AfroGlobal Perspectives
Vol. 3 No. 9 (2026): September 2026
https://doi.org/10.70572/agp.v3i9.58
Original Article

Factors influencing Sickle Cell trait testing among Youths aged 18-35 years in Village Inn Cell, Agulu Division, Apac Municipality, Apac District. A cross-sectional study.

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Abstract

Background:

Sickle cell disease (SCD) is a significant hereditary blood disorder characterized by abnormal hemoglobin production, leading to chronic health complications and premature mortality. The aim of this study was to assess factors influencing sickle cell trait testing among youths aged 18-35 years in Village Inn Cell, Agulu Division, Apac Municipality, Apac District.

Methodology:

The study employed a descriptive cross-sectional study design using quantitative methods of data collection. Informed consent was obtained from a total of 40 participants who were selected using a simple random technique. Data were collected using pretested structured self-administered questionnaires and were analyzed using the Microsoft Excel program and presented in frequency tables, pie charts, and graphs.

Results:

The study had 40 participants, of whom only 25% had heard of SCT testing; 30% of them had received the information from the hospital and media; 20% knew that PMGC is one way of preventing SCD; and 37.5% didn't know how SCD can be diagnosed. Majority 75% were willing to test for SCT where 40% of those unwilling had fear for stigma in case they are carriers and only 32.5% had tested for SCT. Though70% of the participants reported that health facility screen for sickle cell on request however; they noted negative attitudes of the health workers towards sickle cell screening.

Conclusion:

Most of the participants had poor knowledge of sickle cell disease, and poor attitudes of health workers were highlighted as one of the factors influencing SCT testing; however, there is goodwill among healthcare providers to support them to do SCT testing.

Recommendation:

There is a need for the Ministry of Health to do public health education on sickle cell disease and invest more resources for disease prevention, testing, and treatment.

Keywords: *Sickle Cell trait testing, Youths aged 18-35 years, APAC Municipality, APAC District.*
Submitted: *February 23, 2026* ***Accepted:*** *May 12, 2026* ***Published:*** *September 26, 2026*
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Background of the study

Sickle cell disease is defined as an inherited hemolytic anemia that results from homozygous or compound heterozygous inheritance of the sickle hemoglobin gene, thereby resulting in sickle cell crises like Vaso-occlusive phenomenon, chronic hemolysis, and progressive organ damage. Sickle Cell Disease (SCD) is the most common monogenic blood disorder worldwide. It is associated with progressive organ damage coupled with episodes of acute illness. The episodes of acute illness result from the sticky and stiff red blood cells, which clog tiny blood vessels. This often results into various conditions not limited to organ and tissue damage, anemia, increased risk of infection and painful episodes (Griffith, 2015).

Sickle cell screening is a simple blood test used to determine if one has sickle cell disease or sickle cell trait. It is the testing of a person's blood for abnormal types of hemoglobin Alzubaidi et al., 2020). The mortality and morbidity associated with SCD can be greatly reduced by early preventive measures, including newborn screening coupled with comprehensive care and educational programs for affected families Nkya, 2019).

Globally, SCD contributes a significant burden that is not amply addressed WHO, 2018). Approximately 5% of the world's population and over 7% of pregnant women are carriers of a hemoglobinopathy. Although the Hemoglobin S (HbS) trait accounts for 40% of all carriers, due to the clustering of HbS in Africa, it causes over 80% of significant hemoglobinopathies in the world. It is estimated that

worldwide, 312,000 children are born with SCD annually. The WHO estimates that SCD accounts for up to 15% of mortality in children under five years (Nnodu et al., 2020).

Health workers' knowledge of SCD screening is paramount in the fight; however, a study by Byaruhanga (2014) reported that even though 67% of health workers had knowledge of Sickle Cell Trait screening, 53% did not know what was entailed in the test, and 61% did not know where to access these services. 65.6% did not know who was at risk of having a child with either SCT or SCD; 35.9% did not know how SCD spreads.
Furthermore, in Uganda, another study found low knowledge levels in (20%) of health workers; just over a quarter (27.2%) had average knowledge and just over a half (52.8%) had good knowledge. When re-categorized for analysis, knowledge was poor in nearly a third (30.6%), and just over two-thirds had good knowledge (69.4%) (Ayugi, 2018). In addition, in Uganda, 78.9% of Health workers who stayed in urban areas had better knowledge and practical expertise about sickle cell screening. This could have been due to health workers in urban areas being exposed to newspapers, television, and admitting a relatively large number of sickle cell clients compared to their rural counterparts (Okwi et al., 2018). Therefore, the objective of this study is to assess factors influencing sickle cell trait testing among youths aged 18-35 years in Village Inn Cell, Agulu Division, Apac Municipality, Apac District.

Methodology

Study Design and Rationale

A quantitative descriptive cross-sectional study design was adopted for this study; the study design was chosen because it enabled the researcher to study the different outcomes at the same time.

