Public Health Research
Okwe et al. Afr Chron Res Pub J 2025 2(1):25-43
Article URL: https://researchpubjournals.org/?post=1454

Cross-sectional study of age-related differences in knowledge and perception towards management practices among SCD 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: 23/09/2025

Published: 06/10/2025

Public Health Research
Okwe et al. Afr Chron Res Pub J 2025 2(1):25-43
Article URL: https://researchpubjournals.org/?post=1454

Abstract

Background: Sickle cell disease (SCD) is an inherited disease that causes red blood cell deformity. The knowledge & perception towards management practices among patients attending sickle cell disease clinics has been of interest. Yet, the impact of age among those attending SCD clinics in Delta State Nigeria is unknown.

Objective: To evaluate the age-related differences in knowledge, perception and management practices among sickle cell patients attending sickle cell clinics of Delta state.

Method: This cross-sectional descriptive quantitative study analyzed age-related influences on variables like health knowledge and perceptions among 700 SCD patients at Delta State. Likert scaled questionnaires were 9-items for knowledge, and 12-items for perception. Descriptive statistics included frequency distributions and Chi-Square tests used to examine associations and test research hypotheses.

Results: There are positive associations with age and knowledge that having SS, DNA and parents with S gene could cause SCD; and infection of SS blood predisposing to SCD crisis ($p < 0.0001$). There is erroneous perception that having parent with AC or CC gene makes someone vulnerable to SCD ($p < 0.007$). Statistically non-significant negative associations are observed with age regarding marriage, drinking alcohol and having close relatives. The perception of 'being a burden to parents' and that 'SCD is a punishment' are significantly positively associated with age ($p <0.01$), but other considerations are negative and non-significant.

Conclusion: The relationship between age and SCD knowledge and perception is complex. Tailored care, including comprehensive health education, is crucial for different age groups.

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

Public Health Research
Okwe et al. Afr Chron Res Pub J 2025 2(1):25-43
Article URL: https://researchpubjournals.org/?post=1454

1. Background

Sickle cell disease (SCD) is a genetic blood disorder where red blood cells become rigid and abnormally shaped, leading to various health issues (Mangla, 2021). . Research suggests a link between age and perceptions toward SCD, with younger adults (18-28) often showing more positive views than older adults (>50) (Al-Qattan et al., 2019; Matthie et al., 2016; Oyedeji et al., 2019). This may indicate that younger individuals are more open to learning about SCD and adopting preventive measures.

Studies consistently show a strong connection between knowledge of SCD and positive perceptions of the disease. People who understand SCD better are more likely to have positive views on its prevention, screening, and management (Namugerwa et al., 2023). Education level, occupation, and access to information about SCD can all influence these attitudes; for instance, those with higher education or formal training in SCD tend to be more knowledgeable and have more positive perceptions (Kanma -Okafor et al., 2022).

While some studies indicate that older participants may be more knowledgeable about SCD, others show that knowledge scores increase with age but not always significantly. Ultimately, individual experiences, support systems, health education, and coping mechanisms for SCD all play a role in shaping perceptions and attitudes towards the disease. Understanding these factors is crucial for developing effective public health strategies and interventions to improve outcomes for individuals with SCD (Mulumba & Wilson, 2015). A study reported that a significant association was found between good knowledge and positive perception towards SCD (Agbozo et al., 2023). Another reported that older participants were more knowledgeable about SCD (Ikediashi et al., 2023).

Yet, another study supported that the mean knowledge score may increase with age but was not significant (Adewoyin,2015). Therefore, the general patterns in knowledge, perception, health risk behavior, and individual attitudes are shaped by personal experiences, knowledge, support systems, health education, health promotion, and SCD coping mechanisms.

