Public Health Research
Okwe et al. Afr Chron Res Pub J 2025 2(1):1-24
Article URL: https://researchpubjournals.org/?post=1451

Cross-sectional study of the knowledge & perception towards management practices among patients attending sickle cell disease clinics in Delta state, Nigeria.

Okwe UN[1,2], Nwose EU[1,3], Ofili CC[1]

[1]Department of Public and Community Health, Novena University, Ogume, Nigeria
[2]Delta State Ministry of Health, Asaba. Nigeria
[3]School of Health and Medical Sciences, UniSQ, Toowoomba Australia

Corresponding Author:
Dr. Uche Okwe. Delta State Ministry of Health, Asaba. Nigeria. Email: tansinwanney@yahoo.com, Tel: +2348037615027

Received: 18/07/2025
Revised: 20/09/2025
Accepted: 22/09/2025
Published: 06/10/2025

Public Health Research
Okwe et al. Afr Chron Res Pub J 2025 2(1):1-24
Article URL: https://researchpubjournals.org/?post=1451

Abstract

Background: SCD is a genetic disease that can misshape red blood cells. The perceptions of SCD diagnosis in all age groups influence their mental wellbeing which affects the ability to cope with SCD. There are health risk perceptions among these patients.

Objective: Cross-sectional study of the knowledge and perception of management practices among sickle cell patients attending sickle cell clinics of Delta state.

***Method*:** Mixed-methods approach eliciting information on knowledge and perception from 700 SCD patients in the districts of Delta State was used. Data was collected through structured questionnaire on knowledge and perception from clinics randomly selected. Data was analyzed descriptively and presented in frequencies and percentages in various charts and tables.

Results: 672 SCD patients aged 13-65yrs participated. 72% believed SCD can be prevented by genetic screening, counseling & health education, 74.1% opted that clinics were efficient and 91% selected genetic factors as major contribution to SCD. All SCD patients were sad once diagnosed, 71.1% in self- denial, 0.9% perceived it is a spiritual illness and 91.7% felt they were a burden to their parents. With regards to management, 8.3% chose 'herbs' as therapeutic and 96.4% had hope on the management at SCD clinics for survival.

Conclusion: There are over 25% of SCD patients that would benefit from SCD education to improve their knowledge and perception. This calls for the creation of educational programs that promote knowledge to improve perceptions of SCD.

Keywords: SCD, Perception, health risk behavior, health education, Genetic counseling

1.0. Background

Sickle cell Disease is a genetic disease (Booth et al., 2010) with its knowledge in Nigeria mixed with general awareness from friends, media, healthcare workers, and family members (Babalola et al., 2019), but there is some lack of understanding on its cause and management of this clinical condition, particularly regarding various genotypes, transmission, and management. Perceptions vary; while many show some understanding as they grow and the importance of genotype tests (Munung et al., 2024), some still have misconceptions and perceptions influenced by religious beliefs and lack of education (Dennis-Antwi et al., 2018). The healthcare workers due to lack of knowledge and training on the evidence-based management guidelines and new treatments may not properly care for these patients (Jonathan et al., 2022). They however show signs of stigma hostility and abandonment of these patients at the health care facilities (Leger et al., 2018). Improving health awareness, addressing cultural barriers, and access to management strategies are important for better patient outcomes in sickle cell clinics.

In addition, unavailability of basic equipment and health care workers is a major challenge in Nigeria (Isa et al., 2023). In Delta State despite the availability of this equipment at the clinics (Idowu, 2021), financial resource may also be a challenge with parents opting for prayers as a way of coping with the illness (Arue, 2024). These beliefs can significantly influence attitudes towards SCD, particularly regarding genetic tests and management affecting health-seeking behaviors. The need for patient -centered care and setting up sickle cell clinics to improve the quality and availability of care offers more consistent intervention and accurate strategy to the management of this disease (Bell et al., 2024).

Delta State has commissioned sickle cell clinics in 24 Local Government Areas to enable easy accessibility (Adurokiya, 2024; Sadhere (2021), and have introduced the sickle cell control law to ensure control of SCD (Ahon.,2017), early diagnosis and management but challenges are still reported. This study to find out knowledge and perception of SCD patients will enable policy makers improve on its SCD support systems and ensure gaps and challenges mentioned are noted and resolved.

2.0. Statement of the Problem

Most SCD crisis are amenable to treatment especially in Delta state, but the interventions and management are not accessed by majority of the patients that live in low resource settings (Efe, 2013; Odunvbun et al., 2008; Okocha et al., 2022). In Delta State, there are inadequate resources of health (Efe, 2013) to institute care at the hospitals. In Nigeria, the number of sickle cell clinics is inadequate (Adigwe et al., 2023; Collier, 2012; Galadanci et al., 2014) and there is no documented evidence to show the perception of the Delta State SCD patients towards the management practices introduced at the sickle cell clinics of Delta State.

3.0. Objective

3.1. General Objective: Cross-sectional study of the knowledge & perception towards management practices among SCD patients attending Sickle Cell clinics of Delta state, Nigeria.

3.2. Specific Objectives: Two specific objectives include to assess the

i. knowledge of SCD patients towards their diagnosis and management
ii. perception of SCD patients towards their diagnosis and management

4.0. Methods

4.1. Research Design: This was a cross-sectional descriptive quantitative study, using a structured questionnaire to elicit information on knowledge and perception of SCD patients on their diagnosis and management at the SCD clinics. The random selection method for participants was adopted from the principle of *entrepreneurship-informed proportionate sampling research* (Engidaw, 2021).

4.2. Research setting: This Research was conducted in these clinics located in the Government hospitals of Delta State. They were developed to address prompt care of SCD patients. They were randomly selected to reduce bias and enable participation in the study. Each clinic has several registered SCD patients monitored by the Genetic counselors and supervised by the Medical Directors. The Genetic counselors are mainly Nurses and Doctors who have been trained and charged with the sole responsibility of health care delivery, management and counseling of sickle

cell patients and their parents. Monthly data of the newly diagnosed SCD patient and the already diagnosed SCD patient at the clinic are recorded (Hospital Sickle cell registry records).

4.3. Research Participants: The participants are sickle cell patients randomly selected and registered at the 18 sickle cell clinics located at the 24 local Government areas of Delta State.; and six SCD clinics were randomly selected from each senatorial district. The selection criteria were as previously published (Okwe et al; 2024, 2025).

4.4. Sampling technique and variables: The solicited responses to the knowledge questionnaire of the SCD patients included definition, signs, diagnosis, and management. The questionnaire on perceptions of management after diagnosis included causes of SCD, where treatment is better, as well as about their diagnosis and management.

***4.5. Data collection*:** As previously published (Okwe et al; 2024, 2025), data collection was done using a structured paper-based questionnaire that elicited information on their knowledge and perceptions regarding their management practices and health risk behaviors.

4.6. Sample size: 700 SCD patients were randomly selected among 11,000 SCD patients registered in the 24 SCD clinics in the 3 senatorial districts (SMOH/DHPRS Records, 2023). A total of eighteen clinics were also randomly selected as previously published (Okwe et al; 2024, 2025).

4.7. Statistical analysis: This was mainly descriptive using the statistical package for social sciences (SPSS Inc. Chicago 11.) computer software version 20.0 tool for frequencies and percentages to represent the summary of data collected through the questionnaire on knowledge and perception categories. Daily checking of filled questionnaires was carried out by the researcher at the end of each field day, to avoid incomplete data collection and to also ensure accuracy of data. The statistical analysis further delineated the specific objectives, hence sub-sections culminating into the following 2 – vis: assessment of the questionnaires on

1. knowledge of SCD patients towards their diagnosis and management
2. perception of SCD patients towards their diagnosis and management

4.8. Potential bias: To limitations including potential bias are as already published in the study protocol (Okwe et al., 2024). Furthermore, the age-related influences were analyzed in a subsequent study.

