INSIGHTS-JOURNAL OF
HEALTH AND REHABILITATION

INSIGHTS-JHR
INSIGHTS-JOURNAL OF HEALTH AND REHABILITATION

ASSESSING THE KNOWLEDGE AMONG UNDERGRADUATE NURSING STUDENTS REGARDING SICKLE CELL DISEASE, IN UNIVERSITY OF LAHORE

Original Research

Muhammad Adil[1]*, Madiha Asif[1], Hareem Ayesha[2], Ameer Hamza[3]
[1]BSN, Lahore School of Nursing, The University of Lahore, Pakistan.
[2]Doctor of Physical Therapy, Faculty of Allied Health Sciences, Gomal University, D I Khan, Pakistan.
[3]BS Surgical Technology, Faculty of Allied Health Sciences, Gomal University, D I Khan, Pakistan.
Corresponding Author: Muhammad Adil, BSN, Lahore School of Nursing, The University of Lahore, Pakistan. adilhashmi1212@gmail.com
Acknowledgement: The researcher gratefully acknowledges the support of the Lahore School of Nursing and all participating students.

Conflict of Interest: None
Grant Support & Financial Support: None

ABSTRACT

Background: Sickle cell disease (SCD) is a significant global public health concern, particularly prevalent in regions with high rates of consanguinity and malaria endemicity. It is a chronic, inherited hemoglobinopathy that leads to severe complications and reduced quality of life. Nurses, as key healthcare providers, must possess adequate knowledge of SCD to ensure early detection, patient education, and comprehensive care. Despite its importance, knowledge among nursing students remains insufficiently explored in many regions.

Objective: To assess the level of knowledge regarding sickle cell disease among undergraduate nursing students at the University of Lahore.

Methods: A descriptive cross-sectional study was conducted from September to December 2023 among 114 third- and fourth-year BS Nursing students selected through convenience sampling. Data were collected using a semi-structured, self-administered questionnaire consisting of two sections: demographic data and twelve knowledge-based items related to SCD. Responses were rated using a five-point Likert scale. Descriptive statistics were used to analyze frequencies and percentages, and results were categorized into poor (<60%), average (60%–85%), and good (>85%) knowledge levels. Ethical approval was obtained from the University of Lahore's ethical committee.

Results: Out of 114 participants, 104 (91.2%) were aged 18–25 years, and 66 (57.9%) were female. The majority of students, 89 (78.1%), demonstrated poor knowledge, while 22 (19.3%) had average knowledge, and only 3 (2.6%) showed good knowledge of SCD. Despite being in advanced years of study, a significant proportion lacked essential understanding of the disease, highlighting a critical educational gap.

Conclusion: The findings indicate a clear need for enhanced educational interventions and curriculum strengthening to improve knowledge of sickle cell disease among nursing students, thereby equipping future nurses to deliver quality care to affected individuals.

Keywords: Curriculum, Hemoglobinopathies, Knowledge, Nursing Students, Pakistan, Sickle Cell Disease, Students.

INSIGHTS-JOURNAL OF
HEALTH AND REHABILITATION

INSIGHTS-JHR
INSIGHTS-JOURNAL OF HEALTH AND REHABILITATION

INTRODUCTION

Sickle cell disease (SCD) is a genetically inherited hemoglobinopathy marked by the presence of abnormal sickle-shaped erythrocytes caused by a mutation in the β-globin gene. Specifically, this mutation involves the substitution of the polar amino acid glutamic acid with the non-polar amino acid valine at the sixth position of the β-globin chain (1). This seemingly minor alteration results in the formation of hemoglobin S (HbS), which, under deoxygenated conditions, polymerizes and distorts red blood cells into a rigid, crescent shape. These misshapen cells lead to vaso-occlusion, chronic hemolysis, and multisystem complications (1,2). The most severe manifestation, sickle cell anemia (SCA), arises from the homozygous inheritance of the HbS gene and contributes significantly to morbidity and mortality across the globe. Globally, hemoglobin disorders affect around 250 million individuals, with approximately 4.5% of the world's population carrying genes associated with hemoglobinopathies. Sickle cell trait alone is diagnosed in 60 million people every four years according to World Health Organization estimates (3). High prevalence rates are observed in regions such as sub-Saharan Africa, the Middle East, South Asia, and parts of the Mediterranean, largely due to endemic malaria, where the sickle cell trait confers a protective advantage (4). Additionally, cultural practices such as consanguineous marriages further elevate the burden of SCD in countries like Pakistan, where prevalence reaches 1.92% nationally and up to 10% in Baluchistan, with approximately 5.1% affected in Karachi (5).