Study Setting and Rationale

The study was conducted at Village Inn Cell, Agulu Division, Apac Municipality, Apac District. It is located in the northern region of Uganda, about 1km from Apac district headquarters; administratively, the municipality is divided into 4 divisions: Akere, Agulu, Atik and Arocha. Agulu division consists of 5 wads that is Tei-bu, Wormwaka, Aminteng, Odokomach and Awir ward, Agulu division consist of 26 cells/villages in which Village inn is among these located in Tei-buward, there are approximately 5000 youth in Agulu division where Village inn cell has approximately 1000 youth. The language spoken is Lango; the major economic activities are: -Boda-riding, subsistence farming, daily market, retail shop, salons, and many others. It was chosen because it is accessible, and Apac is among the fourteen districts with a high burden of SCD; also, Village Inn Cell, Agulu Division, Apac Municipality has a high number of adults aged 18-35years.

Study population

The study targeted all youth aged 18-35 living in Village Inn Cell, Agulu Division, Apac Municipality, Apac District.

Sample size determination

A sample size of 40 participants was used since a sample size larger than 30 and less than 500 is appropriate for most research (Roscoe.,1975) thus it was used since it's appropriate for generalization. (See appendix: vi)

Sampling procedure.

A simple random sampling technique with the lottery method was employed. The technique was used because it ensured that the sample was representative of the study population, offered equal chances to all members, and was easy to administer.40coparticipants filled in the questionnaire, whereby 10 small pieces of paper numbered 1-10 were written on, folded and put in a closed box. Each adult aged 18-35 was allowed to select a paper and those who selected a paper having 1 to 5 were interviewed using a self-administered questionnaire.

Inclusion Criteria

Only youths aged 18-35 years who were of sound mind and were not known Sickler were included in the study.

Exclusion Criteria.

All youth of 18-35 years who were too busy to participate in the study at the time of the interviews, and those with hearing and visual disability were not included in this study.

Study Variables

Independent Variable

The independent variables were individual factors and Health care provider-related factors.

Dependent Variable

In this study, sickle cell trait testing among youths aged 18-35 years was the dependent variable.

Research Instrument

The tool used comprised a structured and semi-structured questionnaire which employed both open- and closed-ended questions. The questionnaire was developed based on the concepts from the literature review and related studies, and the compiled data were modified. All the necessary questions relevant to answering the questions, purpose, and objectives of the study were included in the questionnaire.

Data Collection Procedure

Upon receiving administrative clearance from Florence Nightingale School of Nursing and Village Inn LCI, the researcher called on the participants. The purpose of the study and its procedure were explained to the participants;

the researcher further explained that there is no consequence for not participating in the study. The participants were then allowed to take a piece of paper each, which had a number from 1-10; only those who had a number from 1-5 were allowed to participate in the study. A consent form was provided which upon signing was returned back to the researcher. The participants then filled out the questionnaire and returned it to the researcher upon completion. The whole process took less than 12 minutes. This was repeated for four consecutive weeks, with 10 participants chosen each week, making a total of 40 participants.

Data Management

All study participants were given a unique identification number that was recorded in the questionnaire. The hard copies of the interview transcripts were kept under lock and key, and the data were accessible only to the researcher.

Data Analysis and Presentation

Data were analyzed manually with the help of Microsoft Excel and presented in the form of tables, pie charts, and frequency tables.

Ethical Consideration

Approval was sought from Florence Nightingale School of Nursing and Midwifery for permission to conduct the study. The researcher then requested an introductory letter from the office of the Principal. The introductory letter was used to introduce the researcher to the chairperson of the Village Inn Cell, who in turn introduced the researcher to the participants. The researcher explained the aims, objectives, and benefits of the study to the participants so as to win their consent. Then, the researcher sought both verbal and written consent from participants before engaging them in the study.

Results

Socio-demographic characteristics of the youth aged 18-35 years in Village Inn Cell.

Table 1: Showing distribution of participants by socio-demographic characteristics (n=40).

Variable	Category	Frequency	Percentage (%)
Gender	Male	13	32.5
	Female	27	67.5
Age	18-23	8	20
	24-29	20	50
	30-35	12	30
Marital status	Single	14	35
	Married	20	50
	Widowed	4	10
	Divorced	2	5
Religion	Catholic	15	37.5
	Islam	10	25
	Seventh-day Adventist	4	10
	Born again	5	12.5
	Anglican	6	15
Education level	Primary	8	20
	Secondary	12	30
	University /tertiary	17	42.5
	No formal education	3	7.5

Source: Primary data 2024

Table 1 shows that up to 67.5% (27) were female, and the majority (50%) of participants were aged between 24- 29 years, only (20%) were aged18-23years, of these (50%) were married.
The majority (37.5%) of the participants were Catholic, while nearly half (52.5%) were self-employed, and only 7.5% were unemployed, though only 42.5% of them had attended education up to university or tertiary level and 7.5%had not attained formal education.