4.9. Operational process: Three research assistants from the Department of Program, Research and statistics of the Ministry of Health trained on program Monitoring and evaluation were recruited. They administered and collected the questionnaires from various clinics. This was done on SCD clinics' days. Questionnaires were checked for proper completion on collection from participants. Data was coded and kept confidential. Collation and analysis of data was done by the researcher.

4.10. Ethical Approval: Ethical clearance was gotten from the Novena University, Ogume and Delta State Ministry of Health, Ethical Committee (MOHREC) Asaba.

4.11. Consent to participate: Consent from the respondents was obtained before the actual study and their confidentiality assured using a typed consent form. The content and scope of this study was explained to them to elicit their co-operation in each of the clinic and there were requests to respond to the questions after the purpose of the research and the questionnaire introduction section was explained.

4.12. Confidentiality of data: Respondents were also informed that any information discussed and collected during the course of study will be kept confidential; the researcher ensured the research instruments was kept anonymous and results made accessible to them.

4.13. Data validity: Masuwai's content and face validity tests were used to evaluate and validate data used for research.

5.0. Results

5.1. ***Assessment of the knowledge of SCD patients towards their diagnosis and management***.

The observations on distribution of participants regarding knowledge of definition (Fig 1), signs (Fig 2), diagnosis (Fig 3), management (Fig 4), and effects (Fig 5) of SCD are presented in sequence. Figures 6 and 7 showed age on self-care and age at diagnosis, respectively; while figure 8 indicates participants' sources of knowledge.

Public Health Research
Okwe et al. Afr Chron Res Pub J 2025 2(1):1-24
Article URL: https://researchpubjournals.org/?post=1451

