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Awareness and perceptions towards sickle cell disease screening among young adults (18–45 years) at Mildmay Institute of Health Sciences, Wakiso District. A cross-sectional study.

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Abstract

Background

Sickle cell trait prevalence ranges between 13% and 20%. The study aims to assess the prevalence of awareness and perceptions about sickle cell disease screening among young adults (18–45 Years) at Mildmay Institute of Health Sciences, Wakiso District.

Methods

A cross-sectional study design, which employed quantitative methods of data collection, was conducted in the Mildmay Institute of Health Sciences. In a duration of 6 days, 52 young adults (18–45 Years) were selected using Stratified random sampling. A structured questionnaire was used to collect data, and it involved closed-ended questions. The data collected was analyzed manually, and findings were entered into a Microsoft Excel 2013, which was then presented in the form of tables, pie-charts, and graphs.

Results

Out of 52 respondents, less than half, 34.6% were aged 31–35 years, and 50% were formally employed. About awareness, (90.4%) had never been tested for sickle cell disease nor had a family member tested, (73.1%) were unsure whether SCD is treatable, and (55.8%) reported receiving information about SCD screening through radio and television. Concerning Perceptions, 67.3% were unsure whether SCD screening is important for young unmarried youth, (73.1%), with reasons for not going for SCD screening as the emotional impact of the results.

Conclusion

Very few had undergone testing, and uncertainty about the treatability of the condition was prevalent and under perception; emotional fears, uncertainty about the importance of screening for unmarried individuals, and reluctance to test even under guaranteed privacy were major barriers.

Recommendation

SCD screening should be incorporated into the routine health packages, especially in antenatal care and youth-friendly services, to normalize the practice and reduce stigma.

Keywords: *Sickle Cell Disease screening, Prevalence of awareness and perceptions, Young adults (18–45 Years), Mildmay Institute of Health Sciences.*
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Background

Sickle Cell Disease (SCD) is a global public health challenge in regions with high malaria prevalence (Mburu & Odame, 2019). SCD is caused by a genetic mutation leading to abnormal hemoglobin formation, which results in sickle-shaped red blood cells and multiple health complications (Coetzee et al., 2022). The World Health Organization (WHO) estimates that approximately 30,000 adults and youth are living with SCD annually, with 80% of these cases occurring in parts of Sub-Saharan Africa

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(Pakhale et al., 2024). In Africa, awareness and perceptions of SCD screening remain low due to limited healthcare infrastructure, cultural misconceptions, and stigma (Munung et al., 2024). For example, studies in Ghana reported that only 23% of young adults were aware of SCD screening programs, with negative perceptions hindering uptake of screening services (Agbozo et al., 2023).

In Tanzania, studies indicate that while 35% of the population is aware of SCD, only 10% have a positive perception of the screening process due to cultural beliefs and fear of stigmatization (Tutuba et al., 2023). While government and non-governmental organizations have implemented awareness campaigns, studies reveal gaps in the awareness and perceptions of the target population, especially among young adults (Asogwa et al., 2021). In Kampala, awareness levels among young adults (18-25 years) are estimated at 15% with only 9% of these young adults holding positive perceptions about the importance of screening (Ndirangu-Mugo, 2024). The study aims to assess the prevalence of awareness and perceptions about sickle cell disease screening among young adults (18–45 Years) at Mildmay Institute of Health Sciences, Wakiso District.

Methodology

Study design

A cross-sectional study design was employed, which employed quantitative methods of data collection. A cross-sectional design allowed for data collection at a specific point in time, providing a snapshot of the study population (Cummings, 2018). It was suitable for this study as the data was collected once without follow-up of participants.