Individual factors influencing sickle cell trait testing among youths.

Nearly all (87.5%) of the participants had ever heard about sickle cell disease, and only a few 12.5% had never heard of it.

Table 2: Showing responses on knowledge about sickle cell disease (n =40)

Variable	Frequency	Percentage (%)
Inherited disorder of red blood cells	7	17.5
A form of cancer of the blood (leukemia)	12	30
An infection of the blood	11	27.5
Don't know	10	25

Source: Primary data 2024

From Table 2, only 17.5% participants knew that SCD is an inherited disorder of red blood cell while quite a big number (30%) believe it is leukemia.

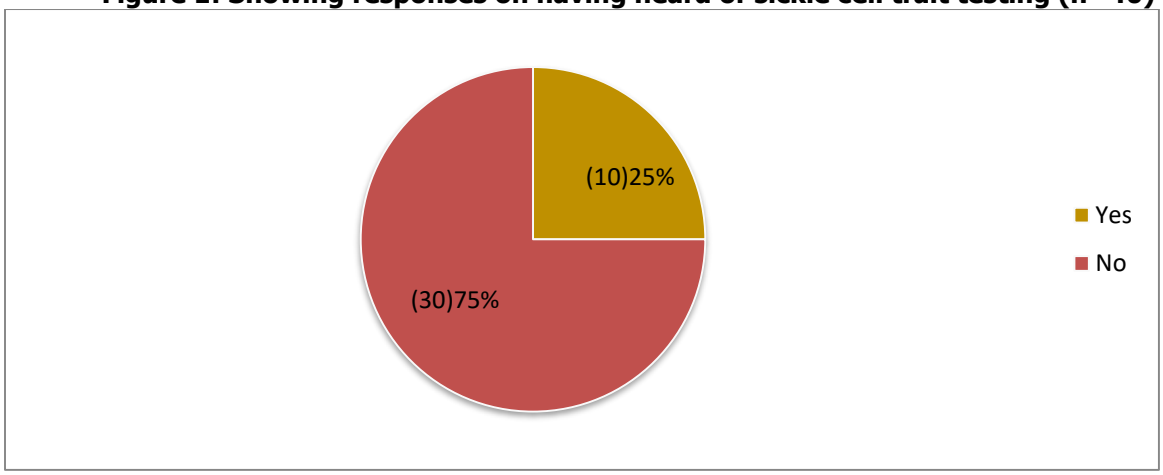
Table 3: Showing responses on how sickle cell disease can be prevented (n=40)

Variable	Frequency	Percentage (%)
Testing all newborn children	11	27.5
Pre-marital screening and counseling	8	20
Stopping two people who both carry the sickle cell gene from having a child together	9	22.5
Don't know	12	30

Source: Primary data 2024

Up to30% of the participants didn't know how SCD can be prevented, and only 20% knew that premarital screening and counseling would help prevent SCD.

Figure 1: Showing responses on having heard of sickle cell trait testing (n=40)

