality of life of individuals with SCA have been the subject of a few studies conducted in Africa, but there hasn't been much research done in Nigeria to examine patients' lived experiences, psychosocial difficulties, pain crisis triggers, and management techniques collectively. The majority of studies that already exist are directed toward the clinical symptoms and healthcare consequences while paying less attention to how the patients deal with the disease socially and psychologically in their lives**.** Understanding these experiences is necessary to create patient-centered interventions, offer more psychosocial support, and develop effective disease management strategies. The aim of this study was therefore to evaluate the experiences and management practices of the people with sickle cell anemia in Nigeria.

2. Materials and Methods

2.1. Study Design

A descriptive cross-sectional study design was employed to investigate the management practices and experiences of sickle cell disease patients in Nigeria. Data were obtained via online Google Forms rather than in-person surveys or interviews. This was intended to gather information over a large geographic area in Nigeria.

2.2. Ethical Declaration

The study was conducted in accordance with the Declaration of Helsinki, and we received ethical permission (no. FMCA/470/HREC/01/2025/26) from the Federal Medical Center's ethical approval committee in Abeokuta, Nigeria.

2.3. Study Population

Patients with sickle cell anemia from Nigeria made up the study population. Eligibility for participation was assessed using the following criteria:

- **Inclusion standards:** Nigerian citizens, either current or former, who were willing to complete the online survey and who had a verified diagnosis of sickle cell anemia (HbSS or other variations).
- **Exclusion Criteria:** Individuals who were not Nigerians and did not have sickle cell disease were excluded from the study.

2.4. Sampling Method

Because the subjects were chosen from among those who were accessible and willing to participate, the current study employed a convenience sample strategy. Every participant was urged to freely fill out the Google Forms survey. The link to the survey was distributed via the WhatsApp community group for individuals with sickle cell disorder, which consisted of 200 members, and the Sickle Cell Aid Foundation, having 107 members. The group comprised people from various regions of Nigeria. This technique was not random but did provide for widespread dissemination amongst the sickle cell population in Nigeria.

2.5. Data Collection Instrument

A questionnaire was developed in the structured format of Google Forms and used in English to gather quantitative data. The questionnaire was developed for this study using a rigorous process that entailed a thorough literature search to identify concepts and themes, the generation of items, and the assessment of the clarity, relevance, and content validity of the instrument by three experts in related fields. This draft questionnaire was then tried out with a small number of 20 participants to determine its clarity, relevance, feasibility, and comprehensiveness. Based on input from the pilot testing, a few minor rewordings of unclear questions and a reordering of questions for clarity were made. Although formal psychometric studies, such as Cronbach's alpha, were not performed, the validity and appropriateness of the questionnaire for the study population were guaranteed through expert review and pilot testing. The final questionnaire detailed 14 questions and was divided into three sections. The first section consisted of the socio-demographic information of the participants, such as gender, country of origin, age group, and genotype. The second section focused on the effects of sickle cell disease on the health and quality of life of the respondents. Environmental and medical circumstances that could probably trigger participants' pain crises, as well as pain management techniques, were covered in the final section.

2.6. Data Collection Process

Two WhatsApp groups for the sickle cell community were used to distribute the survey. The participants were given two to three weeks to complete the survey. Those who started the

survey but did not complete it were frequently urged to do so in order to ensure adequate completion. Individuals who agreed to participate in the study were offered the chance to sign an online informed consent form.

3. Data Analysis

Three primary factors were assessed: demographics, managerial techniques and experiences. Participants' sociodemographic traits were included in the demographics section; causes that cause pain and a history of illness were included in the experiences section; and strategies and various management techniques were included in the management practices section. First, the collected data was exported to a spreadsheet from Google Forms. In order to guarantee the quality of the data, substantial data cleaning was done. This included looking for missing data, screening for abnormalities and outliers, and double-checking the data against the original survey responses to make sure it was accurate and consistent. Following quantitative data collection and cleaning, data was analysed descriptively using SPSS and Excel programs to characterise participants' sociodemographic traits, pain triggers, and disease management techniques.

4. Results

4.1. Characteristics of Respondents

Only 66 of the 307 people contacted throughout the study period answered, yielding a poor response rate of 21.5%. However, as there were no missing values among the respondents, the data gathered from the 66 participants was comprehensive. As seen in Table 1, the majority of respondents were female (69.6%), with men making up 30.3% of the study participants. All responders (100%) were Nigerians, and 51.5% of them were between the ages of 31 and 40, followed by 33.3% who were between the ages of 21 and 30, 9.0% who were between the ages of 10 and 20, and the lowest percentage of 6.0% who were between the ages of 41 and 50. In terms of genotype distribution, 27.2% of respondents had the SC genotype, whereas 72.7% of respondents had the SS genotype.