Despite the global burden and clinical severity of SCD, awareness and understanding of the disease remain inadequate in many healthcare contexts. This is particularly concerning in the case of nursing students who, as future healthcare providers, are expected to offer competent care to individuals affected by chronic conditions like SCD (6). Without adequate training and knowledge, these students may struggle to identify early symptoms, manage pain crises, or educate patients and their families, leading to delayed interventions and worsened health outcomes (6,7). Reports of preventable deaths, particularly among young athletes or military trainees with undiagnosed sickle cell trait (SCT), highlight the necessity of timely diagnosis and preventive education (8). Additionally, complications such as acute chest syndrome, infections, pulmonary embolism, chronic kidney disease, and organ infarction are common causes of death in SCD patients (9). Effective management relies not only on pharmacologic interventions like hydroxyurea and prophylactic antibiotics but also on the healthcare provider's ability to deliver holistic, culturally competent care (10). Health-related quality of life (HR-QoL) in individuals with SCD is often compromised due to the chronic and unpredictable nature of the disease. Studies have shown that appropriate education and support can significantly improve both clinical outcomes and patient well-being (11). Unfortunately, the gap between knowledge and clinical practice remains wide, particularly in settings where training in genetic disorders is minimal or outdated. Enhancing the awareness and preparedness of nursing students is a crucial step in bridging this gap. International literature reflects a positive correlation between healthcare provider knowledge and improved disease management, yet similar assessments in countries with rising SCD prevalence, such as Pakistan, remain limited (12).

Furthermore, increased migration from high-endemic regions to Western countries has led to a broader geographic spread of SCD. Despite this, nursing curricula in many regions still lack comprehensive modules dedicated to hereditary hemoglobinopathies, creating a disconnect between academic preparation and real-world healthcare needs (13). Considering the evolving epidemiological trends and the pivotal role nurses play in chronic disease management, it becomes imperative to assess the extent of knowledge possessed by nursing students about SCD and identify areas needing enhancement. Therefore, this study aims to assess the knowledge of undergraduate nursing students regarding sickle cell disease, with the objective of identifying educational gaps, promoting culturally sensitive care practices, and contributing to curriculum improvement and healthcare equity for at-risk populations.

METHODS

This cross-sectional study was conducted over a period of four months, from September to December 2023, to assess the level of knowledge regarding sickle cell disease (SCD) among undergraduate nursing students. The study was carried out at the University of Lahore, located in Lahore, Punjab, Pakistan, targeting students enrolled in the Bachelor of Science in Nursing (BSN) program. Participants were recruited specifically from the third and fourth academic years of the nursing department. A convenience sampling technique was employed to select participants for the study. The sample size was determined using the formula $n = N / (1 + N(e)^2)$,

INSIGHTS-JHR
INSIGHTS-JOURNAL OF HEALTH AND REHABILITATION

where *N* represents the population size, and *e* denotes the margin of error (0.05). Based on this calculation, the required sample size was 114 students, which was strictly adhered to during data collection to maintain methodological accuracy and representativeness. The inclusion criteria consisted of third- and fourth-year undergraduate nursing students who were fully conscious, oriented, and able to comprehend and follow study-related instructions. Students included in the study were required to be free from any acute or chronic illness, disabling condition, or cognitive impairment that could interfere with participation. Students were excluded if they were absent during data collection, did not provide informed consent, or were enrolled in departments other than nursing (2,4).