Study setting

This study was conducted at Mildmay Institute of Health Sciences, located along Entebbe Road in Wakiso District, Central Uganda. The institute is approximately 12 kilometers southwest of Kampala city center, making it easily accessible from the capital and its surroundings. Mildmay Institute of Health Sciences (MIHS) is a privately owned Institution and has an enrollment of approximately 1,240 students across its various programs. It is comprised of several specialized schools like the School of Applied Sciences, Mildmay Leadership School, School of Clinical Officers, School of Medical Laboratory Technology, and School of Nursing & Midwifery, committed to providing hands-on, context-based education and training to develop competent health professionals. It caters to a population with a significant number of young adults aged 18-45 years who are at a high risk of passing sickle cell to offspring if not prevented earlier. More so, its central location, which enhances accessibility for the target population, its reputable role in health service training, and its established focus on public health initiatives. The geographical coordinates of the institute are 0.2416°N latitude and 32.5581°E longitude.

Study Population and Rationale

The study targeted young adults aged 18-45 years attending the School of Applied Sciences, Mildmay Leadership School, School of Clinical Officers, School of Medical Laboratory Technology, and School of Nursing & Midwifery within Mildmay Institute of Health Sciences. This population was selected because they represented a critical age group for making informed health decisions and were at a stage where awareness and perceptions can significantly influence their health-seeking behaviors.

Sample size determination

The sample size determination followed the guidelines provided by Krejcie and Morgan's table of 1970. According to Mildmay Institute of Health Sciences, there were 1,240 students across its various programs; however, the study only considered N to be 60 as the population size, and so N=60 and S=52 according to Krejcie and Morgan's table, as shown below.

Sampling procedure.

Stratified random sampling was employed to select young adults aged 18-45 years from the Mildmay Institute of Health Sciences, Wakiso District. The population was first divided into strata from each school, considering young adults aged 25-45 years. Within each stratum, a simple random sampling technique was used to select participants, where the study first compiled a list of eligible young adults within each school. To obtain the required sample size, the same color and size papers were made for each stratum, comprising 15 eligible participants. 15 Papers with 11 written on and the other 4 left blank were prepared and put in a single box, 11 participants who picked papers written on were enrolled in the study, and others were left out. This process was done throughout all 5 strata to obtain a sample size of 52 participants.

Inclusion criteria

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All young adults aged 18-45 years attending Mildmay Institute during the period of data collection. The study included only those who were Ugandans.
Those who were in their second and final semesters

Exclusion criteria
All young adults aged 18-45 years attending Mildmay Institute of Health Science who consented but along the way faced some challenge that stopped them from participating in the study.

Definition of Variables
The study focused on three main variables: awareness and perception towards Sickle Cell Disease Screening among Young Adults (18–45 Years).

Independent variables:
- The Proportion awareness towards Sickle Cell Disease Screening among Young Adults (18–45 Years).
- Perception towards Sickle Cell Disease Screening among Young Adults (18–45 Years).

Dependent variables:
Sickle Cell Disease Screening among Young Adults (18–45 Years)

Research instruments
The study used a self-administered questionnaire where a set of questions about the objectives of the study was given to the respondents to answer. The questionnaire consisted of three sections: socio-demographic data, awareness, and perception, designed in English. Each section contained both open and closed-ended questions to assess the youth's responses objectively using stratified random sampling. Pretesting was done to identify potential challenges, refine questions, and improve the study design if necessary.

Data collection procedure
After obtaining an introductory letter from the principal of Mildmay Uganda School of Nursing and Midwifery. The study sought permission from the administration of Mildmay Institute of Health Sciences and explained the purpose of the study. Then, after being given permission, the study also sought permission from the heads of five intended departments. Self-introduction, explaining the purpose of the study, then verbal permission and consent were sought from respondents, where the main purpose of the study and confidentiality were clearly explained to them to ensure their cooperation.

Data Management and Analysis
Data Management
After collecting data, each questionnaire was checked for completeness and accuracy. The data collected was edited, coded, and cleaned before analysis. An accurate and filled questionnaire was kept in a safe place to prevent access by other people, which maximized confidentiality.

Data analysis
The data was analyzed manually, and the findings were entered into the computer using the office programs. The data was analyzed manually using Excel, which presented the data in the form of tables, graphs, and pie-charts.