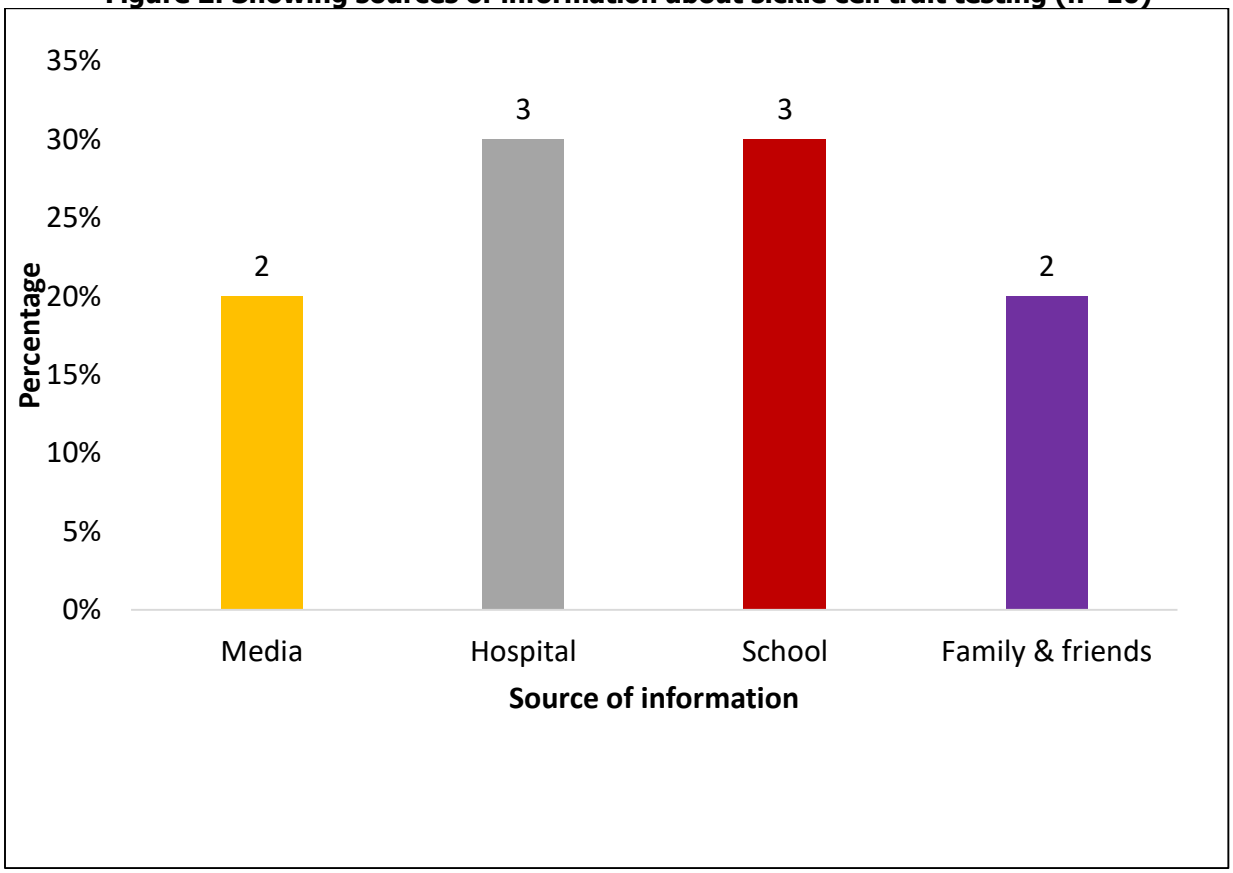


Source: Primary data 2024

Figure 1 shows that more than half (75%) of the participants have never heard of sickle cell trait testing, and only 25% have ever heard of it.

AfroGlobal Perspectives
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https://doi.org/10.70572/agp.v3i9.58
Original Article

Figure 2: Showing sources of information about sickle cell trait testing (n=10)



Source: Primary data, 2024

Figure 2 shows that among the 10 people who had heard of SCT testing, the majority (30%) of the participants got the information on sickle cell trait testing from the hospital and school, while 20% heard of it from the media, family, and friends.

Table 4: Showing responses on how SCD can be diagnosed (n=40)

Variable	Frequency	Percentage (%)
Blood test	12	30
Urinalysis (urine test)	4	10
Physical examination	9	22.5
Don't know	15	37.5

Source: Primary data 2024

From Table 4, only 30% could tell the specimen used for SCD testing, while up to 37.5% had no idea of the procedure.

Table 5: Showing responses on the specimen used to test for SCD (n=40)

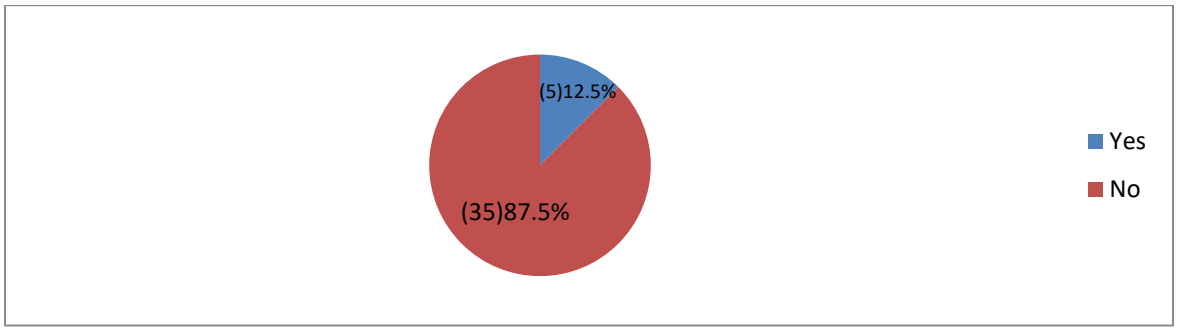
Variable	Frequency	Percentage (%)
A simple urine sample	4	10
Simple blood sample	14	35

Saliva	5	12.5
Don't know	17	42.5

Source: Primary data 2024

Table 5 shows that majority of the participants (42.5%) of the participants didn't know the specimen used to test for SCT and only 35% knew blood sample are used for the test.