2.0. Statement of the Problem

Most SCD crises are amenable to treatment, but interventions and management for all ages 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 affect patient-centred care at the hospitals. In Nigeria, the number of sickle cell clinics is inadequate (Adigwe et al., 2023; Collier, 2012; Galadanci et al., 2014). Therefore, any innovation to improve service delivery is welcomed. There are reports that older patients may be more knowledgeable about SCD but while a more recent report indicate significant association (Ikediashi et al., 2023), another one from 2015 indicated non-significance (Adewoyin, 2015). Therefore, the potential impact of age may require further investigation (Idris et. al., 2022). 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. Thus, there is research need among SCD patients in Delta State as the findings could inform service needs.

3.0. Objective:

3.1. General Objective

To investigate if there are statistically significant age-related differences in knowledge and/or perception SCD patients towards their management practices.

3.2. Research questions and associated hypothesis

Research Question 1: Does age of the SCD patient have an association with the knowledge of the SCD management practice (diagnosis and management)?

Null hypothesis (Ho): there is no significant association between the age of the SCD patients and knowledge of their management practice at the SCD clinics (diagnosis and management)?

Research question 2: Does the age of the SCD patient have an association with the Perception towards their management practice (SCD diagnosis and management)?

Null hypothesis (Ho): there is no significant association between the age and perception towards management practice (diagnosis and management) at the clinics.

4.0. Methods

4.1. Design and previous report: This was a second part to previous report (Okwe et. al, 2025a). Except for data and statistical analysis, the considerations of STROBE guideline including study

design, setting, participants, selection criteria, and ethical considerations are as previously published (Okwe et. al, 2025b).

4.2. Data collection: 9-item Likert scaled questionnaire for assessment on knowledge (Table 1), and 12-item categorical questionnaire on perception (Table 2).

4.3. Statistical Analysis: Descriptive and inferential analyses were performed. Data analysis included descriptive frequency distribution. With a focus inferential statistic at a 95% confidence level using SPSS version 20.0; statistical significance was set at p-value < 0.05. Chi-Square tests used to examine associations and test research hypotheses.

5.0. Results

5.1: Research Question 1: Does age of the SCD patient have an association with the **knowledge** of the SCD management practice? Alternate hypothesis (H_1) – there is significant association between the age of the SCD patients and knowledge of management practice (diagnosis and management) at the SCD clinics. Table 1 shows the SCD categories and the percentage of the Likert scale responses and association concerning the relationship of various age groups and their responses.

5.2. Research question 2: Does the age of the SCD patient have an association with the **perception** towards their management practice? The alternate hypothesis (H_1) – there is significant association between the age and perception towards the management practice (diagnosis and management) at the sickle cell clinics. Table 2 shows the Chi-square test and comparative crosstabs.

Public Health Research
Okwe et al. Afr Chron Res Pub J 2025 2(1):25-43
Article URL: https://researchpubjournals.org/?post=1454

