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Individual 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:

The study aimed to assess individual factors influencing sickle cell trait testing among youths aged 18-35 years in Village Inn Cell Agulu, Division, Apac Municipality, Apac District.

Methodology:

A quantitative descriptive cross-sectional study was conducted among youths aged 18–35 years in Village Inn Cell, Agulu Division, Apac Municipality, Apac District. A sample of 40 participants was selected using simple random sampling through the lottery method. Data were collected using a structured and semi-structured questionnaire containing open- and closed-ended questions. Data were analyzed manually using Microsoft Excel and presented in tables, pie charts, and frequency distributions. Ethical approval and informed consent were obtained before data collection.

Results:

The study involved 40 participants, with 67.5% females and 32.5% males. Most participants were aged 24–29 years (50%), followed by 30–35 years (30%) and 18–23 years (20%). Half were married (50%), while 35% were single. Regarding education, 42.5% had a tertiary education, 30% secondary, 20% primary, and 7.5% had no formal education. Most participants (87.5%) had heard of sickle cell disease, but knowledge was poor, with only 17.5% correctly identifying it as an inherited blood disorder. Misconceptions were common, including 30% believing it was leukemia. Only 25% had heard of sickle cell trait testing, and 67.5% had never tested. Although 75% were willing to test, only 17.5% supported mandatory testing. Fear of stigma (40%) was the main reason for refusal. Lack of information (48%) was the major barrier to testing.

Conclusion:

Poor knowledge and misconceptions about sickle cell disease and sickle cell trait reduced testing uptake, despite participants' willingness to test when informed.

Recommendation:

Health workers should provide regular health education to youths and community members on sickle cell disease, sickle cell trait, and the importance of sickle cell trait testing.

Keywords: *Sickle cell awareness, genetic screening, youth knowledge, premarital testing, health education, screening uptake.*
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BACKGROUND OF THE STUDY

Individual-related factors play a significant role in influencing sickle cell trait (SCT) testing uptake among youths, particularly in relation to knowledge, awareness, attitudes, perceived risk, and socio-cultural beliefs. Evidence from different settings shows variability in awareness and understanding of sickle cell disease (SCD) and SCT, which directly affects testing behavior. In the United States, Siddiqui et al. (2014) reported that 76% of African American participants correctly defined SCD, while 10% had incorrect definitions and 14% lacked any knowledge of the condition. Similarly, Harrison et al. (2017) found that although 68% of respondents had moderate knowledge, only 47% had undergone SCT testing, and 44% expressed unwillingness to know their carrier status, highlighting the gap between knowledge and testing behavior.

In India, awareness levels were even lower, with Babu et al. (2021) reporting that only 32.1% had heard of SCD, 28.6% were aware of diagnostic methods, and just 19.5% recognized that a blood test could diagnose the condition. Furthermore, only 17.9% understood its hereditary nature,

and 13.1% knew it could be prevented, indicating poor genetic literacy as a barrier to testing. In Saudi Arabia, Al-Qattan et al. (2019) found high awareness of newborn screening (98.3%), but substantial knowledge gaps remained regarding specific tests and diseases screened.

In the African context, mixed findings have been reported. In Uganda, Nabwire (2018) found that 71.6% of youths were aware of SCT testing, with radio (42.9%) being the main source of information, followed by hospitals (15.7%) and television (14.6%). However, only 54.9% understood that blood is used for testing, while 28.4% had no awareness of SCT testing. In Nigeria, Olakunle et al. (2013) reported very low knowledge, with only 1.4% correctly identifying blood as the diagnostic sample, despite 89.6% acknowledging the importance of knowing one's SCT status.

Attitudes and perceptions also strongly influence testing uptake. Smith et al. (2021) observed that although participants had generally positive attitudes toward screening, only 26% knew their carrier status. In Ghana, Boadu et al. (2018) found that while 85% were willing to test for SCT, fears related to stigma, partner rejection, and marriage disruption were common, with 34.7% willing to end relationships based on genetic compatibility concerns. Similarly, in Uganda, Nabwire (2018) reported that 39.2% feared stigma and 21.4% felt less confident about relationships if found to be carriers.