Quality control
Validity
This was done by setting questions according to objectives and also by setting questions that were in line with the intentions I had in connection with the study objective. Validity helped in measuring the accuracy of results within a study, and this helps in the formulation of proper interventions that are fit for solving the problem surrounding awareness and perception towards sickle cell disease screening. When valid answers were obtained, accurate solutions were achieved for the existing problem.

Reliability
The questionnaires were pre-tested at Mulago School of Nursing and Midwifery on 10 selected respondents before using them in the research study to ensure consistency and dependability of the study instruments and their ability to tap data that can answer the objectives of the study. In order to ensure the validity and reliability of the study instruments, the results obtained were compared to other relevant data or theory.

Ethical considerations
An introductory letter was obtained from the Chairperson of the Research committee of Mildmay Uganda School of Nursing and Midwifery, which was taken to the Dean of Mildmay Institute of Health Sciences, who permitted the study to seek permission from the head of Mildmay Institute of Health Sciences of the 5 intended schools as my strata. Allowing interaction with young adults. All respondents

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were provided with a written informed consent after receiving a detailed description of the study, and they were reminded of their right to withdraw from the study at any time of their wish. Eligible participants who consented in privacy and no incentives were given. Anonymity of the respondents was ensured at all stages of data analysis.

Results

Socio-demographic data of respondents

Table 1 shows the demographic data of the respondents n=52

Variable	Response	Frequency (n)	Percentage
Gender	Male	18	34.6
	Female	34	65.4
Age	18–21 years	8	15.4
	26–30 years	10	19.2
	31–35 years	18	34.6
	36–40 years	10	19.2
	41–45 years	6	11.6
Religion	Catholic	20	38.5
	Muslim	16	30.8
	Protestant	10	19.2
	Others (specify)	6	11.5
Marital Status	Single	15	28.9
	Married	28	53.9
	Unmarried	9	17.2
Occupation	Student	7	13.5
	Self-employed	12	23.1
	Formal employment	26	50.0
	Casual laborer	7	13.4

Table 1 shows that the majority, 34 (65.4%) of the participants were female, while the minority, 18 (34.6%) were male. Less than half 18 (34.6%) of the respondents were aged 31–35 years, followed by 10 (19.2%) aged 26–30 years, 10 (19.2%) aged 36–40 years, 8 (15.4%) aged 18–21 years and the least 6 (11.6%) were aged 41–45 years. Less than half 20 (38.5%) of the respondents were Catholics, 16 (30.8%) were Muslims, 10 (19.2%) were Protestants, while the least 6 (11.5%) belonged to other religions. Over half 28, 53.9%) of the respondents were married, 15 (28.9%) were single, and 9 (17.2%) were unmarried. Half 26 (50%) of the respondents were formally employed, 12 (23.1%) were self-employed, while the remaining 7 (13.5%) were students, and 7 (13.4%) were casual laborers. Awareness towards Sickle Cell Disease Screening among Young Adults (18–45 Years) at Mildmay Institute of Health Sciences

Figure 1 shows awareness of sickle cell screening (*n=52*)

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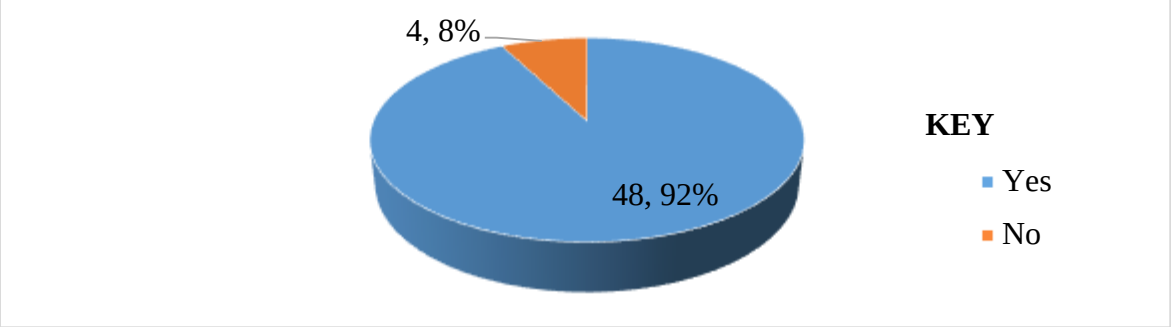