Table 1: Demographic Characteristics of Respondents

Variable	**Frequency (n=66)**	**Percentage (%)**
Gender		
Female	46	69.6
Male	20	30.3
Country		
Nigerian	66	100
Age Group (years)		
18-20	6	9.0
21-30	22	33.3
31-40	34	51.5
41-50	4	6.0
Genotype		
SS	48	72.7
SC	18	27.2

4.2. Impact of Sickle Cell Disease on Respondent Well-Being and Quality of Life

In a total of 66 respondents, the majority of them experience sickle cell crisis frequently (42.4%), followed by those who experience it once or twice a month (33.3%), as presented in Table 2. Only 24.2% of respondents noted they had a crisis infrequently. For most respondents, a sickle cell crisis lasts for a few days (66.6%) before they visit a hospital. A significant number of respondents (27.2%) stated their crisis lasts for a week, while only a small portion (6.0%) finds their crisis resolves within a day. 56.0 % of respondents have parental support; however, there was a strong indication of societal challenges, with the majority of respondents feeling that society makes them feel inferior (62.1 %) and 68.16 % facing societal discrimination. The respondents' lives were significantly impacted by the illness, as 69.7% said that sickle cell disease has changed or impacted their goals in life. Medication (47.0%) and hydration (19.7%) are the most popular methods used by respondents to treat their illness. Other approaches, such as hydration with rest or medication plus hydration, are less popular. The proportion of respondents who said they used herbs or a mix of herbs and pharmaceuticals was extremely low. When it comes to transfusions, the most frequent frequency is twice a year (40.9%), whereas 42.4% of respondents said they never receive transfusions.

Table 2: Experiences and Impact of Sickle Cell Disease on Respondent Well-Being

Variables	**Frequency (n=66)**	**Percentage (%)**
How often do you fall into crisis?		
Bi-annually	16	24.2
Monthly	22	33.3
Bimonthly	28	42.4
How long has your crisis lasted without visiting the hospital?		
Within a day	4	6.0

Few days	44	66.6
A week	18	27.2
Do you have parental support?		
Yes	37	56.0
No	29	43.9
Does society make you feel inferior?		
Yes	41	62.1
No	25	37.8
Do you face societal discrimination?		
Yes	45	68.1
No	21	31.8
Has sickle cell disease affected or altered your life pursuit in any way?		
Yes	46	69.7
No	20	30.3
How do you manage the disease?		
Hydration/Fruits	2	3.0
Medication	31	47.0
Hydration	13	19.7
Medication/Hydration	7	10.6
Hydration/Rest	7	10.6
Herbs	4	6.1
Medication/Herbs	2	3.0
How often do you get transfused?		
Annually	10	15.2
Bi-annually	27	40.9
Bi-monthly	1	1.5
Never	28	42.4

4.3. Percentage Occurrence of Reported Conditions Triggering Pain Crises in Individuals with Sickle Cell Anemia

Malaria was the most frequent cause of pain, accounting for almost 34% of the respondents. It was followed by two noteworthy categories with high reporting rates. About 24% of the respondents reported experiencing both extreme cold and stress along with malaria. In almost 14% of cases, stress was the only factor that triggered pain. Extremely cold weather (12%), extremely cold weather combined with stress (12%), extremely hot weather combined with malaria (4%), extremely hot weather combined with stress (2%), and the category of extremely hot/cold weather only (2%) were the most frequently reported pain triggers (Figure 1).