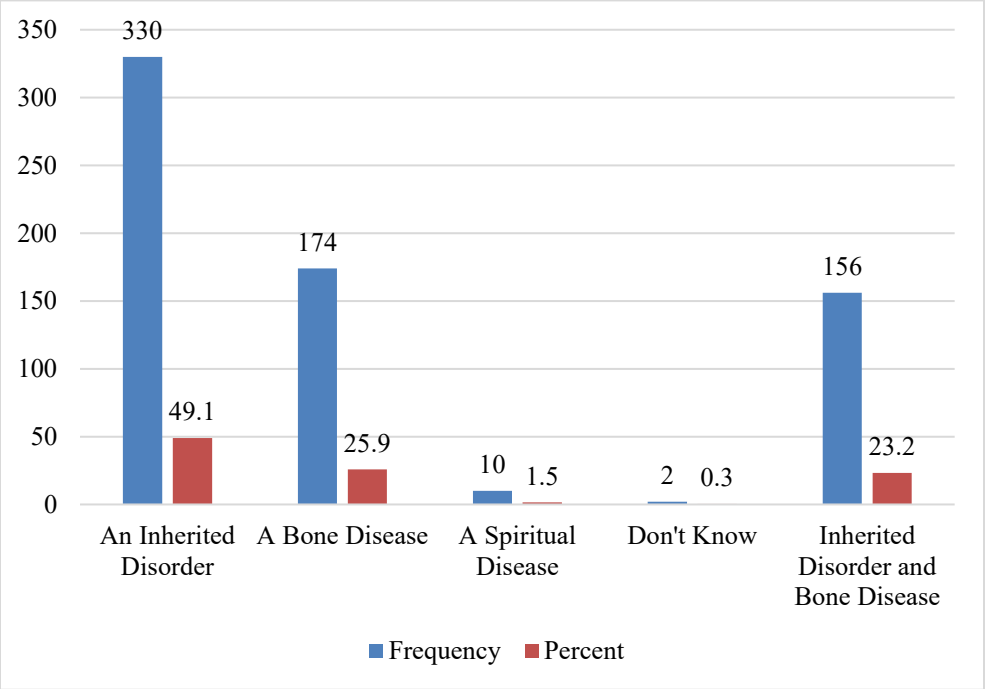

Fig 1. Distribution of responses on definition of SCD

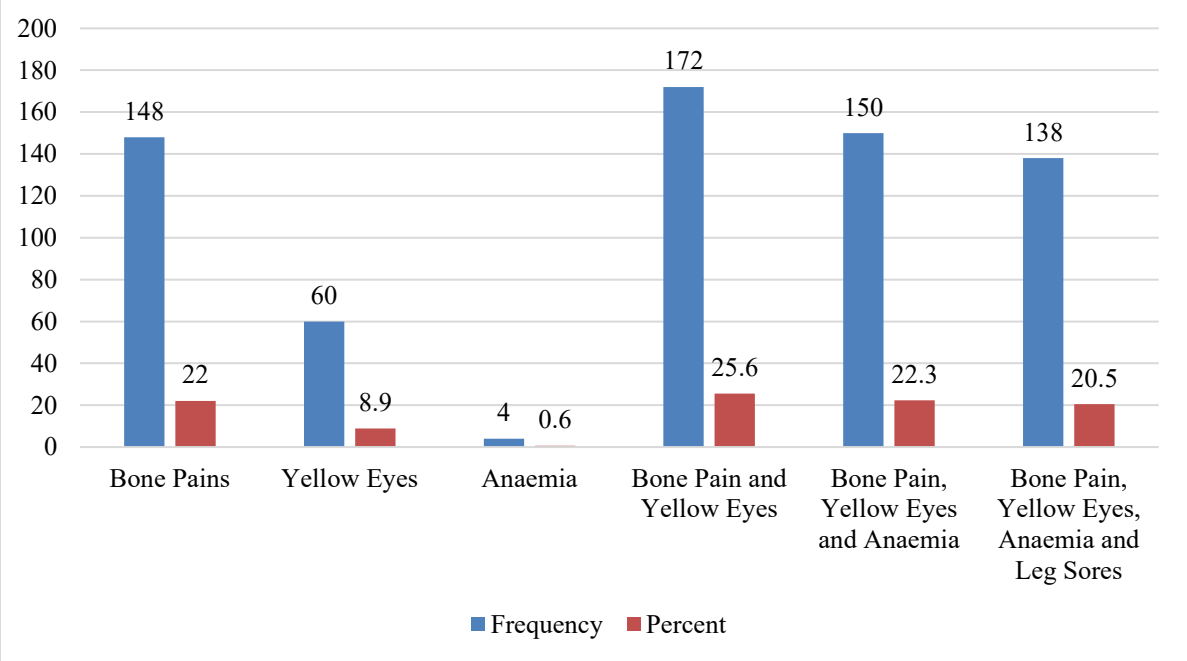

Fig 2. Distribution of responses on signs of SCD

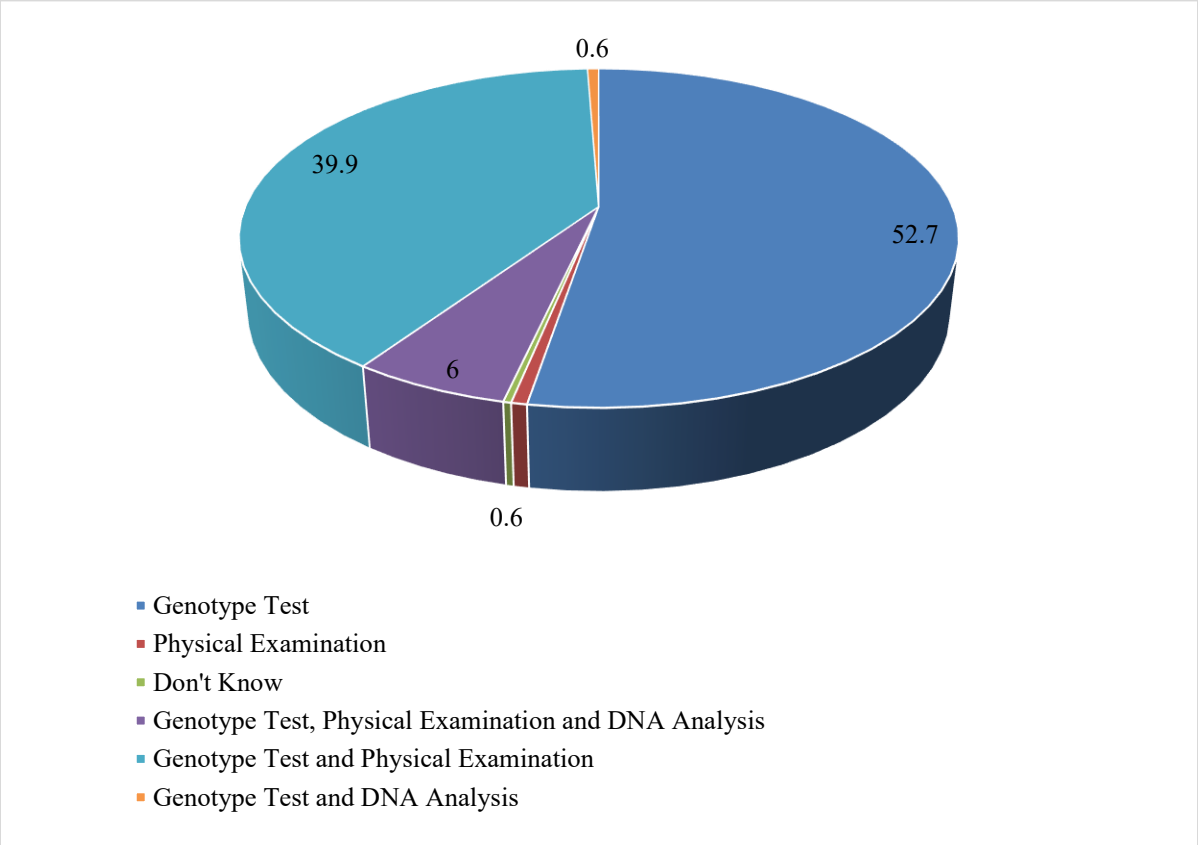

Fig 3. Shows % distribution on ways to detect SCD

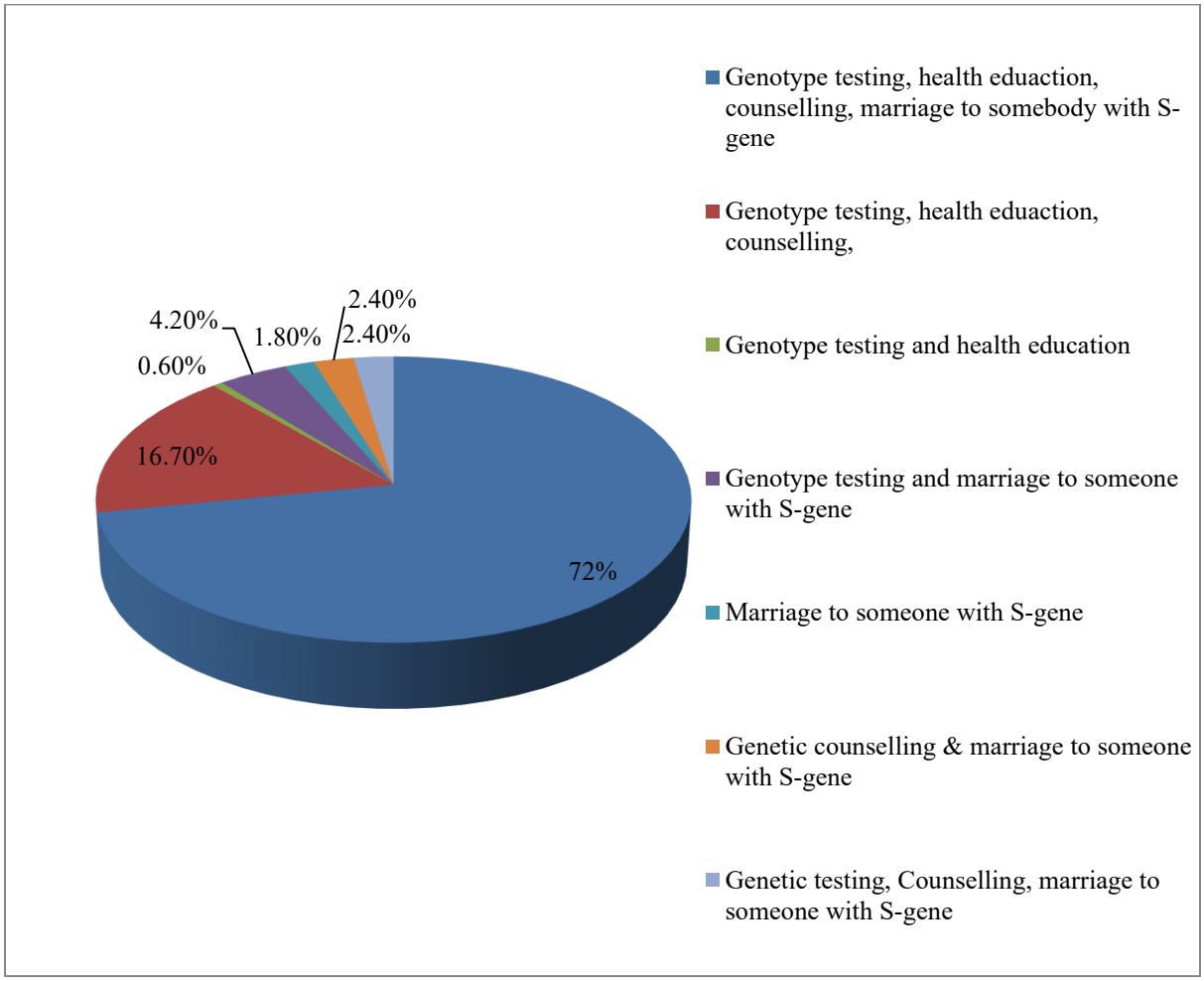

Fig 4. % distribution of ways to prevent SCD

Table 1. % distribution on knowledge/perception of where treatment is better

Better place to treat SCD	**% response**
Going to the hospital/SS Clinic	74.1%
Going to the hospital/SS Clinic/Herbal home	23.2%
Going to Hospital, SS Clinic, Herbal Home, Church, Doctor	2.7%

Public Health Research
Okwe et al. Afr Chron Res Pub J 2025 2(1):1-24
Article URL: https://researchpubjournals.org/?post=1451