Figure 1 indicates that an overwhelming majority, 48 (92.3%) of the participants had ever heard about sickle cell disease (SCD) screening, while a small minority, 4 (7.7%) had not.

Table 2 Shows the definition of SCD, source of information, history of SCD testing, knowledge about SCD, and beliefs about SCD treatment. n=52

Variable	Response	Frequency (n)	Percentage (%)
Understanding of SCD Screening (n=48)	A medical test used to check for sickle cell disease	13	27.1
	Blood tests to detect abnormal hemoglobin causing sickle cell disease	18	37.5
	A preventive measure identifying individuals at risk	17	35.4
Source of Information	Radio and Television	29	55.8
	Hospital	10	19.2
	Family	5	9.6
	School	8	15.4
History of SCD Testing (n=52)	Yes	3	5.8
	No	47	90.4
	Am not sure	2	3.8
Knowledge About SCD (n=52)	A condition that attacks blood cells	29	55.8
	A condition that attacks the lungs	13	25.0
	Inability to walk	10	19.2
Belief About SCD Treatment (n=52)	Yes	4	7.7
	No	10	19.2
	Am unsure	38	73.1
Understanding of the SCD test (n=52)	Through a simple urine test	10	19.2
	Through a simple blood test	40	76.9
	They look sick	2	3.9

From table 2, it was indicated that among those who had heard about SCD screening, 18 (37.5%) said it involves blood tests to detect abnormal hemoglobin, 17 (35.4%) noted it is a preventive measure identifying at-risk individuals, and 13 (27.1%) simply recognized it as a test to check for the disease. More than half 29, 55.8%) reported receiving information about SCD screening through radio and television, 10 (19.2%) cited hospitals, 8 (15.4%) said schools, and only 5 (9.6%) got the information from family. The overwhelming majority, 47 (90.4%), had never been tested for sickle cell disease nor had a family member tested; only 3 (5.8%) reported having done so, and at least 2 (3.8%) were not sure. More than half 29, 55.8%) of the participants understood that sickle cell disease attacks blood cells, 13

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(25%) mistakenly believed it affects the lungs, and 10 (19.2%) thought it causes inability to walk. A significant majority, 38 (73.1%) of respondents were unsure whether SCD is treatable, 10 (19.2%) believed it is not treatable, and only 4 (7.7%) believed it is treatable. Table 2 indicates that a vast majority, 40 (76.9%) of respondents correctly stated that SCD is tested through a simple blood test, 10 (19.2%) wrongly mentioned a urine test, and 2 (3.9%) believed it is identified by appearance.

Perceptions towards Sickle Cell Disease Screening Among Young Adults (18–45 Years) at Mildmay Institute of Health Sciences.

Table 3: Perception on the importance of screening, belief in early screening effectiveness, feelings about knowing SCD status, and willingness to test with privacy ensured

Variable	Response	Frequency (n=52)	Percentage (%)
Perception of the Importance of Screening	Agree	9	17.3
	Disagree	8	15.4
	Not sure	35	67.3
Belief in Early Screening Effectiveness	Yes	29	55.8
	No	13	25.0
	Not sure	10	19.2
Feelings About Knowing SCD Status	It would help make better decisions	8	15.3
	Would cause emotional distress	39	75.0
	Don't think it matters	3	5.7
Willingness to Test with Privacy Ensured	Yes	13	25.0
	No	37	71.2
	Not sure	2	3.8