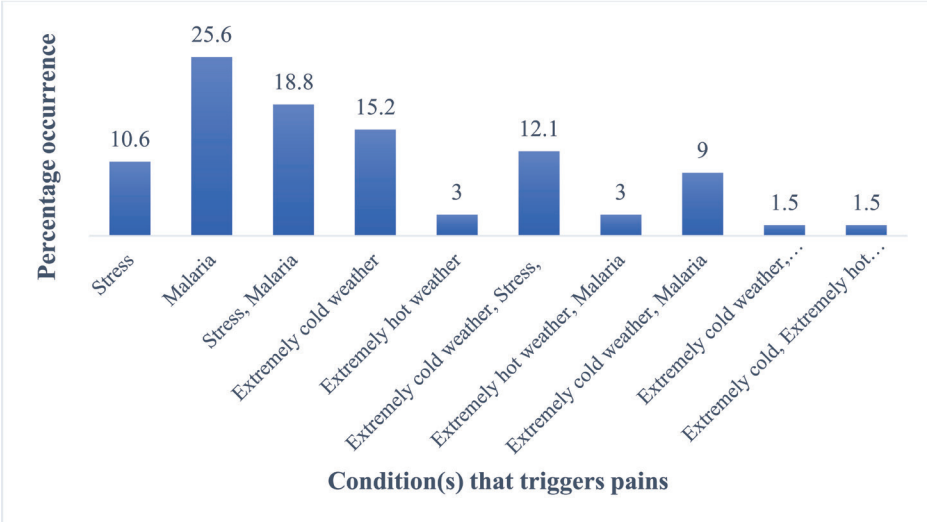

Figure 1: Participant Response to Conditions that Triggers their Pain

4.4. Distribution of Self-Reported Best Approaches for Sickle Cell Crisis Management

Approximately 59% of respondents indicated that visiting the hospital was the most popular method of handling a crisis. About 10.6% of the participants reported using a combination of self-care/medication and hospitalization. Together with traditional herbs, self-care/medication was the third most popular strategy (9%). As shown in Figure 2, the alternative management techniques were far less common, including self-care/medication alone (7.5%), a combination of visiting the hospital and using traditional herbs (7.5%), and traditional herbs alone (6%).

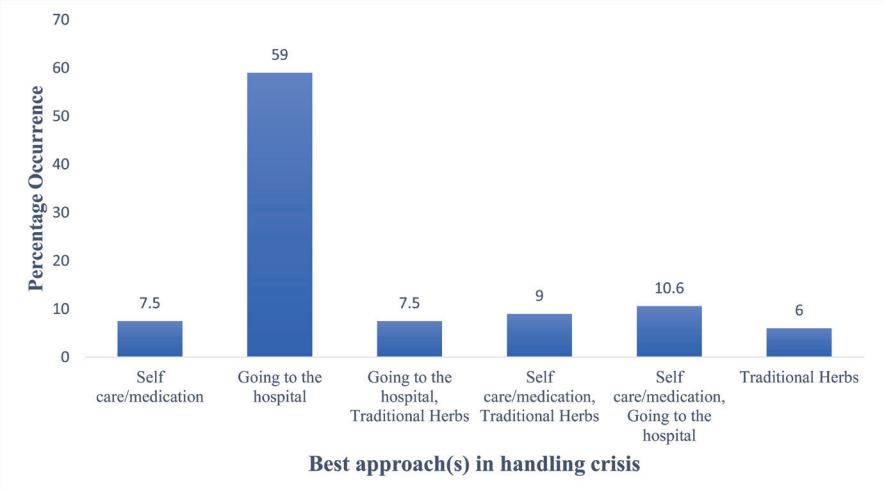

Figure 2: Preferred Crisis Management Strategies among Respondents

5. Discussion

Sickle cell anemia is a hereditary, lifelong condition that typically causes severe suffering for those who have it. Thus, from a medical, genetic, and psychosocial standpoint, it requires particular consideration (Mangla *et al.*, 2025). The purpose of this study was to investigate the management and experience of SCA in Nigeria. In Nigeria, both male and female SCD patients were included in the survey. The majority of responders were female adults, which may be because women are more likely to participate in health research and provide personal health information. This fact has been noted in different fields of health study (Canals-Gispert *et al.*, 2024). This was corroborated by the findings of Adegoke and Kuteyi (2012), which also revealed that the percentage of male constituency that participated in their campaigns was lower than that of the female constituency. This was explained by a variety of factors, including that most men were out of work or less inclined towards participation in the study, as noted by Akodu *et al.* (2013).

Similarly, Verdugo-Castro *et al. (2023)* discovered (2012) that women with sickle cell disease (SCD) are more likely to seek medical attention and take part in health research studies. This finding suggests that socioeconomic and cultural influences may make women more inclined than men to seek medical attention or take part in health activities (1998). According to this study, the most prevalent age group was 31-40 years old, followed by 21-30 years old. In contrast, Juburi *et al. (2012)* found that the study population from Saudi Arabia was younger, primarily between the ages of 15 and 25. The difference may be attributed to better clinical management in Nigeria, which could have led to better survival. This is indicative of the progress reported by Ohene-Frempong (1998), which reported that access to care had increased progressively, leading to improvements in the life expectancy of people living with SCA in the sub-Saharan region.