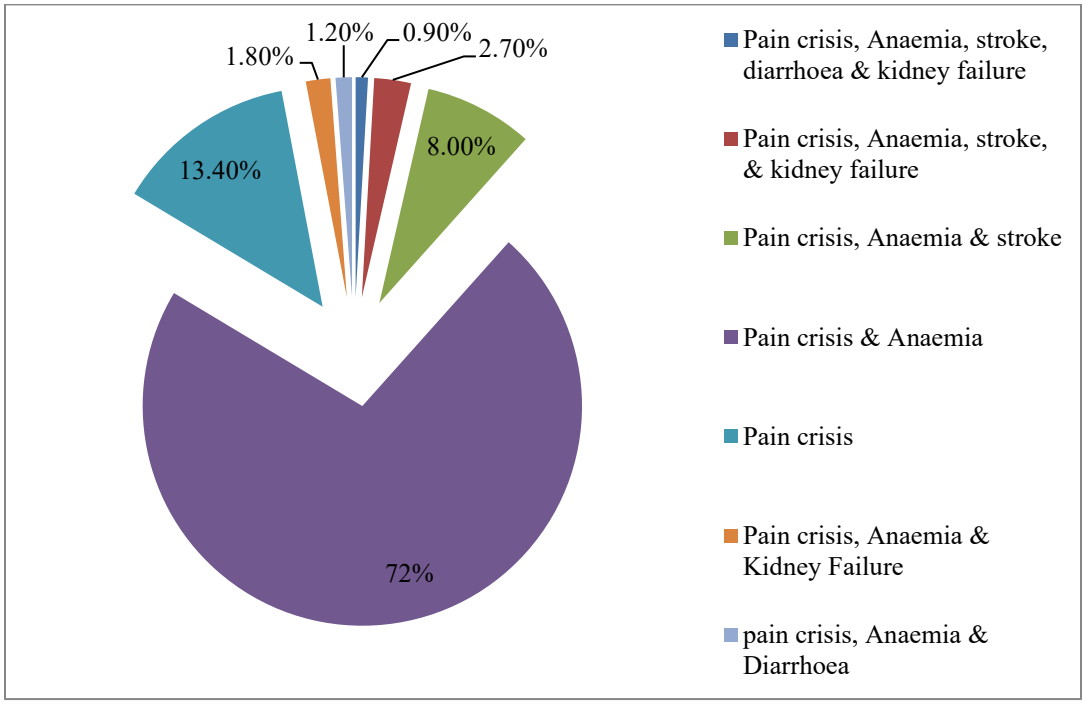

Fig 5. % responses on effects of SCD

Table 2. Knowledge about causes of SCD

Variable	Question	% response
Cause	Mismatch of gene	78%
	Hereditary and parents with sickle cell genes	21%
Disagreement on cause	Having a parent with AA genotype	100%
	Having weak immune system	100%
	Drinking too much alcohol	98.8%
	Infection with SS blood	77.10%
Agreement on cause	Having DNA with SS shows I have SS	68.8%
	Having parents with S-gene	91%
	Having a close relative with SCD or CC parents	87.50%
	Marrying someone with S-Gene if I have S-gene	90.5%
	Having a parent with CC-gene	87.50%
	Having a AC parent makes you vulnerable to SCD	95.8%