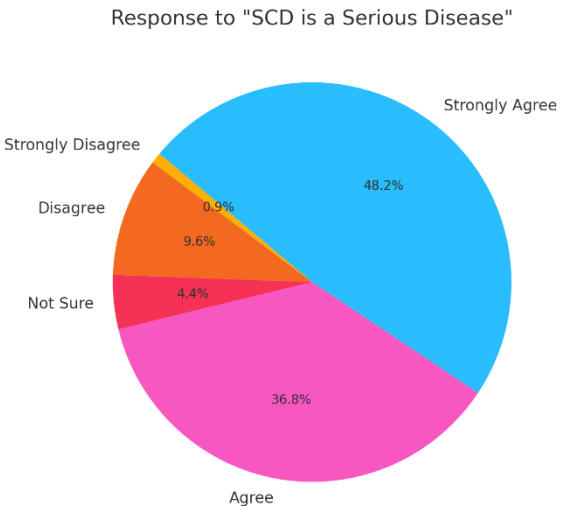
Data collection was carried out using a semi-structured, self-administered questionnaire designed to evaluate participants' knowledge of sickle cell disease. The instrument was developed in alignment with existing literature and underwent preliminary review to ensure clarity, relevance, and appropriateness for the study population. Although the tool was described as well-designed, further details on its psychometric properties, including reliability and validity metrics, were not documented, which limits the ability to evaluate its robustness for future replication. Before participation, all students were informed about the nature and purpose of the study, and written informed consent was obtained. The questionnaire was distributed in person, and students were given adequate time to complete it independently. The anonymity of responses and the confidentiality of personal information were strictly maintained throughout the research process. Participants were reassured that their involvement was voluntary, and that they were free to withdraw from the study at any point without penalty. Ethical approval for the study was obtained from the institutional ethical review committee of the University of Lahore. All research procedures adhered to the ethical principles outlined by the institution, ensuring the protection of participant rights and welfare. Participants were assured that the study involved no physical, psychological, or social risks and that all responses would remain confidential and be used solely for academic and research purposes. The methodological framework applied in this study aimed to ensure transparency, reliability, and ethical rigor in evaluating the knowledge level of nursing students regarding sickle cell disease.

RESULTS

The study included a total of 114 undergraduate nursing students from the University of Lahore, selected from the third and fourth years of the BS Nursing program. Participants ranged in age from 18 to 35 years, with the majority aged between 18 and 25 years (91.2%), and a smaller proportion between 25 and 35 years (8.8%). Among the participants, 57.9% were female and 42.1% were male. In terms of religious background, 92.1% identified as Muslim and 7.9% as non-Muslim. Most students (95.6%) were single, while 4.4% reported being married. The second section of the questionnaire assessed participants' knowledge about sickle cell disease using twelve close-ended statements rated on a five-point Likert scale, ranging from "strongly disagree" to "strongly agree." The majority of students recognized the seriousness of SCD, with 48.2% strongly agreeing and 36.8% agreeing that SCD is a serious condition. Similarly, 63.2% agreed and 19.3% strongly agreed that having a child with SCD would be a frightening experience. When asked whether their life would change if they had a child with SCD, 40.4% agreed and 14% strongly agreed, though a considerable number (29.8%) remained neutral. Perceptions of genetic risk showed varied awareness; 31.6% agreed and 19.3% strongly agreed that their children could be at risk, while 22.8% remained neutral. Likewise, 31.6% agreed and 14% strongly agreed that SCD could occur in their family, yet 21.1% were unsure.