From table 3, it demonstrated that 35 (67.3%) of the respondents were unsure whether SCD screening is important for young unmarried youth, 9 (17.3%) agreed that it is important, while 8 (15.4%) disagreed. More than half 29, 55.8%) of the participants believed that early screening could reduce the number of children born with sickle cell disease, 13 (25%) did not believe it would help, and 10 (19.2%) were not sure. A vast majority, 39 (75%) of respondents reported that knowing their sickle cell status would cause emotional distress, 8 (15.3%) felt it would help them make better decisions, and 3 (5.7%) felt it didn't matter. 37 (71.2%) of the respondents said they would not be willing to take an SCD test even if privacy was guaranteed, 13 (25%) were willing, and only 2 (3.8%) were unsure.

Figure 2: Reasons for not going for SCD screening, n=52

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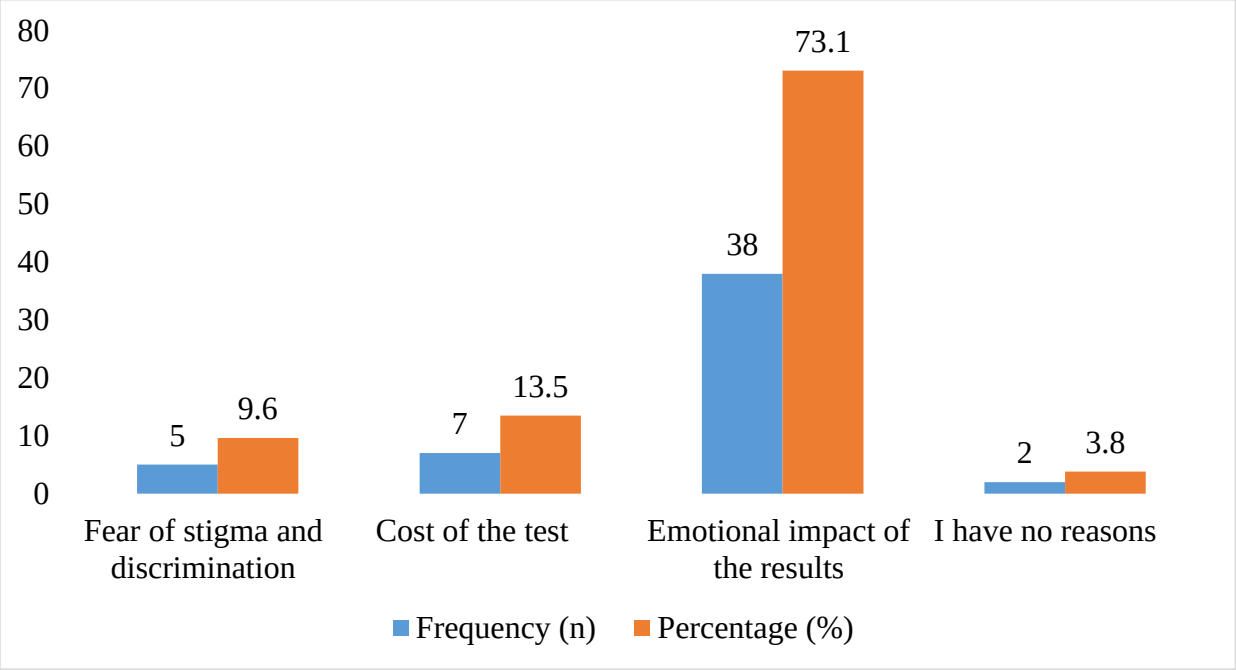

Figure 2 reveals that the leading reason, 38 (73.1%), for not going for SCD screening was the emotional impact of the results, 7 (13.5%) cited the cost of the test, 5 (9.6%) feared stigma and discrimination, and the least 2 (3.8%) had no reason.

Discussion

Awareness towards sickle cell disease screening among young adults (18–45 years) at Mildmay Institute of Health Sciences.