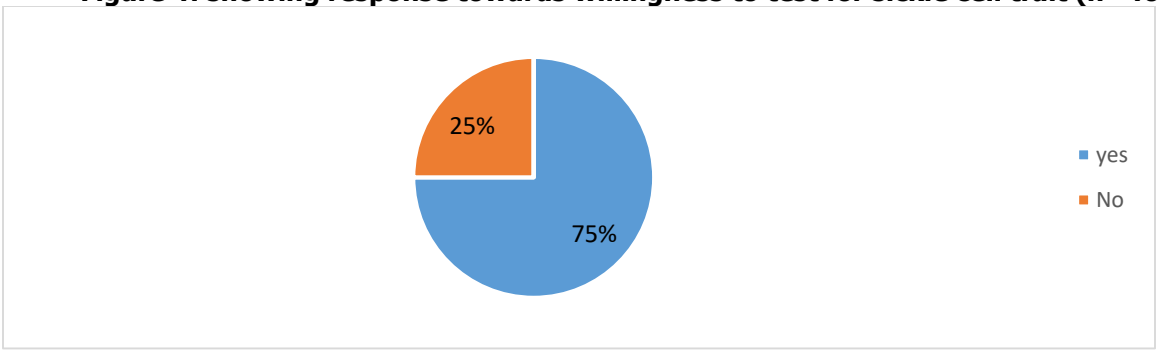
Figure 3: Showing response towards making sickle cell testing for all youth



Source: Primary data 2024

From Figure 3, only 17.5% agreed with the idea of making sickle cell testing for all youths mandatory, while up to 87,5% did not agree.

Figure 4: showing response towards willingness to test for sickle cell trait (n=40)



Source: Primary data 2024

Figure 4 shows majority of the participants (75%) were willing to test for SCT and only few 25% were not willing.

Table 6: Showing reasons for unwillingness to test for sickle cell trait (n=10)

Variable	Frequency	Percentage (%)
Fear of stigma in case I am a carrier	4	40
Fear of losing out on a good partner	2	20
Having the SCT would make me less confident about forming relationships	2	20
Fear of convincing my partner to test	2	20

Source: Primary data 2024

Table 6 documented of the 10 participants who were unwilling to test for SCT, most (40%) of the participants feared stigma in case they are found to be carriers while some (20%) had fear of losing out on a good partner.

AfroGlobal Perspectives
Vol. 3 No. 9 (2026): September 2026
https://doi.org/10.70572/agp.v3i9.58
Original Article

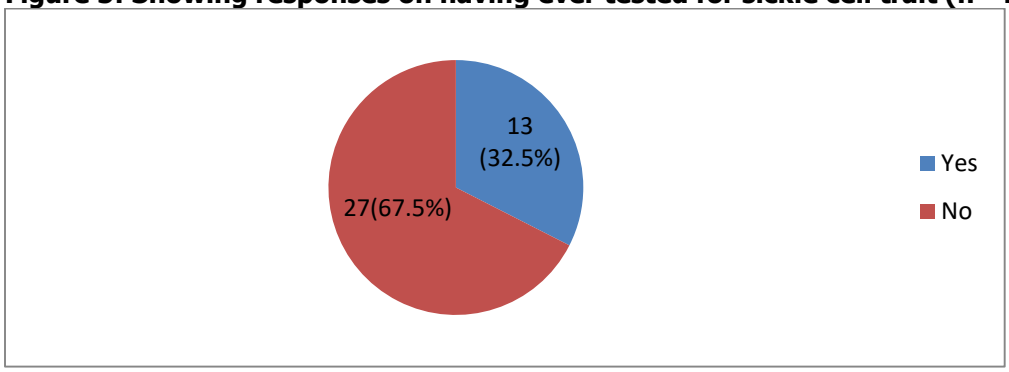
Table 7: Showing responses on whether sickle cell screening could help prevent transmission of genes to others (n=40)

Variable	Frequency	Percentage (%)
Strongly agree	5	12.5
Agree	9	22.5
Not sure	10	25
Disagree	16	40

Source: Primary data 2024

From Table 7, most 16(40%) of the participants disagreed that sickle cell screening can prevent transmission of genes to others, and a few 5(12.5%) strongly agreed.

Figure 5: Showing responses on having ever tested for sickle cell trait (n=40)



Source: Primary data 2024

Figure 5 shows that most (67.5%) of the participants have never tested for SCT, and very few 32.5%) have ever tested for it.