Table 1 showing SCD categories and likert scale responses in research survey

Perceived knowledge of SCD	Age	Strongly disagree	Disagree	Undecided	Agree %	Strongly Agree %	Chi-square	P-value	Comment
Parents with S gene can cause sickle cell	13-18yrs	0	0	0	23.5% [a]	70.8% [b]	33.466[a]	0.0001	positive association
	Adults(≥19)	0	0	0	76.5% [a]	29.2% [b]			
Sibling with S gene makes me prone to SCD	13-18yrs	0	0	0	100% [a]	69.7% [b]	26.511[a]	0.0001	positive association
	Adults(≥19)	0	0	0	0	30.3% [b]			
Marrying someone with S-gene if i have SCD	13-18yrs	0	0	0	68.8% [a]	68.4% [a]	.003[a]	0.957	negative association
	Adults(≥19)	0	0	0	31.2% [a]	31.6% [a]			
DNA with SS shows i have SCD	13-18yrs	57.1%[a]	91.7%[b]	92.1%[b]	100% [b]	93.9%[b]	87.908[a]	0.0001	positive association
	Adults(≥19)	42.9%[a]	8.3%[b]	7.9%[b]	0	6.1%[b]			
Infection of SS blood makes me prone to having SCD crisis	13-18yrs	72.2%[a]	61.8%[a, b]	38.9%[b]	100%	33.3%[a, b]	24.531[a]	0.0001	positive association
	Adults(≥19)	27.8%[a]	38.2%[a, b]	61.1%[b]	0	66.7%[a, b]			
Drinking too much alcohol can cause deliveries of babies with SCD	13-18yrs	68.7%[a]	0	50.0%[a]	100.0%[a]	100.0%[a]	5.907[a]	0.116	Negative association
	Adults(≥19)	31.3%[a]	0	50.0%[a]	0	0			
Close relative with SCD	13-18yrs	78.8%[a]	0	100.0%[a]	66.7%[a]	67.0%[a]	6.617[a]	0.085	Negative association
	Adults(≥19)	21.2%[a]	0	0	33.3%[a]	33.0%[a]			
Parent with CC genotype makes you vulnerable to SCD	13-18yrs	100%[a, b]	16.7%[b]	80.0%[a, b]	73.9%[a]	69.7%[a]	33.343[a]	0.0001	positive association
	Adults(≥19)	0.2	83.3%[b]	20.0%[a, b]	26.1%[a]	30.3%[a]			
Parent with AC genotype makes you vulnerable to SCD	13-18yrs	50.0%[a]	0	20.0%[a]	57.1%[a]	69.6%[a]	12.700[a]	0.007	Positive association
	Adults(≥19)	50.0%[a]	0	80.0%[a]	42.9%[a]	30.4%[a]			

Table 2. Showing crosstab and association between the ages of participants and perception towards their diagnosis and management

Perceptions/attitudes	Group	Y%	N%	Chi -sq	P-value	Comment
I was sad	≤5yrs	20.50%	0.00%	[a]		Sad is constant
	13-18	78.60%	0.00%			
	adult	0.90%	0.00%			
Unacceptable diagnosis	≤5yrs	20.1% a	21.6% a	2.602 [a]	0.272	Negative association
	13-18	78.7% a	78.4% a			
	adult	1.2% a	0			
It is spiritual	≤5yrs	33.3% a	20.4% a	.646[a]	0.724	Negative association
	13-18	66.7% a	78.7% a			
	adult	0	0.9% a			
It is a death sentence	≤5yrs	35.0% a	19.6% b	5.710[a]	0.058	Negative association
	13-18	65.0% a	79.4% b			
	adult	0.00%	0.9% a			
A challenge to overcome	≤5yrs	20.7% a	0.00%	.475[a]	0.788	Negative association
	13-18	78.4% a	16.7% a			
	adult	0.9% a	83.3% a			
Feel anxious of my diagnosis and treatment	≤5yrs	20.1% a	37.5% a	2.982[a]	0.225	Negative association
	13-18	79.0% a	62.5% a			
	adult	0.9% a	0			
Feel Abnormal	≤5yrs	26.7%a	18.8% b	5.015[a]	0.081	Negative association
	13-18	72.0%a	80.5% b			
	adult	1.3% a	0.8% a			
Feel I am a burden to my parents	≤5yrs	43.0% a	12.8 b	72.709[a]	0	Positive association
	13-18	57.0% a	86.0% b			
	adult	0.00%	1.2% a			
SCD is a punishment	≤5yrs	26.3% a	16.70%	9.21[a]	0.007	Positive association
	13-18	72.2% a	82.8% b			
	adult	1.5% a	0.3% b			
Hopeful that the management at the clinics will be of help	≤5yrs	20.50%	0.00%	[a]		Constant
	13-18	78.60%	0.00%			
	adult	0.90%	0.00%			
SCD can be cured by herbs	≤5yrs	25.0% a	20.9% a	1.238[a]	0.539	negative
	13-18	75.0% a	78.1% a			
	adult	0.00%	1.0% a			
Indifferent about my management	≤5yrs	28.6% a	19.6% a	3.662[a]	0.16	Negative association
	13-18	71.4% a	79.4% a			
	adult	0.00%	1.0% a			

6. Discussions

6.1. *Overview*

A total of 672 patients responded to the questions on management and perception. Ages of these patients were classified to subpopulations. The associations of age of participants with knowledge and perceptions on diagnosis and management practice were noted.