INSIGHTS-JHR
INSIGHTS-JOURNAL OF HEALTH AND REHABILITATION

Knowledge about the inheritance and carrier status was also assessed. Regarding whether their partner might be a carrier of the sickle cell trait, 25.4% agreed and 19.3% strongly agreed, but 20.2% were uncertain. Similarly, 28.9% agreed and 22.8% strongly agreed that it is useful to know their partner's carrier status, while 20.2% remained unsure. When asked about personal testing for the sickle cell trait, 38.6% agreed it is useful, and 14.9% strongly agreed, though over one-fifth (21.9%) remained neutral. On the question of whether knowing the risk of having a child with SCD would influence pregnancy planning, 43% agreed and 18.4% strongly agreed, while 22.8% were unsure. Interestingly, 48.2% disagreed with the notion that testing for SCT is painful or difficult, reflecting a generally accurate understanding of diagnostic procedures. A similar response pattern was observed regarding the willingness of a partner to undergo testing, where 35.1% agreed and 22.8% strongly agreed. When asked if they would pay for SCT testing if it were not covered by government insurance, 36.8% agreed and 12.3% strongly agreed, although 35.1% were unsure, indicating economic factors might influence their decision-making regarding screening. Overall, analysis of knowledge scores revealed that 78.1% of participants demonstrated poor knowledge (scoring less than 60%), while 19.3% had average knowledge (60%–85%), and only 2.6% demonstrated good knowledge (above 85%). These results indicate that the majority of nursing students lacked sufficient understanding of sickle cell disease, its inheritance patterns, and preventive strategies.



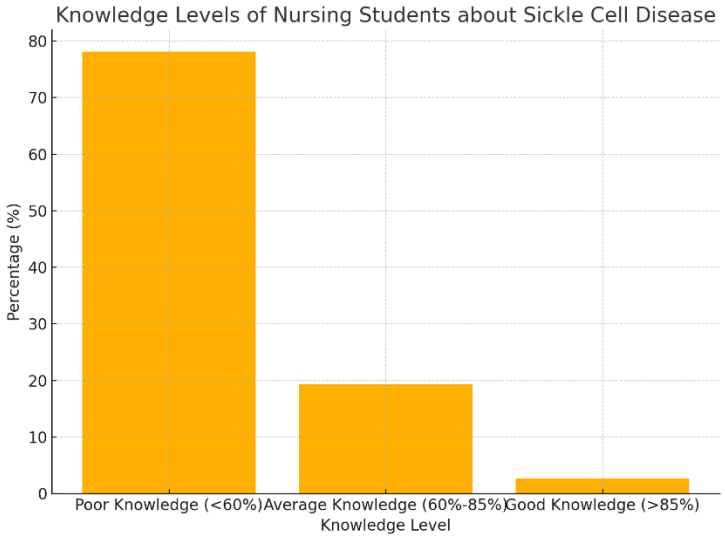


Table 1: Demographic data of the participants

Variables	Frequency (f)	Percentage %
Age		
18-25	104	91.2%
25-35	10	8.2%
Total	114	100%
Sex		
Male	48	42.1%
Female	66	57.9%
Total	114	100%
Religion		
Muslim	105	92.1%
Non-Muslim	09	7.9%
Total	114	100%

INSIGHTS-JHR
INSIGHTS-JOURNAL OF HEALTH AND REHABILITATION

Variables	Frequency (f)	Percentage %
Marital status		
Single	109	95.6%
Married	05	4.4%
Total	114	100%

Table 2: Knowledge regarding Sickle Cell disease among Nursing Student in The University of Lahore, Pakistan. (N= 114)

Questions	Category	Frequency	Percentage
SCD is a serious disease.	Strongly Disagree	1	0.9%
	Disagree	11	9.6%
	Not sure	5	4.4%
	Agree	42	36.8%
	Strongly agree	55	48.2%
Having SCD child would be very scary.	Strongly Disagree	3	2.6%
	Disagree	5	4.4%
	Not sure	12	10.5%
	Agree	72	63.2%
	Strongly agree	22	19.3%
My life would change if I have SCD child.	Strongly Disagree	12	10.5%
	Disagree	6	5.3%
	Not sure	34	29.8%
	Agree	46	40.4%
	Strongly agree	16	14%
My children are at risk for SCD.	Strongly Disagree	18	15.8%
	Disagree	12	10.5%