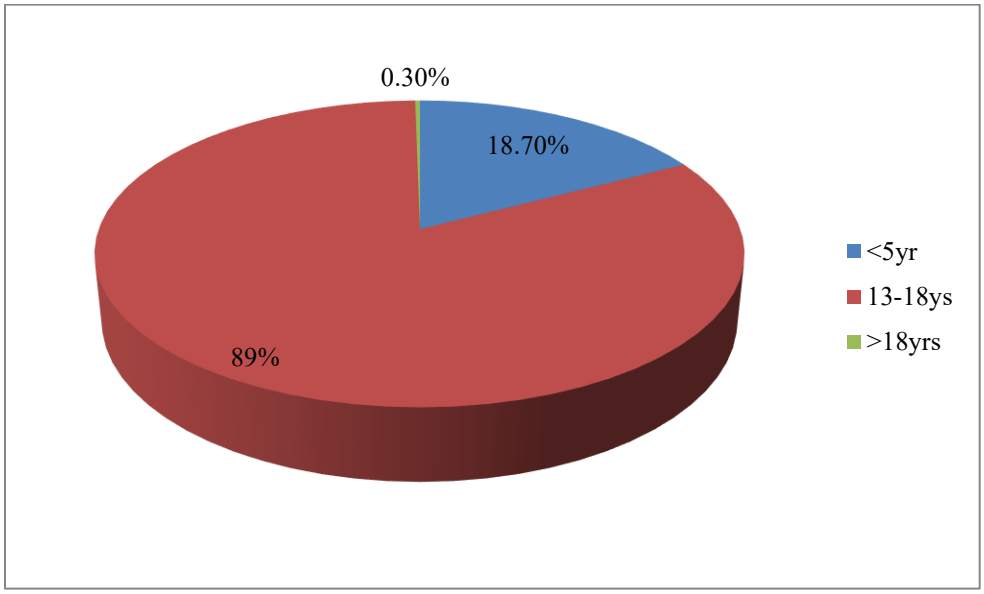

Fig 6. % of age on self –care at SCD clinic

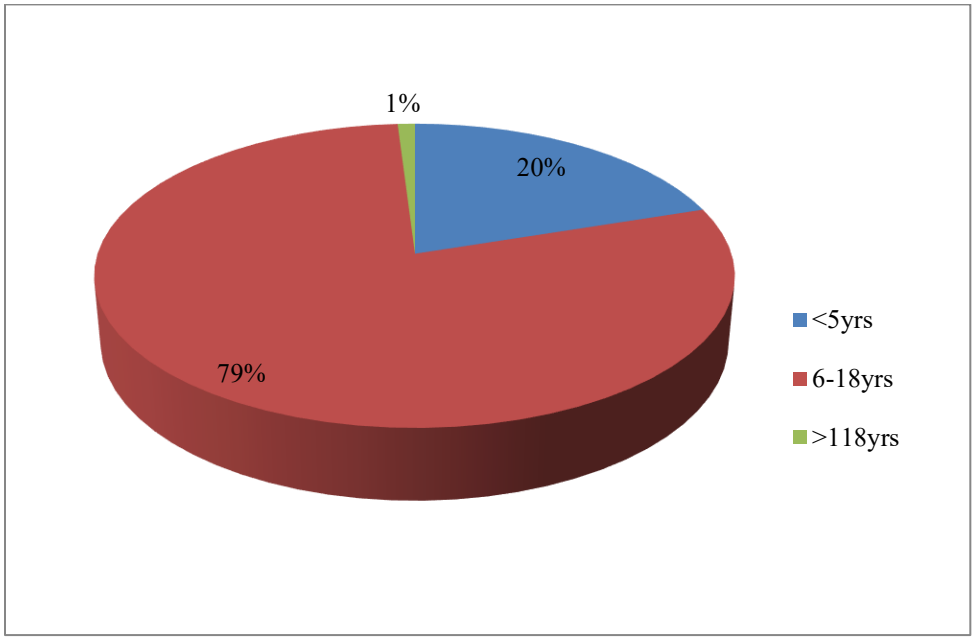

Fig 7. % distribution of age at diagnosis with SCD

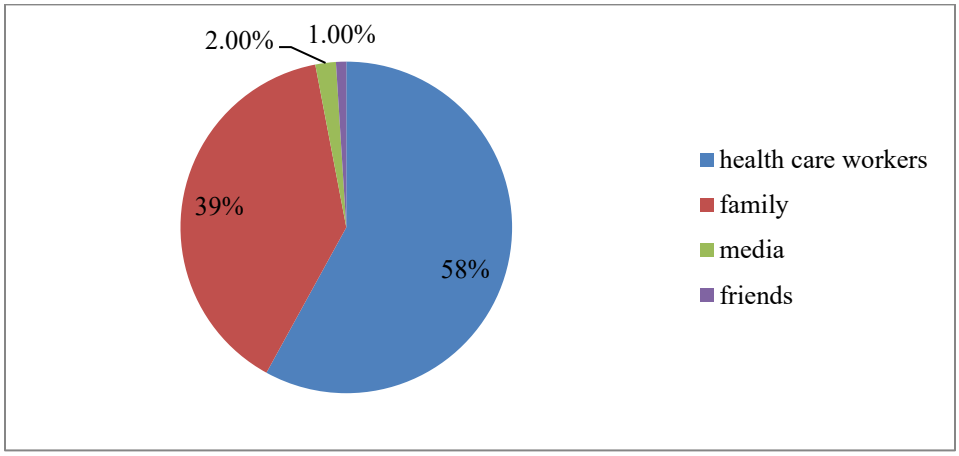

Fig 8. Showing pie chart with source of knowledge of SCD

5.2. Research Question 2: Assessment of perceptions on SCD management practice

Tables 1 and 2 (above) shows the distribution of participants on knowledge and perception about where treatment is better for SCD, and causes of the disease. The table 3, below, shows the perceptions of SCD patients on their diagnosis and management

Table 3. Perceptions of SCD patients on their diagnosis and management

SN	Perceptions on SCD management practices	Yes	No	Y%	N%
1	Sad after diagnosis at the clinic	672	0	100	0
2	Diagnosis was unacceptable	478	194	71.1	28.9
3	I felt It is spiritual	6	666	0.9	99.1
4	It is a death sentence	176	496	26.2	73.8
5	It is a challenge I have to overcome	478	194	71.1	28.9
6	I feel anxious on my diagnosis	485	187	72.2	27.8
7	I feel abnormal	150	522	22.3	77.7
8	I feel I am a burden to my parents and caregivers	616	56	91.7	8.3
9	It is punishment	266	406	39.6	60.4
10.	I am hopeful that the management at the clinics will be of help	648	24	96.4	3.6
11.	SCD can be cured by herbs	56	616	8.3	91.7
12	Indifferent about my diagnosis & management	70	602	10.4	89.6

6. Discussions

6.1 Overview

A total of 672 patients responded to the questions. 28 participants did not submit. 8 hesitated in sharing personal information, 5 because of stigma, 10 had time-constraints, and 5 were unavailable. The observations for the two specific objectives are hereby discussion in the separate sections.

6.2. Do the SCD patients in Delta State have knowledge of SCD?

In the attempt to ascertain knowledge, Fig 1 showed that 49.1% of the patients defined SCD as an inherited disorder. This aligns with a study on sickle cell pathophysiology (Inusa et al., 2019). 25.9% defined SCD as a bone disease as supported in another study where sickle cell disease was described as an orthopaedic/ bone disease (Mulyana et al.,2024; Onuba, 1993) while 23.2% defined it as both inherited disorder and bone disease (Mangla et al.,2023, Inusa et al., 2019).

Patient-reported signs of SCD were varied in fig 2 with bone pain and yellow eyes taking the lead with 25.6% followed by bone pain, yellow eyes and anemia (22.3%), bone pain (22%) and bone pain yellow eyes, anemia (Diwe et al., 2016) and leg sores (20.5%).

On genotype preferences Fig 3 showed that majority of the patients selected genotype testing (52.7%) as a means of detecting SCD. This was supported by Babalola and others in 2019 while 39.9% favored genotype testing and physical examination for detection. While Physical examination is essential for diagnosis (Verma, 2019), it was observed that medical history and typical physical manifestations of SCD led to suspicion. There is a need for adequate knowledge on SCD to enable its diagnosis.

On prevention, Fig 4 indicates that most of the patients72% affirmed that SCD can be prevented through genotype testing, health education, genetic counseling and avoiding carriers while 16.7% acclaimed that it can be prevented through genotype testing, health education, genetic counseling only as acknowledged in a study (Isa et al., 2023).

On management practices, Table 1 showed 74.1% of the patients indicated going to hospital and sickle cell clinics as a way to effectively manage SCD, echoing another study in Nigeria (Isa et al., 2023), while a smaller group 23.2% identified with conventional care and herbal treatment as

reiterated in a study on lessons in Nigeria and Uganda on use of herbs in the management of SCD (Ameh et al., 2012; Lubega et al., 2021).

Figure 5 shows response of the effects of SCD with 72% patients opting for pain crisis and anaemia as the commonest effect of SCD as most common effects of SCD (Abboud, 2020; Mangla, 2021; Tebbi, 2022). On self-care education, Figure 6 identified 89% that benefitted between 6-18 years of age. Self-care education is crucial for SCD patients from childhood to adulthood. It helps them understand their symptoms, make informed decisions about their care, ultimately improving their quality of life. The need for self-care education is essential in adolescence/ young adulthood, as individuals often experience increased medical challenges (Matthie et al., 2015).

Age at diagnosis in Fig 7 indicated an overwhelming response (79%) at 6-18yrs, with less than 5yrs 20.5%, and adult 0.9% respectively. This variability in symptomatology of the disease is based on variables, including genetic factors and environment that can enhance or reduce the severity of the symptoms before presentation. Even in severe form, there is diversity in disease manifestation among patients with identical hemoglobin genotypes, social and environmental factors (Oluwole et al., 2022; Tebbi, 2022). This contrasts with study carried out that in the West where early neonatal screening and hospitalization lead to early diagnosis (Esoh et al., 2021, Lage et al., 2022).

Knowledge sources in Fig 8 showed mass media and friends/co-workers were low sources of information 3%. This is followed in an ascending order by family members and health workers with 39% and 58% respectively consistent with studies emphasizing health worker education and screening (Babalola et al., 2019). On prevention consensus, Table 6 indicated that all participants agree (100%) that SCD can be prevented aligning with a study (Isa et al., 2023). This contrasts with other schools of thought that state that since SCD is genetic, it cannot be prevented by vaccines and medications (Booth et al., 2010) or lifestyle changes or when SCD preventive measures are unknown to majority (Kanma-Okafor et al., 2022). There needs to be adequate knowledge for its prevention.

These observations surmise that SCD patients are increasingly hopeful that with knowledge on SCD, patients can be screened early, anticipate improved management of symptoms with reduced frequency of complications, and potentially live longer healthier lives. This knowledge empowers

individuals to better understand their condition, make informed decisions about their health, and actively participate in their care.

6.3. How are the perception of patients on diagnosis and management practices?

On sadness according to Table 3, 100% of sickle cell disease (SCD) patients reported feeling sad upon diagnosis, reflecting the innate risk of sadness associated with this chronic, debilitating condition. Factors associated to these depressive symptoms are recurrent painful crises, frequent hospitalizations, blood transfusions, negative body image perceptions, and multiple organ damage (Jiya et al., 2024; Stokoe et al., 2021).

On reactions & misconceptions an overwhelming majority (71.1%) experienced self-denial after diagnosis, a common struggle linked to the disease's variable severity, stigma, and life challenges (Jeanerette et al., 2010; Leger et al., 2018). This stigma was highlighted by a patient noting that in Nigeria, SCD is often a taboo topic, discouraging open discussions (Abayomi, 2022). A minority (0.9%) perceived SCD as a spiritual illness, a view also noted in other studies (Anie, 2024). Similarly, 26.2% felt it was a death sentence, although research from Delta State and elsewhere refutes this, emphasizing that individuals can live well with proper management (Idowu, 2021; Oluwagbemi, 2025). Conversely, 71.1% viewed SCD as a challenge they hoped to overcome (Forrester et al., 2015). Anxiety was also highly prevalent (72.2%) leading to poor treatment adherence, increased pain, and disruptions in various aspects of life (Essien et al., 2023).