(92.3%) Respondents were aware of sickle cell screening. This might be because public health campaigns, media coverage, and health education have increased over the years. This implies that awareness creation strategies are working, but further efforts are needed to bridge the gap between knowledge and action (i.e., going for screening). This study is in line with a study done by Gilpin-Macfoy et al. (2023), which showed that 78% of the participants were aware of SCD screening.

Many (37.5%) described SCD screening as a blood test to detect abnormal hemoglobin. This may be because accurate information may have been provided through schools, hospitals, or the media, leading to correct comprehension. This implies that factual and clear messaging about screening methods should be emphasized in educational materials to maintain and improve understanding. This is contrary to a study carried out by Singhal et al. (2022), which revealed that 55.5% mistakenly believed a urine test could detect SCD, while 43.1% admitted ignorance of the screening method altogether. More than half (55.8%) received information via radio and television. This might be because mass media remains the most accessible and widely used source of information for the public in Uganda. This is in disagreement with a study conducted by Houwing et al. (2021), which showed that information about SCD was being provided by healthcare providers.

Very few (5.8%) participants had been tested or had family members tested. This could be because, despite being aware, individuals may not perceive personal risk or may fear knowing their status. This implies that awareness alone is insufficient; efforts must address behavioral and emotional barriers to testing. This agrees with a study carried out by Hussaini et al. (2019), which indicated that 40% of the study participants had undergone testing. Most (55.8%)

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participants rightly recognized that sickle cell affects the blood. This might be because educational materials and media platforms have likely emphasized this aspect of the disease. This implies that knowledge campaigns are having an impact, but there is still a need to correct misconceptions like SCD affecting the lungs or walking ability. This is contrary to a study carried out by Kanzi et al. (2020), which showed that 59% were aware of their genetic inheritance patterns, including their genotypes.

The majority (73.1%) were unsure whether sickle cell disease can be treated. This could be because there is limited public understanding of chronic disease management versus curability, particularly for genetic conditions. This implies that public health messaging should focus more on explaining the difference between management and cure of SCD to reduce uncertainty. This agrees with a study conducted by Phillips et al. (2022), which indicated that 31.6% believed that SCD was curable.

Most (76.9%) knew SCD is detected via blood testing. This was because blood tests are a common diagnostic method, and this knowledge may be more intuitive or frequently communicated. This implies that educational strategies should continue to stress the simplicity and accessibility of SCD testing to encourage more people to get screened. This disagrees with a study by Singhal et al. (2022), which indicated that only 1.4% knew it could be performed using a blood test.

Perceptions towards Sickle Cell Disease Screening Among Young Adults (18–45 Years) at Mildmay Institute of Health Sciences

A large number (67.3%) were unsure if SCD screening is important for unmarried youth. This might be because many may associate screening only with marriage or pregnancy, not personal health or future planning. This implies that there is a critical need to reframe SCD screening as a preventive health strategy that is relevant regardless of marital status. This disagrees with a study conducted by Oladiran (2021), which showed that 68% of participants perceived SCD screening as vital for making informed marital choices.

Most (55.8%) believed early screening could reduce the births of children with SCD. This may be because some level of understanding exists that screening helps identify carriers and guide reproductive choices. This implies that reinforcing this preventive message can drive uptake of screening services among reproductive-age individuals. This is in agreement with a study carried out by Oladiran (2021), which revealed that 45% considered it a priority for reducing the prevalence of SCD.

A majority (75%) feared emotional distress from learning their SCD status. This was because of fear of stigma, isolation, or difficult family planning decisions. This implies that psychosocial support must be included in screening programs to reduce emotional barriers and improve acceptability.

Most (71.2%) were still unwilling to test even with guaranteed privacy. This was because the emotional burden and fear of consequences outweighed perceived confidentiality. This implies that interventions must go beyond privacy guarantees and tackle deeper concerns such as fear, stigma, and perceived life limitations from a positive diagnosis.

The emotional impact of results was the most cited reason for avoiding screening (73.1%).