INSIGHTS-JHR
INSIGHTS-JOURNAL OF HEALTH AND REHABILITATION

Questions	Category	Frequency	Percentage
	Not sure	26	22.8%
	Agree	36	31.6%
	Strongly agree	22	19.3%
SCD could happen in my family.	Strongly Disagree	21	18.4%
	Disagree	17	14.9%
	Not sure	24	21.1%
	Agree	36	31.6%
	Strongly agree	16	14%
My partner may be a carrier of SC trait.	Strongly Disagree	18	15.8%
	Disagree	22	19.3%
	Not sure	23	20.2%
	Agree	29	25.4%
	Strongly agree	22	19.3%
It is useful to know if my partner has SC trait.	Strongly Disagree	18	15.8%
	Disagree	14	12.3%
	Not sure	23	20.2%
	Agree	33	28.9%
	Strongly agree	26	22.8%
It is useful to know if I have sickle cell trait.	Strongly Disagree	13	11.4%
	Disagree	15	13.2%
	Not sure	25	21.9%
	Agree	44	38.6%

INSIGHTS-JHR
INSIGHTS-JOURNAL OF HEALTH AND REHABILITATION

Questions	Category	Frequency	Percentage
	Strongly agree	17	14.9%
Knowing the risk of having a child with SCD would change how I plan a pregnancy.	Strongly Disagree	9	7.9%
	Disagree	9	7.9%
	Not sure	26	22.8%
	Agree	49	43%
	Strongly agree	21	18.4%
Testing for SCT is painful and difficult.	Strongly Disagree	14	12.3%
	Disagree	14	12.3%
	Not sure	20	17.5%
	Agree	55	48.2%
	Strongly agree	11	9.6%
My partner would be hard to conceive to have testing.	Strongly Disagree	6	5.3%
	Disagree	22	19.3%
	Not sure	20	17.5%
	Agree	40	35.1%
	Strongly agree	26	22.8%
To pay for SCT testing if it is free or paid by government insurance.	Strongly Disagree	9	7.9%
	Disagree	9	7.9%
	Not sure	40	35.1%
	Agree	42	36.8%
	Strongly agree	14	12.3%

INSIGHTS-JHR
INSIGHTS-JOURNAL OF HEALTH AND REHABILITATION

Table 3: Knowledge Level Distribution

	Frequency	Valid Percent
poor knowledge less than 60% (< 36 out of 60)	89	78.1
Average knowledge 60% to 85% (36 to 51 out of 60)	22	19.3
Good knowledge >85% (> 51 0ut of 60)	3	2.6
Total	114	100.0

DISCUSSION

The findings of this descriptive cross-sectional study revealed that the majority of undergraduate nursing students at the University of Lahore demonstrated inadequate knowledge regarding sickle cell disease (SCD), with 78.1% exhibiting poor knowledge, 19.3% showing average understanding, and only 2.6% attaining a good level of knowledge. This indicates a significant knowledge deficit among future nursing professionals who will be at the frontline of patient care (14). Such a gap not only reflects a potential shortcoming in the current educational curriculum but also raises concerns about the preparedness of nursing students to effectively manage and educate patients affected by hemoglobinopathies such as SCD. When compared to findings from similar studies conducted in other regions, a comparable trend of limited awareness is evident. A study conducted among university students demonstrated that only 26.78% had good awareness of SCD, with those in higher academic years and in medical fields showing better comprehension (15,16). These students also tended to be single, and their awareness was positively associated with socioeconomic background and academic exposure to the disease. This suggests that knowledge acquisition is influenced not only by curriculum content but also by personal and social determinants (17). Another study involving healthcare trainees reported that nearly half of the participants had a reasonable understanding of SCD, and factors such as age and source of information played a notable role. Those exposed to accurate and structured information through educational institutions were more likely to have favorable attitudes toward screening and a better grasp of the disease burden (18).

