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Understanding Knowledge, Attitude, and Practices towards Sickle Cell Disease among Adult Outpatients: Insights from Lira Regional Referral Hospital, Northern Uganda

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ABSTRACT

This study investigates the knowledge, attitude, and practices (KAP) regarding sickle cell disease (SCD) among adult outpatients at Lira Regional Referral Hospital (LRRH) in Northern Uganda. Employing a descriptive cross-sectional qualitative approach, data were collected from 100 adult patients aged 18 years and above attending the general outpatient department (OPD) at LRRH. Results revealed a substantial level of awareness of SCD among respondents, predominantly sourced from healthcare facilities and media outlets. While many recognized SCD as hereditary, misconceptions regarding its etiology and symptoms were evident. Notably, there was a knowledge gap regarding the treatability of SCD. Attitudes towards marrying individuals with SCD were predominantly negative, reflecting concerns about genetic transmission. However, there was a positive inclination towards premarital SCD testing. Regarding practices, reliance on medical facilities for SCD treatment was predominant, with minimal engagement with alternative therapies. Recommendations include sustained awareness campaigns, integration of SCD prevention and control initiatives, and further research to elucidate regional SCD prevalence determinants. Efforts to enhance male involvement in SCD advocacy and capacity building among healthcare providers are advocated to optimize SCD management and prevention strategies within the community.

Keywords: Knowledge, Attitude, Practices, Sickle Cell Disease, Outpatients

INTRODUCTION

Sickle cell disease (SCD) is a blood disorder inherited from parents, with the most common type being sickle cell anemia. This results in an abnormality in hemoglobin, leading to a rigid, sickle-like shape. SCD is more common in African or Caribbean families [1]. Problems typically begin around 5 to 6 months of age, and can lead to health problems such as pain, anemia, swelling, bacterial infections, lung problems, and stroke. Long-term pain can interfere with education, employment, and psychosocial development. SCD varies from mild to serious, with an average life expectancy of 40 to 60 years in the developed world. The life expectancy can vary depending on the specific type of SCD, treatment, and the patient's experiences [2, 3].

SCD is a prevalent inherited genetic blood disorder affecting humans worldwide. It occurs when a person inherits abnormal copies of the beta-globlin gene (HBB), which makes hemoglobin, from each parent. If both parents have the gene, there is a 1 in 4 chance of each child being born with SCD [4]. The child's parents are carriers of the sickle cell trait, which occurs on chromosome 11. A person with a single abnormal copy of the HBB does not usually have symptoms and is known as a carrier. Diagnosis of SCD can be done through simple blood tests, often found at birth during routine newborn screening tests in the United States. Screening for SCD status can also be done as part of care before marriage. The best tests to determine risk include complete blood count, mean corpuscular volume, hemoglobin electrophoresis, and sickle cell solubility tests. Early diagnosis is crucial as children with SCD are at an increased risk of infection and other health problems [5].

Sickle cell disease (SCD) is a chronic disease that can lead to pain episodes and complications. Treatments are available to prevent complications and prolong life, and are typically delivered by healthcare professionals in specialized centers. Self-care measures, such as avoiding triggers, handwashing, and managing pain, are also important. Treatments include fluids, painkillers, daily antibiotics, vaccinations, blood transfusions, folic acid

supplementation, and hydroxyurea. The FDA only approves stem cell or bone marrow transplants for SCD [6]. In Africa, complementary and alternative medicines (CAM), particularly herbal medicine, have been reported, but the extent of use in Uganda is not documented [7].

Africa contributes to three-quarters of global SCD cases, with 2% of new-borns affected in Nigeria. The carrier frequency varies across equatorial Africa, with Uganda being the highest. SCD contributes to 5% of under-five deaths, with up to 16% in some countries. The highest frequency is found in tropical regions, particularly sub-Saharan Africa [8].

SCD prevalence in Uganda is 13.3%, with over 20% in eight districts. The disease affects about 15,000 babies per year in Uganda, with significant variation across tribes. In Eastern Uganda, the prevalence of SCD is 17.5%, while in Western Uganda, it is 13.4% and 3% [9]. The disease is primarily caused by hereditary factors and can be prevented through pre-marital counseling. People have a high level of knowledge about SCD, believing it is caused by hereditary factors and can be diagnosed through blood tests. Most people are satisfied with the treatment in public and private clinical settings, compared to traditional or herbal therapy [10]. Patients and caretakers can identify the health causes of their VOC, and providers rely on non-validated forms of pain assessment. Premarital screening is agreed upon, but few agree to marry a partner with SCD. Practices regarding SCD are limited, with most patients never testing for SCD or knowing their partner's status [11]. Blood transfusion is considered an effective treatment, and some regional hospitals lack diagnostic tests and hydroxyurea therapy. Counseling and prevention of causes and infections are currently offered to SCD patients [12]. In Uganda, SCD prevalence is 14% in northern Uganda, but recent studies have not assessed knowledge, attitude, and practices. Studying these aspects could increase community awareness, increase healthcare utilization, and reduce psychological distress in children, adolescents, adults, and their families [11]. The study aims to evaluate the knowledge, attitude, and practices of adult outpatients at Lira Regional Referral Hospital about sickle cell disease, as well as determine their attitudes towards the disease and identify their practices regarding it. The objectives include assessing the level of knowledge, understanding, and practices of the patient population.