Willingness to test is further shaped by socio-demographic and economic factors. In Oman, Al-Farsi et al. (2014) reported variation in willingness by sex, education, and marital status, with males (37.5%) and females (29.5%) showing differing willingness levels. In addition, 32.2% of youths in Uganda were unwilling to pay for SCT testing if not free, indicating financial barriers (Nabwire, 2018). Access and screening uptake also vary, with only 24.7% of Ugandan youths having undergone testing, and most testing occurring in hospitals (79%) rather than community or school settings.

The study aimed to assess individual 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 wards, that is Tei-bu, Wormwaka, Aminteng, Odokomach, and Awir ward. Agulu division consists of 26 cells/villages, in which Village Inn is among these, located in Tei-bu ward. There are approximately 5000 youth in the Agulu division, where the 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, saloons, and many others. It was chosen because it's accessible and Apac is among the fourteen districts with a high burden of SCD, and 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 a representative of the study population, offered equal chances to all members, and was easy to administer.40 participants 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 with 1 to 5 were interviewed using a self-administered questionnaire.

Inclusion Criteria

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

Exclusion Criteria.

All youth aged 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 variable was individual factors related to the factors.

Dependent Variable

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

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Research Instrument

The tool used was comprised of 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, where the compiled data was 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 the 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 to 10; only those who had a number from 1 to 5 were allowed to participate in the study. A consent form was provided, which, upon signing, was returned 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 for 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 was 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 the 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

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

The socio-demographic characteristics of the participants are comprised of gender, age, marital status, religion, and level of education.

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

Up to67.5% (27) were female, and the majority (50%) of participants were aged between 24-29while, while 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 response to 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

Only a few 17.5% participants knew that SCD is an inherited disorder of red blood cells, while quite a big number (30%) believe it is leukemia.

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

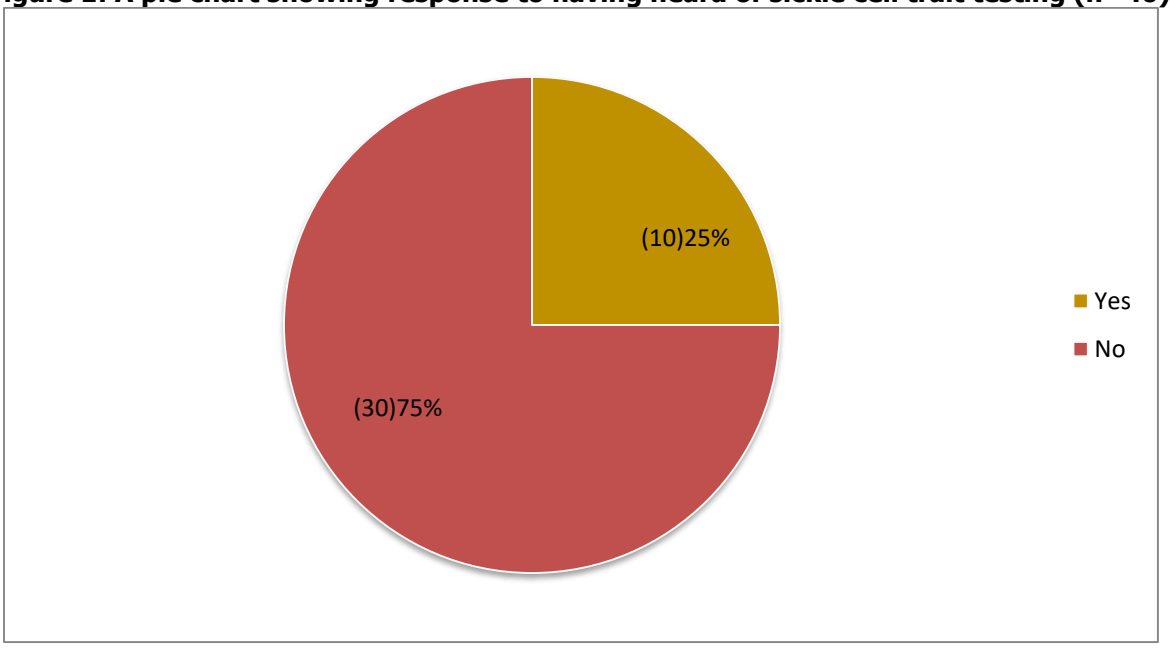
Variable	Frequency	Percentage (%)
Testing all the newly born children	11	27.5
Premarital screening and counseling	8	20
Stopping two people who both carry the sickle cell gene from having a child together	9	22.5
Don't know	12	30