These findings reinforce the necessity of integrating targeted educational strategies into nursing education. The observed knowledge gaps may reflect insufficient coverage of genetic and chronic disease content in nursing curricula, limited clinical exposure, and a lack of interactive learning methodologies (18,19). Strengthening these areas can be a pivotal step in improving future nurses' competencies, ultimately translating to enhanced patient care, especially in high-risk populations. This study carries notable strengths, including its focus on a specific and under-researched population—undergraduate nursing students—and the use of a structured questionnaire to assess knowledge objectively. However, it is essential to acknowledge the limitations that may influence the interpretation of the findings. The reliance on self-reported data introduces potential bias, as students may respond in a socially desirable manner rather than reflect actual understanding. Additionally, the study measured only theoretical knowledge without assessing clinical competence or application, which are essential dimensions of healthcare practice. Further limitations include the absence of analysis linking demographic variables to knowledge scores, which could have offered a more nuanced understanding of the factors influencing awareness. Moreover, the lack of qualitative data restricts exploration into the underlying reasons for poor knowledge, such as gaps in educational delivery or misconceptions surrounding genetic disorders. To address these gaps, future research should aim to include multicenter samples and mixed-method approaches, combining quantitative assessment with qualitative interviews to uncover deeper insights. Evaluating knowledge retention over time and during clinical rotations would also offer valuable information about the effectiveness of current teaching strategies (20). Integrating simulations, case-based learning, and structured genetic counseling modules may offer meaningful ways to bridge the divide between theoretical knowledge and practical readiness. In conclusion, this study highlights a critical need to revisit and strengthen nursing education related to sickle cell disease. By doing so, educational institutions can ensure that future nurses are not only aware of the disease but are also capable of delivering culturally competent, evidence-based care that meets the complex needs of individuals living with SCD.

INSIGHTS-JHR
INSIGHTS-JOURNAL OF HEALTH AND REHABILITATION

CONCLUSION

This study concluded that undergraduate nursing students demonstrated an overall insufficient level of knowledge regarding sickle cell disease, highlighting a critical gap in their preparedness to manage and educate patients with this chronic genetic condition. Given the essential role nurses play in patient education, screening, and long-term care, these findings emphasize the urgent need to enhance curricular content and clinical training related to hemoglobinopathies. Strengthening education through targeted interventions, practical learning opportunities, and integrated teaching strategies can empower future nurses with the competence and confidence to deliver informed, culturally sensitive, and evidence-based care to individuals affected by sickle cell disease.

Author Contributions

Author	Contribution
Muhammad Adil*	Substantial Contribution to study design, analysis, acquisition of Data Manuscript Writing Has given Final Approval of the version to be published
Madiha Asif	Substantial Contribution to study design, acquisition and interpretation of Data Critical Review and Manuscript Writing Has given Final Approval of the version to be published
Hareem Ayesha	Substantial Contribution to acquisition and interpretation of Data Has given Final Approval of the version to be published
Ameer Hamza	Contributed to Data Collection and Analysis Has given Final Approval of the version to be published

REFERENCES

1. Gilpin-Macfoy F, Perilla MJ, Koehly LM. Variability in sickle cell knowledge by sickle cell status. J Genet Couns. 2023;32(4):916-25.

2. Roque J. The typically atypical sickle cell patient and the fight for equitable care. Pediatr Res. 2021;89(1):246-7.

3. de Montalembert M, Anderson A, Costa FF, Inusa BPD, Jastaniah W, Kunz JB, et al. Sickle Cell Health Awareness, Perspectives, and Experiences (SHAPE) survey: Perspectives of adolescent and adult patients, caregivers, and healthcare professionals on the burden of sickle cell disease. Eur J Haematol. 2024;113(2):172-82.

4. Grygiel A, Ikolo F, Stephen R, Bleasdille D, Robbins-Furman P, Nelson B, et al. Sickle cell disease in Grenada: Quality of life and barriers to care. Mol Genet Genomic Med. 2021;9(1):e1567.

5. Om A, Mathew N, Nawaz A. Quality and Reliability of YouTube Videos on Sickle Cell Disease. J Pediatr Hematol Oncol. 2021;43(8):e1247-e8.