Table 8: Showing responses on the reason for testing (n=13)

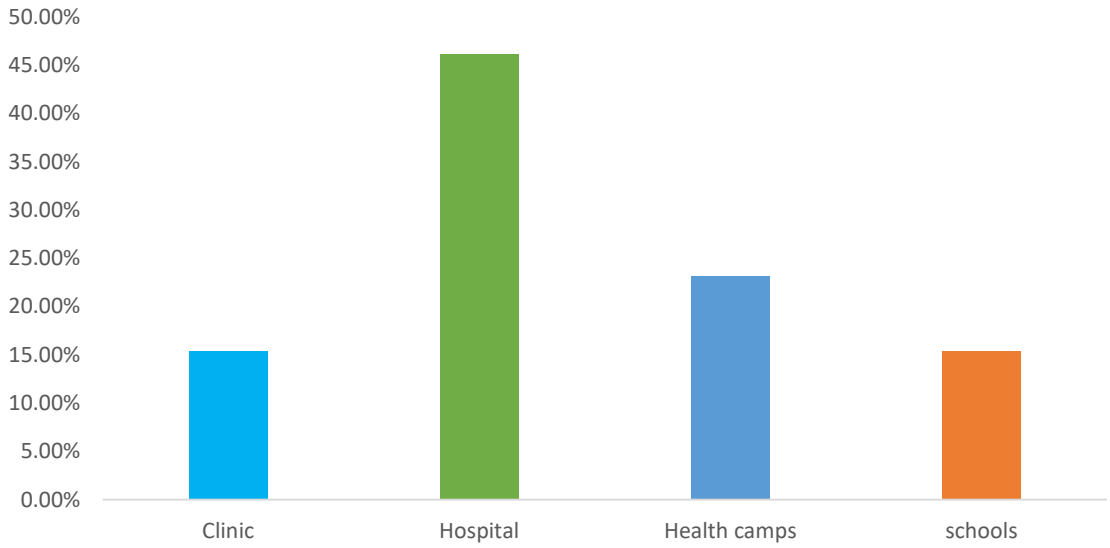
Variable	Frequency	Percentage (%)
Curiosity	2	15.3
Doctors request	3	23.1
Premarital testing	4	30.8
Others, such as employment and school requests	4	30.8

Source: Primary data 2024

From Table 8, most 30.8%) tested due to premarital testing, others matter such as employment and school requests while few of them (15.3%) was out of curiosity.

AfroGlobal Perspectives
Vol. 3 No. 9 (2026): September 2026
https://doi.org/10.70572/agp.v3i9.58
Original Article

Figure 6: Showing responses on where they tested (n=13)



Source: Primary data 2024

Figure 6 documented that the majority (46.1%) of the participants had tested at the hospital, while 15.4% had tested at schools.

Table 9: Showing responses on why they haven't tested (n=27)

Variable	Frequency	Percentage (%)
Didn't receive enough information about sickle cell disease	13	48
I didn't know that the test was available	9	33
Wasn't sure about where to go to test	5	19

Source: Primary data 2024

From Table 9, almost half (48%) of the participants had not tested because they didn't receive enough information about SCD, and 19% because they weren't sure of where to go for the test.

Health care provider-related factors influencing sickle cell trait testing among youths

Table 10: Showing health care provider-related factors influencing sickle cell

Variable	Category	Frequency(f)	Percentages(%)
Does the nearby health facility provide screening services for sickle cell trait?	Yes	20	50
	No	20	50
How often does your health facility screen for sickle cell?	Everyday	4	10
	Once a week	8	20
	On request	28	70
Do you receive your results instantly after testing for SCT?	Yes	0	0
	No	40	100
Attitudes of the health workers towards screening for SCT	Very good	2	5
	Good	4	10
	Negative	28	70
	Positive	6	15
Are health workers in favor of taking the blood screening test	Yes	4	10
	No	36	90

Do health workers support you in ensuring that you screen for sickle cell?	Yes	20	50
	No	20	50

Source: Primary data 2024

Table 10 documented that only half (20; 50%) of the youths reported that the nearby health facility provides screening services for sickle cell trait, whereas the majority, 28(70%), of the participants reported that their health facility screens for sickle cell on request.

All 40(100%) of the participants reported they never received their results instantly after testing.

Most (28; 70%) of the participants reported negative attitudes of the health workers towards screening for SCT, while minority 2(5%) said they had positive attitudes.

Nearly everyone (90%) of the participants affirmed that the health workers encouraged sickle testing andhalf 20(50%) of the participants reported that health workers supported them in ensuring that they screen for sickle cell.

Discussion

Individual factors influencing Sickle Cell Trait Testing among youths aged 18-35 years in Village Inn Cell.

This study analyzed the individual factors that influenced SCT and the study results indicated that more three quarter of the participants had heard of sickle cell disease this could be due to the fact that information about SCD is being passed onto community members via a number of channels such as radio, television among others, however this finding is in contrary to the study by Babu et al (2021) in India where less than a half of the participants knew about sickle disease. This finding therefore shows that there is still more room for community sensitization on SCD.

Regarding the meaning of sickle cell disease, the study found that the majority of the participants knew SCD as a form of leukemia (cancer of the blood), while less than a quarter defined it as an inherited disorder of blood or red blood cells. This may be as a result of inadequate health education regarding SCD; this is in disagreement with the study by Harrison et al. (2019) in the USA, where more than 3 in 4 of the participants were able to correctly define SCD. These differences in findings could be a result of literacy rates in the two communities. This therefore indicates there is still more room for community sensitizations.