6.2: Does age of the SCD patient have an association with the knowledge of the SCD management practice?

6.3. Significant Chi- Square associations with Z test follow-up was found in the some variables like parents with S-gene cause SCD, siblings with S-gene cause SCD, infection with SS blood cause SCD. A significant association was found between age and the understanding that parents with the S gene can cause SCD (Table 1). Both adolescents (14-18) and adults agreed, but the specific distribution of "agree" vs. "strongly agree" responses differed significantly between age groups (Z-test). This finding aligns with studies showing participant genotype as a predictor of understanding SCD inheritance (Aldossary et al., 2022).

A significant association was also found between age and the belief that having siblings with the S- gene makes one prone to SCD (Table 1). Both age groups agreed on this link, indicating a lack of disagreement regarding sibling genetics and SCD risk, despite the statistical association. This supports the emphasis on the genetic cause of SCD where it was stated that SCD is a monogenetic disorder due to a single base-pair point mutation in the β-globin gene resulting in the substitution of the amino acid valine for glutamic acid in the β-globin chain. Phenotypic variation in the clinical presentation and disease outcome is a characteristic feature of the disease (Inusa et al., 2019). However, having a sibling with Sickle Cell Disease (SCD) does not automatically make one prone to it, but it does indicate a potential family risk, as SCD is an inherited genetic condition (Graff et al., 2010). Another significant association was found between age and the response that infection with SS blood makes one prone to SCD (Chi-square $p < 0.05$). However, the subsequent Z-test revealed no significant difference in responses between age groups. This suggests the initial association may be due to random chance rather than a true age effect. In a study, Thein and Howard in 2018 identified that the primary goal in management of the older adult with SCD is improving anemia

and minimizing organ damage and postulated that curative therapies previously offered to the younger patient be considered and discussed early, before complications including infections render the patients ineligible for these treatments.

6.4. Non- Significant associations with age (Chi-square)

This association was DNA with SS shows SCD, marrying someone with S-Gene, alcohol causes SCD in babies, close relative with SCD causes sickle cell and parent with AC trait cause SCD.

There was no strong statistical correlation was found between age and the response that having DNA with SS means one has SCD (Z-test). This suggests age does not significantly influence the understanding of diagnosis based on genotype, despite known phenotypic variation in disease severity (Inusa et al., 2019; Thein & Howard, 2018).

There was no association between age and the response to the idea of marrying someone with the S gene if one has SCD (p=0.957). Age does not appear to influence attitudes towards potential partners in this context. This lack of correlation is important because it suggests that factors other than age are likely driving decisions about who to marry when considering sickle cell status. For example, some studies have shown that awareness of sickle cell phenotypes, willingness to take risks, and understanding of the implications of SCD can influence these decision (Adesola et al., 2025).

No association was found between age and the response that drinking too much alcohol can cause the delivery of babies with SCD (p = 0.116). This perception does not vary significantly with age. There is no established link of this as it is an inherited disease; alcohol can exacerbate complications in individuals with SCD (Wilson et al., 2020). There was also no association found between age and the response that having a close relative with SCD could cause it in oneself (p = 0.085). This lack of association between age and belief about familial inheritance of SCD is important because it suggests that regardless of age, individuals may hold similar beliefs about how SCD is passed down through families. This is supported in some studies where there is a perceived likelihood to be a parent in young adults with SCD or SCT was also shown to be influenced by others (Aldossary et al.,2022; Egesa et al., 2022).