This could be because SCD is often associated with lifelong complications and societal judgment, creating fear around knowing one's status. This implies that emotional counseling and destigmatization must be prioritized in awareness campaigns to improve uptake of screening. This is in disagreement with a study conducted by DeBaun et al. (2020), which demonstrated that 29% of participants perceived the cost of screening as discouraging, leading to negative attitudes towards the screening process.

Conclusion

Regarding the awareness, the majority had heard about SCD screening, understood it as a blood test to detect abnormal hemoglobin, and were largely informed through radio and television. Very few had undergone testing, and uncertainty about the treatability of the condition was prevalent.

Regarding perceptions, most respondents acknowledged the role of early screening in preventing the birth of children with SCD. However, emotional fears, uncertainty about the importance of screening for unmarried individuals, and reluctance to test even under guaranteed privacy were major barriers.

Limitations of the Study

Weather fluctuations, such as sudden rain showers or excessive sunshine, potentially impacted the study.

Sample size and generalizability of the study's findings were limited by the sample size and specific characteristics of young adults.

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Self-reporting bias, since the study involved self-administered questionnaire responses, was influenced by self-reporting biases.

Recommendations

The Ministry of Health should design and implement comprehensive health education programs focused on deepening understanding of sickle cell disease and the importance of early screening, especially targeting youth through mass media and community outreaches.

SCD screening should be incorporated into the routine health packages, especially in antenatal care and youth-friendly services, to normalize the practice and reduce stigma.

Considering cost was a barrier for some participants, the Ministry should provide free or highly subsidized SCD screening services, particularly for vulnerable populations such as youth and unmarried individuals.

The Ministry of Health should consider integrating psychological support into SCD screening programs to help individuals cope with emotional distress associated with testing and results.

To the Management of Mildmay Institute of Health Sciences

The institution should conduct regular internal campaigns and sensitization seminars to educate staff, students, and community members about the benefits and process of SCD screening.

To address concerns about privacy and stigma, the institute should ensure that SCD testing environments are confidential, youth-friendly, and non-discriminatory.

Management should equip healthcare workers with the skills to provide effective pre- and post-test counseling that addresses emotional impacts and reduces fear around screening.

To the Community and Study Participants

Community members, especially youth, are encouraged to proactively seek screening services and learn their sickle cell status early to make informed reproductive and lifestyle decisions.

The community should work together to break the silence and stigma surrounding SCD by openly discussing the condition, supporting affected individuals, and promoting positive attitudes towards testing.

Participants and local influencers should act as change agents by sharing accurate knowledge gained from this study and encouraging peers to participate in SCD screening and education programs.

Nursing implications

Since the majority of respondents were unsure whether sickle cell disease is treatable and held various misconceptions about its symptoms, nurses should intensify health education efforts. This involves using simple, clear language to explain the causes, effects, and management of sickle cell disease, while correcting misinformation during health talks and individual patient interactions.

Because many participants associated screening with emotional distress, nurses should offer empathetic counseling services before and after testing. They should help clients understand the emotional impact of results and provide coping mechanisms to reduce anxiety and fear, especially among young adults.

As the majority of respondents did not view screening as important for unmarried youth, nurses must promote early screening as a reproductive health strategy. They should emphasize that knowing one's sickle cell status before marriage or childbearing helps prevent transmission to offspring, empowering individuals to make informed decisions.

Given that many respondents were unwilling to test due to privacy concerns, nurses should ensure a confidential and respectful care environment. This includes offering private spaces for testing and assuring clients that their health information will be protected.

List of abbreviations

SCD: Sickle Cell Disease

Source of funding

The study was not funded

Conflict of interest

The author did not declare any conflict of interest

Author contribution

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Ritah Kobugabe collected data and drafted the manuscript of the study
Hasifa Nansereko supervised the study

Data availability
Data is available upon request

Author biography
Ritah Kobugabe is a student of a diploma in nursing at Mildmay Uganda School of Nursing and Midwifery.
Hasifa Nansereko is a lecturer at Mildmay Uganda School of Nursing and Midwifery.

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