When asked about the way of preventing sickle cell disease, slightly more than 1 in every 4 participants didn't know how sickle cell disease can be prevented, and only less than a quarter knew that premarital screening and counseling can help prevent SCD, and this may be due to inadequate knowledge about PMGC. The results do not agree with a study carried out in Saudi Arabia by Al-Qattan et al. (2019), where nearly all were aware that PMGC limits the rate of inherited blood disorder; this therefore put more emphasis on community sensitization on the importance of PMGC.

This study analyzed the knowledge of the youth on SCT, the findings revealed three quarter had not heard of SCT and only 1 in 4 knew it and this may be as a result of lack of information and inadequate sensitization of the public about SCT, this in line with Harrison et al (2017) 's study where less than half knew SCT existed. This finding therefore implies there is more need for community sensitization on SCT.

Regarding the source of information on SCT, the majority of the participants got the information from hospitals and schools, while a small number got the information from media, family, and friends. Probably this is so because most participants had friends, relatives, and community members who have SCD. This is similar to a study conducted by Al-Farsi et al (2014), where most of the information was from health workers; thus, based on the study results, if any information or education about SCD needs to be passed on to the people, other means of communication should be considered, like radios, since most people own radios and televisions.

As per test done to diagnosed SCD less than 2 in 3of the participants knew blood sample was used in diagnosis SCD while other mentions samples like urine among others. This can be attributed to a low level of health-seeking behaviors among youth. This finding is in agreement with the study by Ayugi (2018), where less than half were aware of sickle cell screening methods; this finding further agrees with a related study by Babu et al. (2021), where less than a quarter said that a laboratory test can diagnose SCD. This finding put more emphasis on the need for community sensitization.

The results further indicated that most of the participants were willing to test for SCT; this could be attributed to the high number of cases of sickle cell disease in the community, accompanied by the SCD economic burden, which put pressure to prevent having offspring with the disease.

Although most of the participants were willing to do SCT, nearly 3 in 4 of the participants had never tested for SCT. This could be due to a lack of awareness of the free services offered by the government at all its health facilities in the country. This finding is in line with a study by Nabwire (2018) where only 24.7% had tested for SCT.

This study further indicated that the majority of those who tested did so as a result of premarital testing, and their reasons included employment, school, and curiosity; this was in line with Adewoyin et al. (2015), where the majority screened because of curiosity and school requirements.

In this study nearly a half of the participants had tested from the hospital and less than few from the clinic and schools. This is similar to a study by Nabwire (2018) while majority had tested at the hospital and few tested from schools and the least claimed to have been tested by a traditional healer.

The study revealed that a half of the participants who were married didn't know if there partners had ever screened for SCT, nearly a half knew there genotype and less than a quarter didn't know and this is probably because the churches and mosques don't request for SCT testing results as a requirement for a couple to do a marriage ceremony thus most can get married minus getting screened for SCT this was differing from the results of Gbeneol et al (2015) and majority had screened for SCT with their partners before they got married and these were advised by health workers etc.

According to the study results, most of the participants who had not screened for SCT, nearly a half had not tested because they didn't know that the test is available, less than a half didn't receive enough information about SCD and less than a quarter weren't sure about where to go and this is in line with a study by Nabwire (2018) where Possible reasons for the low uptake could be because the youth in the study had moderate knowledge about both SCT testing and SCD with an average knowledge scores and the moderate knowledge levels could be why only a few had spared time to test for SCT even though average were aware that SCD existed and a quarter knew of a family member that had the disease correspondingly, more than a quarter were not aware that SCT testing existed whereas nearly a half did not know that all that was needed to do the test was a blood sample.

According to the study findings, nearly half had been screened for SCD, and this means that more than half of the participants are still unaware of their sickle cell status; thus, there are higher chances that they will unknowingly marry or have a child with someone who also is unaware of the status, and they might unfortunately end up having a child with SCD in the case both of them were carriers of the SCT. Therefore, continuous sensitization of communities about SCD and the importance of sickle cell trait testing is required in order to improve the uptake of SCT testing services in the different communities.

Health care provider-related factors influencing sickle cell trait testing among youths.

This study further analysed the health care providers' factors that influenced SCT; the results showed that the majority of the participants reported that the health facility only screens for sickle cell on request. This implied that without a patient requesting the test, they would miss it. This could be because of inadequate knowledge and logistic problem that affects most of the health centers this finding coincides with a similar study by Djan and Mensah (2020) who highlighted inadequate knowledge by the health workers these findings therefore call for more training on provision of SCT services among health care providers.

All of the participants stated that their results often arrive late after picking the specimens. This could be related to the fact that there are often logistical problems in the lower health facilities, which delay delivery of services. This finding therefore reminds administrations in health facilities to always ensure a constant supply of logistics necessary for SCT to avoid delays.