There was no association of age and SCD can be cured with herbs. This is significant as a study carried out in Northern Uganda indicated that while hydroxyurea has been introduced as a

treatment for SCD, herbal medicines remain widely used across Africa (Awor et al., 2025). A Chi-square test indicated a significant association between age and the response that a parent with AC trait and CC genotype makes one vulnerable to SCD, the Z-test showed no significant difference in responses. This indicates the association is weak and likely not meaningful. This aligns with studies carried out (Tarazi et al., 2007).

Overall, while Chi-square tests initially suggested relationships between age and responses to several knowledge questions, subsequent Z-tests revealed that most of these apparent associations were not significant. This indicates that the observed patterns in the Chi-square results were likely due to chance and do not reflect a strong, consistent correlation between patient age and their responses regarding SCD knowledge and genetics

6.5. Does the age of the SCD patient have an association with their perception?

6.6. Hypothesis testing revealed that age generally had a negative association with most perceptions of SCD management practices (as summarized in Table 2) and there were two perceptions which showed a positive association with age which are feeling like a burden to parents and viewing SCD as a punishment. Younger patients more likely view SCD as a punishment or death sentence due to limited understanding and emotional regulation challenges. They often experience heightened anxiety and feelings of abnormality stemming from symptom unpredictability and hospitalizations (Egesa et al., 2022) while older patients are less likely to view SCD as a punishment or death sentence as they develop coping strategies and have gained a better understanding of the disease leading to reduced anxiety (Tebbi et al., 2022).

Patients across ages maintained a consistent level of hopefulness aligning with other studies that show new interventions introduced in the cure for SCD (Christy & Fisher, 2025). Cultural emphasis on traditional remedies (Matthie et al., 2016) and disease complexity can shape beliefs. Younger patients' understanding of SCD cures may be limited. Older patients in some studies may become less hopeful about herbal cures as they experience the disease's chronic nature, while others attribute their diagnosis to spiritual causes and use spiritual coping mechanisms (Harrison et al., 2005). Conversely this this study found younger adults less likely to use spirituality,

influenced by individual circumstances, culture and personal beliefs as supported by Carey in 2018.

Specific Perceptions that are constant across all ages include feelings of sadness were reported by patients of all ages and hopefulness that clinic management and interventions would be helpful was expressed across age groups. This was acknowledged in some studies (Jiya et al., 2024; Kanter et al., 2020). Being a burden to parents showed various findings that ranged from complex and sometimes contradictory associations with age across studies. There were positive associations in a 2023 study of Adolescent health which found that adolescents between 13 -19years reporting increased feelings of being a burden to their parents as they grew older especially as they transitioned to independence at 20-39 years (Clayton-Jones, 2023). Negative associations were expressed in children in a study in 2023 where children between 8-12 years reported decreased perception of being a burden to parents as they grew older (Campbell et al., 2023). Another study in the SCD adolescent research showed no significant association and was neutral (Abadesso et al., 2022). Influencing factors showed variations which depend on developmental stage, disease severity and family dynamics and coping strategies.

It suffices that the relationship between patient's age and their perception of SCD is complex and multifaceted (Matthie et al., 2016). However, findings vary significantly depending on the specific perception being examined and the age- group studied. While the overall trend in this study indicated a negative association between ages and most perceptions (leading to acceptance of the null hypothesis), the exceptions and nuances highlighted above are crucial this complexity underscores the importance of tailoring care. Delta State SCD clinics should prioritize targeted interventions, including comprehensive health education for families, caregivers, and patients, to improve understanding and management outcomes across all age groups.

There were constant perceptions on being sad in all age groups when diagnosed with SCD as well as being hopeful that the management at the clinics will be of help. Depression and its symptoms are frequently observed in individuals with SCD. This observation has led to a higher probability of adverse health outcomes (Jiya et al., 2024; Sheriff et al., 2023).