In terms of genotype distribution, the SS genotype was displayed by 72.7% of respondents, while the SC genotype was the least common. This is in line with Adigwe *et al.* (2023) discovery that the HbSS genotype is the most common SCD genotype among Nigerians. This is due to the fact that the clinical symptoms of HbSS are typically more incapacitating than those of HbSC, which is likely to motivate SS sufferers to seek medical attention more frequently (Nelson *et al.,* 2024). The high percentage of respondents who reported having numerous crises supports the findings of Ballas *et al.* (2010), who showed that SCD crises differ significantly among people, with a sizable portion going through many crises per month. Similarly, Tewari *et al.* (2015) noted that crisis variability was influenced by environmental triggers, genotype severity, and adherence to the crisis management strategy. According to Adewoyin (2015), Nigeria's tropical environment, vulnerability to infectious diseases like malaria, and lack of comprehensive care facilities when compared to other nations may also account for the high frequency of crises seen.

Parental assistance was more prevalent among those with less severe crises or infrequent hospital stays. This is consistent with Serjeant's (2013) findings that family support is essential for managing sickle cell disease (SCD), its effects on health outcomes, psychosocial well-being, and crisis management. It's interesting to note that individuals without parental support experienced longer or more frequent crises. This suggests that social and familial support is a protective factor that lowers stress and improves illness management, a theory supported by Anie and Green (2015). Another interesting finding of the study was that 62.1% of people indicated that society had made them feel inferior,

while 68.1% indicated discrimination by society remained. This seeming contradiction is in line with the findings of Brown *et al.* (2010), who noted that while stigmatization is still prevalent in African countries, individuals with SCA are placing an increasing emphasis on self-advocacy and empowerment. Anie (2005) specifically pointed out that people with SCA frequently experience two realities: one of acceptance and resilience, and another of marginalization, especially in the areas of work, marriage, and education. Poor public knowledge of the hereditary and non-contagious nature of sickle cell disease (SCD) and persistent myths and misconceptions serve as justifications for ongoing prejudice (Bulgin *et al.,* 2018).

The majority of individuals reported that SCD has affected their life goals, particularly with regard to their own financial, marital, and intellectual endeavors. The chronic nature of the condition, many hospital stays, social discrimination, and the physical limitations imposed by periodic painful crises could all be contributing factors to the numerous disruptions in life's endeavors (Thomas and Taylor, 2002). In a different study, Shapiro *et al.* (1995) detailed how individuals with SCD often have difficulty pursuing further education, finding employment, and sustaining a committed relationship. Prescription medication was the most frequently reported method of managing the illness, although a significant number of individuals also reported using traditional remedies, with the combination of both being the least frequently reported. The findings are consistent with those of Ameh *et al.* (2012), who found that while some SCD patients in Nigeria use herbs because they think they are helpful or because they cannot afford the prescribed medications, the majority of them take the hospital-provided medication nearly entirely. According to Ambe *et al.* (2001), there are problems in the availability, pricing, and/or provision of care because some respondents reported self-medication or employing several distractions. Consistent usage of herbal treatments may be linked to the continuation of traditional health practices in African communities, while consistent usage of these prescription drugs may be linked to ongoing public education about the importance of following prescriptions (Mutombo *et al.,* 2023). The frequency of transfusions varied; some people received them twice a year, while others received them every month or every two months. The findings support those of Diaku-Akinwumi *et al.* (2015), who reported that in Nigeria, people with severe anemia or frequent crises are usually given regular transfusions, whereas others manage crises without transfusion.

Malaria was shown to be the most frequent cause of pain, followed by cold weather or stress related to malaria. This finding supports the findings of Olatunya *et al.* (2021), who concluded that malaria remains a major cause of sickle cell crises in malaria-endemic regions like Nigeria. According to Bunn (1997), sickling is caused by dehydration, hypoxia, and systemic inflammation, which are all facilitated by cold temperatures, stress, and diseases like malaria. As a result, the current findings are supported from a biological standpoint and represent the established pathophysiology of sickle cell pain crises. Furthermore, the high percentage of respondents who mentioned stress and extreme weather also points to an environmental and psychosocial component. This supports previous research by Hassell (2010), which found that psychosocial stressors are crucial to the occurrence and intensity of crises. The most popular management option was medication alone, followed by water and medication plus hydration. These management patterns are comparable to those described by Yusuf *et al.* (2010), who demonstrated that medication therapy, specifically hydroxyurea and analgesics, as well as hydration, remain the cornerstones of sickle cell disease treatment.