6. Hazzazi AA, Ageeli MH, Sharahili KA, Hamaly HM, Aqeeli MH, Altherwi TI, et al. Physicians' and nurses' perceptions and attitudes toward sickle cell disease patients in Jazan, Saudi Arabia. Saudi Med J. 2020;41(8):841-8.

7. Aljuhani O. Pain in sickle cell diseases; physicians' knowledge, attitude, and barriers: A cross sectional study. J Pak Med Assoc. 2022;72(10):2043-7.

8. Nirmal G, Pendharkar D, Gupta N, Raj A. Knowledge, Attitude, and Practice of Patients Suffering From Sickle Cell Disease in an Endemic Zone. J Pediatr Hematol Oncol. 2025;47(2):86-90.

9. Oluwole EO, Okoye CD, Ogunyemi AO, Olowoselu OF, Oyedeji OA. Knowledge, attitude and premarital screening practices for sickle cell disease among young unmarried adults in an urban community in Lagos, Nigeria. Pan Afr Med J. 2022;42:8.

10. Pecker LH, Sharma D, Nero A, Paidas MJ, Ware RE, James AH, et al. Knowledge gaps in reproductive and sexual health in girls and women with sickle cell disease. Br J Haematol. 2021;194(6):970-9.

11. Reich J, Cantrell MA, Smeltzer SC. An Integrative Review: The Evolution of Provider Knowledge, Attitudes, Perceptions and Perceived Barriers to Caring for Patients with Sickle Cell Disease 1970-Now. J Pediatr Hematol Oncol Nurs. 2023;40(1):43-64.

12. Ezenwosu OU, Olawepo JO, Lacroix-Willliamson LJ, Itanyi IU, Ogidi A, Onyeka TC, et al. Health education to promote knowledge about sickle cell disease and newborn screening in pregnant women: a community-based pilot study using the healthy beginning initiative. BMC Pregnancy Childbirth. 2024;24(1):321.

13. Sharma A, Young A, Carroll Y, Darji H, Li Y, Mandrell BN, et al. Gene therapy in sickle cell disease: Attitudes and informational needs of patients and caregivers. Pediatr Blood Cancer. 2023;70(6):e30319.

14. Ngwengi NY, Fon PN, Mbanya D. Distribution of haemoglobin genotypes, knowledge, attitude and practices towards sickle cell disease among unmarried youths in the Buea Health District, Cameroon. Pan Afr Med J. 2020;37:109.

15. Peninah A, Olivia N, Andabati CD, Euniky M, Tracy N. Determinants of knowledge, attitudes, and practice towards sickle cell disease in Alebtong district, Lango region, Northern Uganda. BMC Public Health. 2025;25(1):910.

16. Roe AH, Wu J, McAllister A, Aragoncillo S, Nunyi E, Voltaire S, et al. Contraceptive Attitudes and Beliefs of Women With Sickle Cell Disease: A Qualitative Study. Womens Health Issues. 2024;34(4):409-16.

17. Setiawan H, Suhanda S, Setiawan D. Coaching Clinic as a Strategy to Improve Knowledge and Competence of Nurses in Providing Genetic Counseling Interventions among Thalassemia Patients. Int J Community Based Nurs Midwifery. 2022;10(1):84-5.

18. Beeman CM, Abrams MA, Zajo K, Stanek J, Martinez-Mendez A, Creary SE. Closing knowledge gaps among parents of children with sickle cell trait. Pediatr Blood Cancer. 2023;70(7):e30384.

19. Hardy ELT, Williams B, Harden C, Oshinowo O, Copeland R, Carden MA, et al. Building the foundation of health-related knowledge via near-peer education for children with sickle cell disease. Pediatr Blood Cancer. 2022;69(4):e29566.

20. Persaud Y, Mandrell BN, Sharma A, Carroll Y, Irvine M, Olufadi Y, et al. Attitudes toward COVID-19 vaccine among pediatric patients with sickle cell disease and their caregivers. Pediatr Blood Cancer. 2023;70(5):e30274.