On its psychological impact patients reported feeling abnormal (22.3%) (Ambrose et al., 2024) and overwhelmingly believed they were a burden to their parents (91.7%). This perception of being a burden stems from the chronic nature of SCD, the need for constant care, and the financial/emotional strain caused by crises and hospitalizations as noted in some studies (Adegoke & Kuteyi, 2012; Muoghalu, 2016). In addition, 39.6% felt SCD was a punishment (Anie, 2024), and 8.3% believed herbs could cure it. On anxiety, 72.2% were anxious when diagnosis. This is a common attitude (Essien et al., 2023). Depression and anxiety were prevalent among individuals with SCD.A small group (10.4%) was indifferent to their diagnosis (Adesoye, 2024). Adesoye noted that many who were addressed as ‘sicklers’ were offended in reaction while certain others by contrast were indifferent to being labeled ‘sickler’.

On spirituality, coping & hope despite challenges, played a role for some, offering comfort, anxiety relief, and social support, though it could also be impaired (Gomes et al., 2019, Harrison et al.,2005). In some communities SCD is perceived as a spiritual illness or a punishment, leading to a lack of understanding and support for individuals and families affected by the condition. Individuals with SCD experience spirituality motivated by their hope for a miracle and fear of death. Crucially, nearly all patients (96.4%) expressed hope that management at SCD clinics would help restore their health with a good quality of life (Abadesso et al., 2022; Abboud, 2022; Kanter et al., 2020).

Some people believe that sickle cell disease is a death sentence. Contrary to this, in Delta State and in several studies conducted it has been stated it is not a death sentence (Idowu, 2021, Oluwagbemi, 2025).There is a need to appropriately manage patients with sickle cell disease, not just from a pain perspective, but also from a whole life perspective using a more comprehensive model. To address this, there is a need for better education for health care providers and increased research funding (Kanter & Kruse-Jarres., 2013).

71.1% felt it was a challenge and had the hope it would be overcome. This is supported in a study (Forrester et al., 2015). Study admitted that SCD can be very challenging for the adolescent, but with positive self-concept and increased social support, especially from family and peers, these adolescents effectively cope with their condition and live productive lives.

These findings underscore the profound psychosocial impact of SCD and the need for a comprehensive care model addressing not just pain, but the whole patient. This requires better education for healthcare providers, increased research funding (Kanter & Kruse-Jarres, 2013), and the essential role of specialized SCD clinics. These clinics, supervised by the Ministry of Health in Delta State, are vital vehicles for implementing key interventions, providing sensitization, caregiver training, health education, and genetic counseling.

7. Conclusion on Knowledge and Perception

The analysis reveals a complex interplay between patient knowledge, emotional responses, and socio-cultural perceptions of Sickle Cell Disease (SCD). While patients show a foundational understanding of SCD as an inherited disorder, significant gaps, challenges and misconceptions

persist, with many misidentifying it primarily as a bone disease or conflating both aspects. This incomplete knowledge may stem from limited access to accurate information and the influence of cultural belief. Emotionally, diagnosis triggers overwhelmingly negative reactions, with all participants reporting sadness and anxiety. Common initial perceptions include viewing SCD as a "death sentence" or a "punishment", reflecting deep-seated stigma and fear. A majority experience self-denial, partly due to societal taboos in Nigeria that discourage open discussion of SCD. The perception of being a burden underscores a psychological toll. Despite these challenges most believe the sickle cell specialized clinics offer hope and succor highlighting trust in patient-centred care, most patients endorse genotype testing and education as key to prevention, though a minority still believe in herbal cures. Socially family and health workers far outweigh media, emphasizing the critical role of healthcare providers in education.

In summary, while patients exhibit hope and optimism about advances in treatment (e.g., gene therapy) and the efficacy of specialized clinics, their knowledge is often fragmented, and their emotional burden is profound. Addressing misconceptions, reducing stigma, and expanding access to accurate education especially through healthcare providers are essential to improving SCD management and quality of life(Abadesso et al., 2022). The findings advocate for a holistic care model that integrates medical, psychological, and social support.

Acknowledgements

The staff and colleagues at Novena University, Ogume; as well as in Delta State Ministry of Health, Asaba and the Hospital Management Board are highly appreciated for their various supports during ethics process and data collection.

Funding: Nil

Conflict of Interest: nil

Data repository: All data are as presented

References

Abadesso, C., Pacheco, S., Machado, M. C., & Allen Finley, G. (2022). Health-Related Quality of Life Assessments by Children and Adolescents with Sickle Cell Disease and Their Parents in Portugal. *Children*, *9*(2). https://doi.org/10.3390/children9020283

Abboud, M. R. (2020). Standard management of sickle cell disease complications. *Hematology/oncology and stem cell therapy*, *13*(2), 85–90. https://doi.org/10.1016/j.hemonc.2019.12.007

Abayomi, A. (2022). Sickle Cell and Living in Denial. *Sickle cell.com* [Online]. https://sickle-cell.com/living/denial-stigma

Adegoke, S. A., & Kuteyi, E. A. (2012). Psychosocial burden of sickle cell disease on the family, Nigeria. *African Journal of Primary Health Care and Family Medicine*, *4*(1). https://doi.org/10.4102/phcfm.v4i1.380

Adesoye, O. (2024). How 'sickler' perpetuates harmful stigmas about sickle cell warriors. Sickle cell Disease news [Online]. https://sicklecellanemianews.com/columns/how-sickler-perpetuates-harmful-stigmas-about-sickle-cell-warriors/

Adewoyin, A. S. (2015). Management of sickle cell disease: A review for physician education in Nigeria (Sub-Saharan Africa). *Anemia* 2015(1). https://doi.org/10.1155/2015/791498

Adigwe, O. P., Onavbavba, G., & Onoja, S. O. (2023). Impact of Sickle Cell Disease on Affected Individuals in Nigeria: A Critical Review. *International Journal of General Medicine*, *Volume 16*. https://doi.org/10.2147/ijgm.s410015

Adurokiya, E. (2021). Okowa inaugurates 18th sickle cell clinic, as Warri chair assures accessibility to facility. *Nigerian Tribune nespapers[online]*. https://tribuneonlineng.com/okowa-inaugurates-18th-sickle-cell-clinic-as-warri-chair-assures-accessibility-to-facility/

Ahon, F. (2017) . Delta Assembly adopts report on Sickle cell bill. *Vanguard newspapers[online]*. https://www.vanguardngr.com/2017/07/delta-assembly-adopts-report-sickle-cell-bill/

Ambrose E., Samson A., Aloyce, D., Smart, L.R (2024).Understanding Sickle Cell Disease Pain: Perception from Patients, Parents and Healthcare Providers in Northwestern Tanzania, .*Blood.* Volume 144, Supplement 1, Pg 5351. https://doi.org/10.1182/blood-2024-210336.