Most of the participants reported that the healthcare providers have negative attitudes towards screening for SCT. This could be related to increased workload for health workers, hence reducing the rate at which youths take up sickle cell trait screening. This finding adds more weight to a related study conducted by Al-Hamdan et al. (2017), who highlighted negative attitudes towards screening for sickle cell trait as a major factor influencing sickle cell testing.

Almost all the participants affirmed that the health workers supported them to do SCT testing this could be because of the rampant cases of sickle cell diseases the healthcare is burdened with, this bring both financial and physical contains the hospital. This finding shows that there is still more room for improvement.

Although the participants reported negative experiences with the health workers, at least half of those who went for SCT reported that health workers supported them in ensuring that they were screened for sickle cell. This could be because of the heavy workload that burdens most of the e health care system worldwide. This is in line with a study by Ayugi (2018), which reported that health workers cared for and supported clients to screen for SCD and considered screening fully as their responsibility. This therefore shows that there is a need for health workers to put extra time into supporting SCT.

Conclusion

Even though most of the participants had poor knowledge of sickle cell disease, and poor attitude of health workers was highlighted as one of the factors influencing SCT testing, there is willingness among healthcare providers to support them to do SCT testing. Thus, there is a need for the Ministry of Health to do public health education on sickle cell disease and invest more resources for disease prevention, testing, and treatment. However, regarding the limitation of the study, some data may have been left out of the study as a result of the use of semi-structured questionnaires so that participants could choose whether or not to complete all the questions. Participants could not have remembered everything about sickle cell disease suggested in the questionnaire, which could lead to recall bias.

The study's quantitative cross-sectional design restricted it from revealing the youth's extensive experiences with SCT testing.

It was limited by long distance from school to Village inn cell was overcome by hiring a boda-boda cyclist.

Recommendation

More rigorous approaches of educating people about SCD, SCT and provision of lists of the public hospitals where the testing services are provided should be considered. It is also important that emphasis is made about the availability of

these services at a free cost since many participants thought that they had to pay for the services.

Health workers within the area should be better educated about SCD and encouraged to include SCD and the importance of SCT testing among the health education they provide to their patients.

Acknowledgement
I would like to thank the following people who have made my academic journey at the nursing school worthwhile because I certainly could not have made it on my own without their support in all kinds of ways and their encouragement.
First, I am thankful to God for providing me with most of what I needed to start and complete this academic journey. Even in those times when I had completely given up, he would make a way out for me.
I am greatly indebted to my family for the financial, emotional, material, moral, and spiritual support they accorded me during this journey; you have really inspired me to be the person I am. I love you and thank you for everything.
Many thanks to my supervisor, Mrs. EPILA JOSEPHINE, for the guidance and commitment she extended to me from the beginning to the end of producing this research report. It was an honor for me, and I learnt a lot from you. Thank you.
I am grateful to my classmates and friends, and I thank them for walking this journey with me. It was not an easy ride, but we persevered till the end.
I thank the staff at the Local Council 1 of Village Inn Cell, Agulu Division, Apac Municipality, for the help they provided to me when I went to them.
Lastly, I also thank the people who participated in this study; this report would not have been complete without them.
May the Almighty God bless you all abundantly.

List of Abbreviations
HbS: Sickle cell Hemoglobin
PMGC: Premarital genetic counseling
SCD: Sickle cell disease
SCT: Sickle cell trait
WHO: World Health Organization

Source of funding
This study was not funded.

Conflict of interest
No conflicts of interest were declared.

Author contributions
BO designed the study, conducted the data collection, cleaned and analyzed the data, and drafted the manuscript; RA supervised the study from conceptualization of the topic to manuscript writing and submission; JE supported in study conceptualization and general supervision as well as mentorship.

Data availability
Data are available upon request.

Ethical approval
Ethical approval for this study was obtained through formal procedures. An introductory letter from the Principal of Florence Nightingale School of Nursing and Midwifery was presented to relevant local authorities in Village Inn Cell, Agulu Division, Apac Municipality. The study team engaged with community leaders to ensure support and guidance during the research process. Respondents were assured of maximum privacy and confidentiality, and only numbers instead of names were used to identify the respondents. The study only commenced after the objectives of the study had been well explained to participants, and they had consented to participate in the study.

Informed consent
Participants were given clear, easily understandable information about the study's purpose, objectives, methods, benefits, and risks. They were assured of their voluntary participation, the right to withdraw at any time, and the confidentiality of their responses. Additionally, they were informed that their involvement could help raise awareness about Sickle Cell Trait testing and improve access to related healthcare services.

Author Biography
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AfroGlobal Perspectives
Vol. 3 No. 9 (2026): September 2026
https://doi.org/10.70572/agp.v3i9.58
Original Article

PUBLISHER DETAILS

AfroGlobal Press

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