7. Conclusion.

This study indicates that age significantly influences SCD patients' knowledge and perceptions towards management. Older patients generally exhibit better knowledge and understanding of their condition which fosters more realistic expectations. This enhanced understanding, often gained through sustained access to clinic-based education, care, and management services, contributes to the development of better coping mechanisms and established support systems. Consequently, older patients report increased feeling of security, increased resilience and stability. In contrast, younger patients often display decreased hopefulness and a belief in herbal cure. They may also feel guilty about the impact of their condition on their parents and abnormal due to unpredictability of SCD symptoms. However, individual perceptions vary widely depending on personal experiences, knowledge of the condition, cultural background and support systems**.** This study holds significant implications in policies of the Ministry of Health regarding the effective care of SCD patients in all Sickle cell clinics of the State. It underscores the importance for early detection and intervention to identify SCD early especially in high risk populations to initiate timely treatment and implement effective management strategies in infection prevention, nutrition and hydration, health education, monitoring and follow up as it boosts improvement of health outcomes of SCD .

Conflict of Interest: nil

Funding: nil

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

Adeleke, S., Nnodu, O. E., Emodi, I., Ahmed, S., Osegbue, A. O., Akinola, N., et al. (2023). Psychosocial challenges of persons with sickle cell anemia: A narrative review. *Medicine*, *102*(47), e36147. https://doi.org/10.1097/MD.0000000000036147

Adesola, A.A., Lawal, J.S., Akoki, D.M. *et al.* Determinants of marital decision despite sickle cell status awareness: a mixed method study. *BMC Public Health* **25**, 1824 (2025). https://doi.org/10.1186/s12889-025-23066-8

Adewoyin, A. S. (2015). Management of sickle cell disease: A review for physician education in Nigeria (Sub-Saharan Africa). In *Anemia* (Vol. 2015). 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

Agbozo, W. K., Amanor, E., Acheampong, E. O., Kotei, B., Attoh, L. N., Yeboah, D., et al. (2023). Assessing knowledge of sickle cell disease and health beliefs on premarital genetic screening among healthcare trainees at a tertiary institution: A cross-sectional study. *Health science reports*, *6*(2), e1128. https://doi.org/10.1002/hsr2.1128

Aldossary, D. S., Black, V., Ezenwa, M. O., Gallo, A. M., Johnson-Mallard, V. M., et al. (2022). Characteristics associated with the perceived likelihood to become parents among young adults with sickle cell disease or sickle cell trait in the USA. *Journal of Genetic Counseling*, *31*(3). https://doi.org/10.1002/jgc4.1535

Al-Qattan, H. M., Amlih, D. F., Sirajuddin, F. S., Alhuzaimi, D. I., Alageel, M. S., Bin Tuwaim, R. M., & Al Qahtani, F. H. (2019). Quantifying the Levels of Knowledge, Attitude, and Practice Associated with Sickle Cell Disease and Premarital Genetic Counseling in 350 Saudi Adults. *Advances in hematology*, *2019*, 3961201. https://doi.org/10.1155/2019/3961201

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

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

Awor, S., Opee, J., Ocaya, D., Ocaya, J., Abola, B., Malinga, G. M., et al. (2025). "We Cure Sickle Cell Disease with Herbs": Perspectives of Herbal Medicine Practitioners Treating Sickle Cell Disease in the Acholi Sub-Region. *Journal of Multidisciplinary Healthcare*, *18*, 4267–4277. https://doi.org/10.2147/JMDH.S534707

Campbell, A., Rizio, A., McCausland, K., Iorga, S., Yen, G., Paulose, J., & Lee, S. (2023). The Burden of Sickle Cell Disease on Children and Their Caregivers: Caregiver Reports of Children's Health-Related Quality of Life and School Experiences, Caregiver Burden, and Their Association with Frequency of Vaso-Occlusive Crises. *Patient Related Outcome Measures*, *Volume 14*. https://doi.org/10.2147/prom.s419607

Carey L.B. (2018). The Use of Religion in the Management of Depression in Sickle Cell Disease: A Systematic Review. *Journal Of Religion and Health*. https://link.springer.com/journal/10943/articles?filterOpenAccess=false&IFA&page=25