Source: primary data

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

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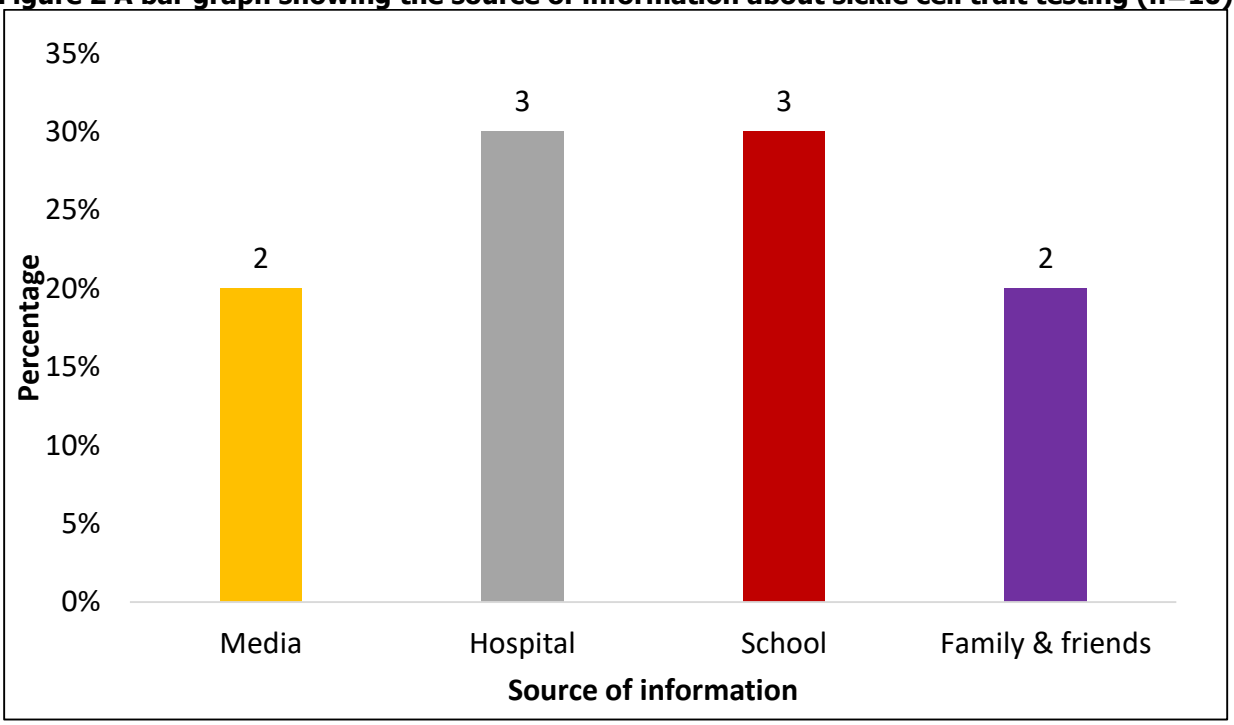
Figure 1: A pie chart showing response to having heard of sickle cell trait testing (n=40)



Source: primary data

More than half (75%) of the participants have never heard of sickle cell trait testing, and only 25% had ever heard of it.

Figure 2 A bar graph showing the source of information about sickle cell trait testing (n=10)



Source: primary data

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 response 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