Going to the hospital was the most popular way to handle a crisis, according to an assessment of the most popular strategies (approximately 59% of the participants chose this technique). The severity of VOCs and the lack of resources to treat the pain at home may justify this over-reliance on formal care for the resolution of acute crises, so the patient is ready to go to a formal setting for dependable and effective pain treatment that is more potent than the options available at home. Combining self-care/medication with a hospital visit was the second most popular tactic, utilized by roughly 10.6% of people, followed by a combination of self-care/medication and traditional herbs by roughly 9% of individuals. The low percentage of those who relied solely on self-care or medicine (7.5%) suggests that effective analgesic drugs for at-home use may not be readily available or reasonably priced. However, the persistence of health diversity in Nigeria is demonstrated by the continuous use of traditional herbs, either on their own (6%) or in conjunction with hospital care (7.5%). In contrast to formal care, which is expensive and geographically restricted, conventional procedures are more commonly used despite having no formal evidence because they are accessible, culturally acceptable, and economical (Berhe *et al.*, 2024). This two-part approach highlights the need for conversations that are sensitive to cultural differences.

6. Limitations of the Study

This study has provided useful information; however, there are certain limitations to be aware of. Due to the study's cross-sectional online survey design, a causal relationship between the variables could not be established. The low response rate (21.5%) may be a cause of non-response bias since there may be variations in the experiences, health-

seeking behaviors, or severity of the disease between the respondents and the non-respondents, which could limit the study's applicability to the greater number of sickle cell anemia patients in Nigeria. Although professionals examined and pre-tested the questions, rigorous psychometric studies such as Cronbach alpha were not carried out to improve their applicability and intelligibility. Additionally, because the data collection method was done online, respondents with limited internet connections, lower levels of education, or less experience with digital technologies would have been excluded, which could have affected the study population's representativeness. Nonetheless, the study provides insightful details about the lives of sickle cell patients in Nigeria as well as beneficial avenues for future investigation.

7. Conclusion

The study's findings clearly illustrate the severe physical, social, and financial hardships that sickle cell disease patients in Nigeria face. Other major problems for those impacted include the repeated nature of the pain crises, societal discrimination, and the disruption of education, interpersonal relationships, and income. The continued use of traditional herbs suggests that cultural attitudes continue to play a role and that access to and price of healthcare services may be limiting, even though most participants reported using prescription medication and inpatient care to deal with the crisis. Malaria and environmental variables were found to be major causes of pain attacks, as was stress. This highlights the need for psychosocial assistance and preventive medical care.

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Authorship Contribution

Abidemi Esther Ojo conceived and designed the study. Reghina Oghenevwede Golagha performed the computational analyses, interpreted the data, and prepared the manuscript draft. Olugbenga Anthony Ojo contributed to the design of the study and supervision. Adejare Rasaq Oloyede supervised aspects of the research, and google form design. Oluwabusola Oluwayemi Adegbesan assisted with literature review, manuscript editing, draft and supervision. Eniola Akindele contributed to the field work and data curation. Abidemi Esther Ojo, Golagha, Reghina Oghenevwede Golagha, Olugbenga Anthony Ojo, Adejare Rasaq Oloyede, Adegbesan, Oluwabusola Oluwayemi Adegbesan and Eniola Akindele reviewed, revised, and approved the final version of the manuscript.

Ethical Approval

Ethical approval with number FMCA/470/HREC/01/2025/26 was obtained for the study from the ethical approval committee of the Federal Medical Centre, Abeokuta, Nigeria.

Conflict of Interest

The authors declare that there is no conflict of interest regarding the publication of this paper.

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Declarations

The authors declare that the manuscript is original, has not been published previously, and is not under consideration for publication elsewhere. All sources of information used in this study have been appropriately acknowledged and cited.

Data Availability Statement

Survey data were examined after being imported from an online survey system, which is held and managed by the research group in the Federal University of Agriculture Abeokuta, Ogun State, Nigeria. The datasets generated and analyzed from the survey in this current study are available from the corresponding author, Adegbesan, O.O., on reasonable request.

Human and Animal Rights

This study was conducted in accordance with the ethical principles of the Declaration of Helsinki and relevant institutional guidelines for research involving human participants. Ethical permission (no. FMCA/470/HREC/01/2025/26) was obtained from the Federal Medical Center's ethical approval committee in Abeokuta, Nigeria. An online signed consent form was obtained from voluntary participants before inclusion

in the study. Only individuals who consented and were capable of understanding the study were enrolled. Participants who were not willing, were excluded from the study. Participation was entirely voluntary, participant confidentiality was maintained throughout the study, and all data were used solely for research purposes. No animals were involved in this study.

Figure Permission

All figures included in this manuscript were created by the authors, and no permission from third parties is required

AI Disclosure Statement

The authors declare that no artificial intelligence (AI) tools were used in the writing, analysis, or preparation of this manuscript.

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