Christy, M., & Fisher, B. (2025). Gene Therapy: A New Hope in Sickle Cell Disease Treatment. *Journal of Pediatric Health Care; 39*(1), 122–129. https://doi.org/10.1016/j.pedhc.2024.07.007

Clayton-Jones, D. L., Hamilton, J. B., Haglund, K., Ong, L. Z., Kennedy, K. C., Pena, S., Stamper, L., & Jenerette, C. (2023). Sickle cell disease and adolescents' perspectives on self-care management resources. *Health Care Transitions*, *1*. https://doi.org/10.1016/j.hctj.2023.100026

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

Egesa, W. I., Nakalema, G., Waibi, W. M., Turyasiima, M., Amuje, E., Kiconco, G., et al. (2022). Sickle Cell Disease in Children and Adolescents: A Review of the Historical, Clinical, and Public Health Perspective of Sub-Saharan Africa and Beyond. *International journal of pediatrics*, *2022*, 3885979. https://doi.org/10.1155/2022/3885979

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

Feinstein, A. R. (1987). Clinimetric perspectives. *Journal of Chronic Diseases*, *40*(6). https://doi.org/10.1016/0021-9681(87)90027-0

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

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

Gomes, M. V., Xavier, A. da S. G., Carvalho, E. S. de 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

Graff, J. C., Hankins, J. S., Hardy, B. T., Hall, H. R., Roberts, R. J., & Neely-Barnes, S. L. (2010). Exploring parent-sibling communication in families of children with sickle cell disease. *Issues in comprehensive pediatric nursing*, *33*(2), 101–123. https://doi.org/10.3109/01460861003663987

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

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., Isezuo, K. O., & Abba, M. H. (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

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

Idris, I. M., Botchwey, E. A., & Hyacinth, H. I. (2022). Sickle cell disease as an accelerated aging syndrome. *Experimental biology and medicine (Maywood, N.J.)*, *247*(4), 368–374. https://doi.org/10.1177/15353702211068522

Jiya, F. B., Jiya, N. M., Baba, J., Bakare, A. T., Ibitoye, P. K., Adamu, A., Isezuo, K. O., & Abba, M. H. (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

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

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* (Vol. 3). https://doi.org/10.1016/j.ijans.2015.08.002

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

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

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., Nwose, E.U. (2025). Assessment of demographic variables of patients at sickle cell clinics of Delta state, Nigeria. African Chronicles Research Publication journals. 1(1):37-66. https://researchpubjournals.org/wp-content/uploads/2025/09/ACRPJ_20250619001.-Demography-of-SCD-patients-Delta-State.pdf

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

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, Fourth Edition, by D. L. Streiner and G. R. Norman." *Journal of Biopharmaceutical Statistics*, *19*(6). https://doi.org/10.1080/10543400903244262

Sheriff, M. M., Sr, Alsharif, A. K., Almalki, F. A., Alqurashi, W. A., Alqurashi, D. A., Abusabah, H. H., et al. (2023). The Occurrence of Depression Among Adults With Sickle Cell Disease in Saudi Arabia. *Cureus*, *15*(9), e44595. https://doi.org/10.7759/cureus.44595

Stokoe, M., Zwicker, H. M., Forbes, C., Abu-Saris, N. E. L. H., Fay-McClymont, T. B., 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

Tarazi, R. A., Grant, M. L., Ely, E., & Barakat, L. P. (2007). Neuropsychological functioning in preschool-age children with sickle cell disease: The role of illness-related and psychosocial factors. *Child Neuropsychology*, *13*(2). https://doi.org/10.1080/09297040600611312

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

Wilson, J. D., Lanzkron, S., Pecker, L. H., Bediako, S. M., Han, D., & Beach, M. C. (2020). Psychosocial and Clinical Risk Factors Associated with Substance Use in Observational Cohort of Patients with Sickle Cell Disease. *Substance use & misuse*, *55*(13), 2205–2212. https://doi.org/10.1080/10826084.2020.1797807

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.