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

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

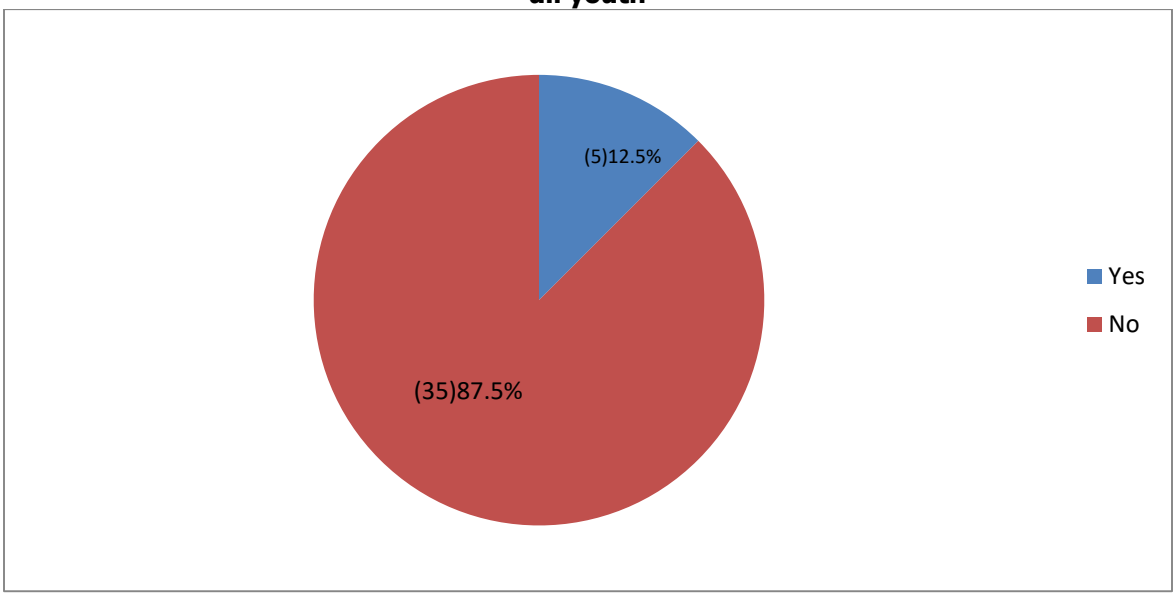
Variable	Frequency	Percentage (%)
A simple urine sample	4	10
Simple blood sample	14	35
Saliva	5	12.5
Don't know	17	42.5

Source: primary data

The majority of the participants (42.5%) of the participants didn't know the specimen used to test for SCT, and only 35% knew that blood samples are used for the test.

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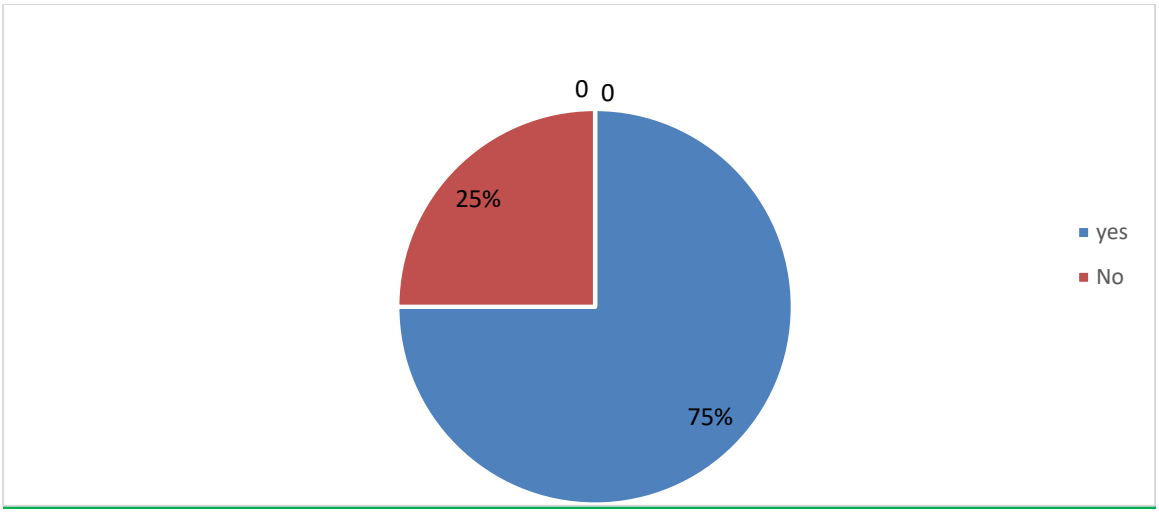
Figure 3: A pie chart showing the response towards making sickle cell testing available for all youth



Source: primary data

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

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



Source: primary data

The majority of the participants (75%) were willing to test for SCT, and only a few 25% were not willing.