Ameh, S. J., Tarfa, F. D., & Ebeshi, B. U. (2012). Traditional herbal management of sickle cell anemia: Lessons from Nigeria. In *Anemia* 2012(1). https://doi.org/10.1155/2012/607436

Anie K. A. (2024). The intersection of sickle cell disease, stigma, and pain in Africa. *Hematology. 2024*(1), 240–245. https://doi.org/10.1182/hematology.2024000549

Bell, V., Varzakas, T., Psaltopoulou, T., & Fernandes, T. (2024). Sickle Cell Disease Update: New Treatments and Challenging Nutritional Interventions. *Nutrients*, *16*(2), 258. https://doi.org/10.3390/nu16020258

Booth, C., Inusa, B., & Obaro, S. K. (2010). Infection in sickle cell disease: a review. *International journal of infectious diseases : IJID : official publication of the International Society for Infectious Diseases*, *14*(1), e2–e12. https://doi.org/10.1016/j.ijid.2009.03.010

Collier, R. (2012). The downside of genetic screening. CMAJ 184(8): 862-864. https://doi.org/10.1503/cmaj.109-4169

Diwe, K., Iwu, A., Uwakwe, K., Duru, C., Merenu, I., Ogunniyan, T., Oluoha, U., Ndukwu, E., & Ohale, I. (2016). Prevalence and Patterns of Sickle Cell Disease among Children Attending Tertiary and Non-Tertiary Health Care Institutions in a South Eastern State, Nigeria: A 10 year Survey. *Journal of Research in Medical and Dental Science*, *4*(3). https://doi.org/10.5455/jrmds.2016432

Dennis-Antwi, J. A., Ohene-Frempong, K., Anie, K. A., Dzikunu, H., Agyare, V. A., Boadu, R. O et al (2018). Relation Between Religious Perspectives and Views on Sickle Cell Disease Research and Associated Public Health Interventions in Ghana. *J Genet Couns*, 10.1007/s10897-018-0296-7. https://doi.org/10.1007/s10897-018-0296-7

Efe, I. (2013). Health care problem and management in Nigeria. *Journal of Geography and Regional Planning*, *6*(6). https://doi.org/10.5897/jgrp2013.0366

Esoh, K., Wonkam-Tingang, E., & Wonkam, A. (2021). Sickle cell disease in sub-Saharan Africa: transferable strategies for prevention and care. In *The Lancet Haematology* (Vol. 8, Issue 10). https://doi.org/10.1016/S2352-3026(21)00191-5

Galadanci, N., Wudil, B. J., Balogun, T. M., Ogunrinde, G. O., Akinsulie, A., Hasan-hanga, F., et al. (2014). Current sickle cell disease management practices in Nigeria. *International Health*, *6*(1). 23-28. https://doi.org/10.1093/inthealth/iht022

Essien, E. A., Winter-Eteng, B. F., Onukogu, C. U., Nkangha, D. D., & Daniel, F. M. (2023). Psychosocial challenges of persons with sickle cell anemia: A narrative review. *Medicine*, *102*(47), e36147. https://doi.org/10.1097/MD.0000000000036147

Forrester, A. B., Barton-Gooden, A., Pitter, C., & Lindo, J. L. (2015). The lived experiences of adolescents with sickle cell disease in Kingston, Jamaica. *International journal of qualitative studies on health and well-being*, *10*, 28104. https://doi.org/10.3402/qhw.v10.28104

Gomes, M. V., Xavier, A. D. S. G., Carvalho, E. S. S., Cordeiro, R. C., Ferreira, S. L., & Morbeck, A. D. (2019). "Waiting for a miracle": Spirituality/Religiosity in coping with sickle cell disease. *Revista Brasileira de Enfermagem*, *72*(6). https://doi.org/10.1590/0034-7167-2018-0635

Harrison, M. O., Edwards, C. L., Koenig, H. G., Bosworth, H. B., Decastro, L., & Wood, M. (2005). Religiosity/spirituality and pain in patients with sickle cell disease. *Journal of Nervous and Mental Disease*, *193*(4). https://doi.org/10.1097/01.nmd.0000158375.73779.50

Idowu, S. (2021). Sickle cell not Death sentence, Dame Edith Okowa declares. *This day newspaper [Online]*. https://www.thisdaylive.com/index.php/2021/08/12/sickle-cell-not-death-sentence-dame-okowa-declares/

Ikediashi, B. G., Ehrmann, C., Gomez, S., & Michel, G. (2023). Disease knowledge and health literacy in parents of children with sickle cell disease. *EJHaem*, *4*(4), 956–962. https://doi.org/10.1002/jha2.762

Inusa, B. P. D., Hsu, L. L., Kohli, N., Patel, A., Ominu-Evbota, K., Anie, K. A., & Atoyebi, W. (2019). Sickle Cell Disease-Genetics, Pathophysiology, Clinical Presentation and Treatment. *International journal of neonatal screening*, *5*(2), 20. https://doi.org/10.3390/ijns5020020

Isa, H., Okocha, E., Adegoke, S. A., Nnebe-Agumadu, U., Kuliya-Gwarzo, A., Sopekan, A., et al. (2023). Strategies to improve healthcare services for patients with sickle cell disease in Nigeria: The perspectives of stakeholders. *Frontiers in genetics*, *14*, 1052444. https://doi.org/10.3389/fgene.2023.1052444

Jenerette, C. M., & Brewer, C. (2010). Health-related stigma in young adults with sickle cell disease. *Journal of the National Medical Association*, *102*(11), 1050–1055. https://doi.org/10.1016/s0027-9684(15)30732-x

Jiya, F. B., Jiya, N. M., Baba, J., Bakare, A. T., Ibitoye, P. K., Adamu, A., et al. (2024). Depressive Symptoms among Children with Sickle Cell Anemia in a Tertiary Health Facility in North-Western Nigeria. *Nigerian Journal of Basic and Clinical Sciences*, *21*(1). https://doi.org/10.4103/njbcs.njbcs_62_23

Jonathan, A., Tutuba, H., Lloyd, W., Ndunguru, J., Makani, J., Ruggajo, P., et al. (2022). Healthcare Workers' Knowledge and Resource Availability for Care of Sickle Cell Disease in Dar es Salaam, Tanzania. *Frontiers in genetics*, *12*, 773207. https://doi.org/10.3389/fgene.2021.773207

Kanma-Okafor, O. J., Abolarinwa, A. O., Ojo, O. Y., & Ekanem, E. E. (2022). Sickle cell disease prevention: How prepared are the senior secondary school students in Surulere Local Government Area, Lagos, Nigeria? *African Journal of Primary Health Care and Family Medicine*, *14*(1). https://doi.org/10.4102/phcfm.v14i1.3260

Kanter, J., & Kruse-Jarres, R. (2013). Management of sickle cell disease from childhood through adulthood. *Blood Reviews*, *27*(6). https://doi.org/10.1016/j.blre.2013.09.001

Kanter, J., Smith, W. R., Desai, P. C., Treadwell, M., Andemariam, B., Little, J et al. (2020). Building access to care in adult sickle cell disease: Defining models of care, essential components, and economic aspects. *Blood Advances*, *4*(16). https://doi.org/10.1182/bloodadvances.2020001743

Leger, R. R., Wagner, L. D., & Odesina, V. (2018). Stigma in adults with sickle cell disease and family members: Scale development and pilot study in the USA and Nigeria. *International Journal of Africa Nursing Sciences*, *9*. https://doi.org/10.1016/j.ijans.2018.06.003

Lubega, I., Ndugwa, C. M., Mworozi, E. A., & Tumwine, J. K. (2015). Alpha thalassemia among sickle cell anaemia patients in Kampala, Uganda. *African Health Sciences*, *15*(2). https://doi.org/10.4314/ahs.v15i2.48