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

Variable	Frequency	Percentage (%)
Fear of stigma incase 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

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

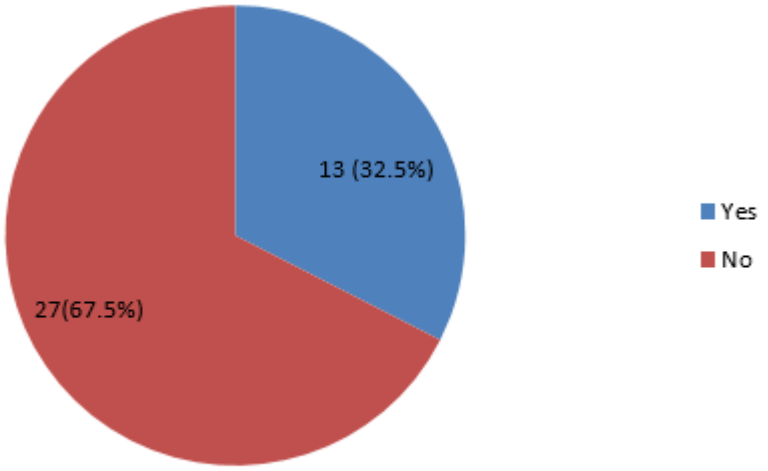
Table 7: Showing response on whether sickle cell screening could help prevent transmission of genes to others (n=40)

Variable		Frequency	Percentage (%)
Strongly agree	24	5	12.5
Agree		9	22.5
Not sure		10	25
Disagree		16	40

Source: primary data

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: A pie chart showing response to having ever tested for sickle cell trait (n=40)



Source: primary data

Most (67.5%) of the participants have never tested for SCT, and very few 32.5% had ever tested for it.

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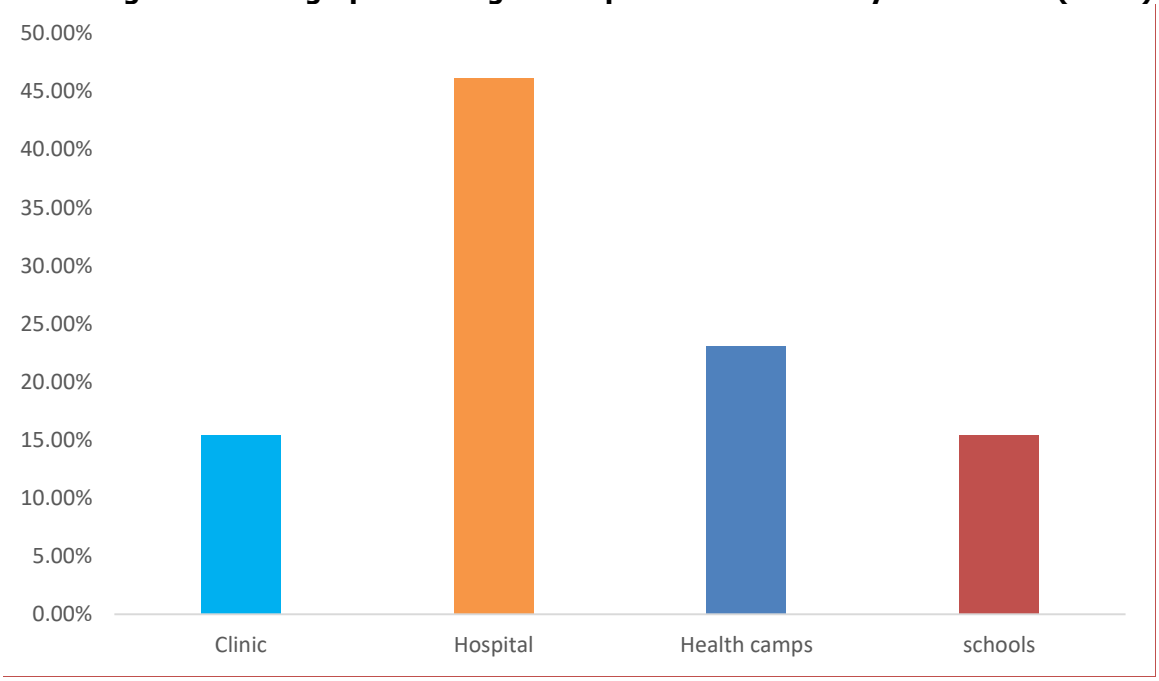
Table 8: Showing response on reason for testing (n=13)

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

Source: primary data

Most 30.8% of them were tested due to premarital testing, others matter, such as employment and school requests, while a few of them (15.3%) were out of curiosity.

Figure 6: A bar graph showing the response on where they tested from (n=13)



Source: Primary data

The majority (46.1%) of the participants had tested from the hospital, while a few 15.4% had tested from the schools.