Mangla, A., Ehsan, M., Agarwal, N., Maruvada, S., & Doerr, C. (2021). Sickle Cell Anemia (Nursing). In *StatPearls* *https://www.ncbi.nlm.nih.gov/books/NBK568706/*

Masuwai, A., Zulkifli, H., & Hamzah, M. I. (2024). Evaluation of content validity and face validity of secondary school Islamic education teacher self-assessment instrument. *Cogent Education*, *11*(1). https://doi.org/10.1080/2331186X.2024.2308410

Matthie, N., Hamilton, J., Wells, D., & Jenerette, C. (2016). Perceptions of young adults with sickle cell disease concerning their disease experience. *Journal of Advanced Nursing*, *72*(6). https://doi.org/10.1111/jan.12760

Matthie, N., Jenerette, C., & McMillan, S. (2015). Role of Self-Care in Sickle Cell Disease. *Pain Management Nursing*, *16*(3). https://doi.org/10.1016/j.pmn.2014.07.003

Mulumba, L. L., & Wilson, L. (2015). Sickle cell disease among children in Africa: An integrative literature review and global recommendations. In *International Journal of Africa Nursing Sciences* 3: 56-64. https://doi.org/10.1016/j.ijans.2015.08.002

Munung, N. S., Kamga, K. K., Treadwell, M. J., Dennis-Antwi, J., Anie, K. A., Bukini, D., et al (2024). Perceptions and preferences for genetic testing for sickle cell disease or trait: a qualitative study in Cameroon, Ghana and Tanzania. *European journal of human genetics : EJHG*, *32*(10), 1307–1313. https://doi.org/10.1038/s41431-024-01553-7

Muoghalu, C. (2016). The Burden of Sickle Cell Disease to Parents of Sufferers in Nigeria. *International Journal of Genetic Science*, *3*(1). https://doi.org/10.15226/2377-4274/3/1/00113

Namugerwa, C.H., Gavamukulya, Y. & Barugahare, B.J. (2023). Knowledge and attitude towards sickle cell anemia among care givers of paediatric sickle cell patients at a tertiary hospital in Eastern Uganda: a cross-sectional study. *BMC Res Notes* **16**, 351. https://doi.org/10.1186/s13104-023-06633-3

Nihan, S. T. (2020). Karl Pearsons chi-square tests. *Educational Research and Reviews*, *15*(9). https://doi.org/10.5897/err2019.3817

Odunvbun, M. E., Okolo, A. A., & Rahimy, C. M. (2008). Newborn screening for sickle cell disease in a Nigerian hospital. *Public Health*, *122*(10):1111-6. https://doi.org/10.1016/j.puhe.2008.01.008

Oguntoye, A. O., Eades, N. T., Ezenwa, M. O., Krieger, J., Jenerette, C., Adegbola, M., et al. (2022). Factors associated with young adult engagement with a web-based sickle cell reproductive health intervention. *PEC Innovation*, *1*. https://doi.org/10.1016/j.pecinn.2022.100063

Okocha, E. C., Gyamfi, J., Ryan, N., Babalola, O., Etuk, E. A., Chianumba, R et al (2022). Barriers to Therapeutic Use of Hydroxyurea for Sickle Cell Disease in Nigeria: A Cross-Sectional Survey. *Frontiers in Genetics*, *12*. https://doi.org/10.3389/fgene.2021.765958

Okwe, U. N., Ofili, C. C., & Nwose, E. U. (2024). Perception of sickle cell patients on their diagnosis and management practices at the eighteen sickle cell clinics of Delta State Nigeria: The research protocol. *Protocol.io*. https://www.protocols.io/view/perception-of-sickle-cell-patients-on-their-diagno-261gerxjjl47/v1

Okwe, U. N., Ofili, C. C., & Nwose, E. U. (2025). Assessment of demographic variables of patients at sickle cell clinics of Delta state, Nigeria. *Afr Chron Res Pub J*, *1*(1), 37-66. https://researchpubjournals.org/?post=1442

Oluwagbemi, A. (2017).Sickle cell disease, not death sentence – Expert. *Punch[online]*. https://punchng.com/sickle-cell-disease-not-death-sentence-expert/

Oluwole, E. O., Okoye, C. D., Ogunyemi, A. O., Olowoselu, O. F., & Oyedeji, O. A. (2022). Knowledge, attitude and premarital screening practices for sickle cell disease among young unmarried adults in an urban community in Lagos, Nigeria. *Pan African Medical Journal*, *42*. https://doi.org/10.11604/pamj.2022.42.8.27705

Onuba, O. (1993). Bone disorders in sickle-cell disease. *International Orthopaedics*, *17*(6). https://doi.org/10.1007/BF00180461

Osei-Boakye, F., Nkansah, C., Appiah, S. K., Abbam, G., Derigubah, C. A., Ukwah, B. N., et al (2024). Self-reported high-risk behavior among first-time and repeat replacement blood donors; a four-year retrospective study of patterns. *PloS one*, *19*(8), e0308453. https://doi.org/10.1371/journal.pone.0308453

Oyedeji, C., Strouse, J. J., Crawford, R. D., Garrett, M. E., Ashley-Koch, A. E., & Telen, M. J. (2019). A multi-institutional comparison of younger and older adults with sickle cell

disease. *American journal of hematology*, *94*(4), E115–E117. https://doi.org/10.1002/ajh.25405

Rees, D. C., Brousse, V. A. M., & Brewin, J. N. (2022). Determinants of severity in sickle cell disease. In *Blood Reviews* (Vol. 56). https://doi.org/10.1016/j.blre.2022.100983

Rodenberg CA (2009). A Review of: "Health Measurement Scales: A Practical Guide to Their Development and Use. 4th Ed, by D. L. Streiner and G. R. Norman." *Journal of Biopharmaceutical Statistics*, *19*(6). https://doi.org/10.1080/10543400903244262

Sadhere, F. (2021). Dame Okowa commissions sickle cell clinic in Warri. *Business day NG[Online]*. https://businessday.ng/news/article/dame-okowa-commissions-sickle-cell-clinic-in-warri/

Stokoe, M., Zwicker, H. M., Forbes, C., Abu-Saris, N. E. L. H., Fay-McClymont, T. B., Désiré, N., et al. (2022). Health related quality of life in children with sickle cell disease: A systematic review and meta-analysis. In *Blood Reviews* (Vol. 56). https://doi.org/10.1016/j.blre.2022.100982

Tebbi, C. K. (2022). Sickle Cell Disease, a Review. In *Hemato* (Vol. 3, Issue 2). https://doi.org/10.3390/hemato3020024

Thein, S. L., & Howard, J. (2018). How I treat the older adult with sickle cell disease. *Blood*, *132*(17). https://doi.org/10.1182/blood-2018-03-818161

Vaske, J. J., Beaman, J., & Sponarski, C. C. (2016). Rethinking internal consistency in Cronbach's Alpha. *Leisure Sciences*. 39(2), 163-173. http://dx.doi.org/10.1080/01490400.2015.1127189

Verma, H. K. (2019). Clinically diverse sickle cell disease influenced by genetic factors. In *Hematologia* (Vol. 10, Issue 4). https://doi.org/10.5603/Hem.2019.0036

Zaki, R., Bulgiba, A., Ismail, R., & Ismail, N. A. (2012). Statistical methods used to test for agreement of medical instruments measuring continuous variables in method comparison studies: A systematic review. *PLoS One 7(5), e37908*. https://doi.org/10.1371/journal.pone.0037908.