Table 9: Showing response 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

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.

DISCUSSION

Social demographic data of the participants.

Concerning the Socio-demographic characteristics, more than half of the participants were females. This could be so because females generally have a good health-seeking behavior, which is in contrast to a study by Al-Farsi et al (2014), where more than half were males. These findings, therefore, show there is still more need for male involvement in health care services.

There was nearly equal distribution of participants regarding age, though the age between 26 and 30 years was slightly above a quarter. This could be so because a big percentage of the country's population is mainly made up of youth.

One in two of the participants was married since by the age of 18-35, most of the people are getting married and settling down during that time, and the majority of the participants were Catholics.

Regarding employment status, more than half of the participants were self-employed. Of this, nearly half had attained at least a tertiary level of education. This could be attributed to the free education services by the government from primary to tertiary level of education, and the microfinance support provided by the government to support small-scale businesses.

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 findings 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 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 and this may be as a result of in adequate health education regarding SCD, this is in disagreement with the study by Harrison et al (2019) in USA where more than 3 in 4 of the participants were able to correctly define SCD this differences in findings could be as a results of literacy rate label 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 1 in every 4 participants didn't know how sickle cell disease can be prevented, and only 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 puts 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 a 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 the 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 onto the people, other means of communication should be considered, such as radios, and since most people own radios and televisions (UBOS, 2017).

As per the test done to diagnose SCD, less than 2 in 3of the participants knew a blood sample was used in the diagnosis of SCD, while others mentioned 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. These findings further agree with a related study by Babu et al (2021), where less than a quarter said that a laboratory test can diagnose SCD. This finding puts 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 cases of sickle cell disease in the community, accompanied by the SCD economic burden, which puts demand to prevent 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. However, these finding disagrees with a related study by Yalma et al (2021) in Nigeria, where less than 1 in 4 had never had genotype screening.

This study further indicated that the majority of those who tested did so as a result of premarital testing, and their reasons were employment, school, and curiosity, which was

in line with Adewoyin et al (2015), where the majority screened because of curiosity and school requirements.

In this study, nearly half of the participants had been tested at the hospital, and a few from the clinic and schools. This is similar to a study by Nabwire (2018), where the majority had tested at the hospital, a few had 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 a half had screened for SCD, and this means that more than half of the participants are still unaware of their sickle cell status and thus there are higher chances that these 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.

CONCLUSION

The study found that most participants had poor knowledge regarding sickle cell disease (SCD) and sickle cell trait (SCT) testing. Misconceptions about the disease, its transmission, prevention, and the availability of testing services negatively influenced SCT testing uptake among youths. Despite these knowledge gaps, participants expressed willingness to undergo SCT testing when provided with adequate information and support.

RECOMMENDATION

Health workers should provide regular health education to youths and community members on sickle cell disease, sickle cell trait, and the importance of sickle cell trait testing.

Health workers should inform community members about the availability of free sickle cell trait testing services and provide information on health facilities where these services can be accessed.

Community leaders should conduct continuous sensitization campaigns through community meetings, schools, universities, radio programs, and other communication channels to increase awareness and knowledge about sickle cell disease and sickle cell trait testing.

The District Health Team should promote premarital and pre-conception sickle cell trait screening programs following adequate community education to reduce the risk of sickle cell disease among newborns.

Researchers should conduct similar studies in other regions of Uganda to assess factors influencing sickle cell trait testing and generate findings that can be generalized to wider populations.

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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

SCD – Sickle Cell Disease
SCT – Sickle Cell Trait

PMGC – Premarital Genetic Counseling
UBOS – Uganda Bureau of Statistics
USA – United States of America
LCI – Local Council I

Source of funding
The study received no external funding.

Conflict of interest
The authors declare no conflict of interest.

Author contributions
BO: collected the data.
JE: supervised the study.
DO: supervised the study.

Data availability
Data is available upon request from the author.

Informed consent
Written informed consent was obtained from all participants prior to their inclusion in the study. Participants were informed about the purpose of the study, procedures involved, potential risks and benefits, and their right to withdraw at any time without penalty.

Author biography
Belbore Ogwang**:** a student pursuing a diploma in nursing extension.
Josephine Epila**:** research supervisor at Florence Nightingale School of Nursing and Midwifery
Denis Obong**:** research supervisor at Florence Nightingale School of Nursing and Midwifery

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