METHODOLOGY

Study Design

This was a descriptive cross-sectional qualitative study method of data collection that determined the knowledge, attitude and practices about sickle cell disease among adult general out patients in Lira Regional Referral Hospital.

Study Site

The study was conducted in general OPD, Lira Regional Referral Hospital, Lira district, in Northern Uganda. This hospital is referral to eight districts in Lango sub- region and beyond, with the catchment area of about five million people.

Study Population

This study was conducted among adult patients aged 18 years and above attending general OPD at Lira Regional Referral Hospital.

Inclusion criteria

Any adult individual patient aged 18 years and above attending OPD in Lira Regional Referral Hospital during the exercise that consented qualified to participate in the study.

Exclusion Criteria

Any individual below 18years, and who was not a patient attending OPD at Lira Regional Referral Hospital, or not available during the exercise or did not consent was automatically excluded.

Sample Size determination

The sample was determined using the formula below.

$n= z^2p(1-p)/d^2$ (Kish and Lisle [13])

Where; -

n= desired sample size

z= standard normal deviation usually set at 1.96 which correspond to 95% confidence level.

p= proportion of survey population with particulars under investigation and where it is unknown, 50% is used.

d= desired precision of error 9.8% (0.098).

Therefore;

$n= 1.96^2(0.5)(1-0.5)/(0.098)^2$

n= 100

The sample size included 100 subjects based on accessible target group and consecutively enrolled as they came and were interviewed for convenience due to limited time and lack of enough resources.

Sampling techniques

Patients attending general OPD in the hospital who were adults were consecutively enrolled as they came and consented for the exercise that gave equal opportunity for every patient to participate in the study that avoided bias.

Questionnaires

The researcher asked both closed and open ended and semi structured questions to collect data, the attitude of respondents was determined using ordinal scale because of the flexibility.

Interviews

This was used to gather information from the patients' interview guide that helped to get their level of awareness, attitude and practices about sickle cell disease.

Data Analysis

After collecting data, it was cleaned and entered into Statistical Package for the Social Sciences (SPSS) program for analysis. Data from interviews was linked to variables and their relationship was established and interpreted using correlation. All data was presented in a flow chart, graphs, frequency tables, pie-charts, figures and descriptive summary.

Ethical Considerations

The proposal was approved by the Kampala International University Teaching Hospital and Research Committee Western Campus, and the researcher was introduced to Lira Regional Referral Hospital administration. Three research assistants were employed to administer questionnaires and data analysis, develop consent forms, and ensure confidentiality. Respondents were informed about study risks and benefits. The questionnaire was administered to participants after obtaining informed consent. The researcher linked participants' sickle cell status to the general procedure, ensuring a comprehensive understanding of the study.

RESULTS

Table 1: Showing the Social-demographic status of the respondents

Variables	Demographic	Frequency	Percentage (%)
Gender	Male	44	44.0
	Female	56	56.0
Age Group	21-30	33	32.4
	31-40	26	25.5
	41-50	20	19.6
	51-60	15	14.7
	61-70	6	5.9
	71-80	2	1.9
	Langi	97	97.0
Tribe	Acholi	2	2.0
	Others	1	1.0
	Peasant Farmer	60	59.4
Occupation	Health Work	2	2.0
	Teacher	8	7.9
	Soldier	1	0.9
	Student	12	11.9
	Business Person	4	4.0
	Others	14	13.9
Level of Education	None	19	19.0
	Primary	31	31.0
	Secondary	20	20.0
	Tertiary	30	30.0
Religion	Catholic	37	36.3
	Anglican	52	51.0
	Pentecostal	10	9.8
	SDA	3	2.9
Marital Status	Single/ Divorced	19	19.0
	Married	80	80.0
	Widow	1	1.0

As shown in table 1 above, by gender female had the highest number of respondents 56(56.0%) as compared to male gender 44(44.0%), age group of 21-30 had the highest number of 33(32.4%) with the age group of 71-80 having lest number of 2(1.9%), by tribe, the Langi dominated with the number of 97(97.0%), most of the respondents were peasant farmers 60(59.4%), where most of them had attained primary level of education 31(31.0%), most of the respondents were Anglican by religion 52(51.0%), while majority were married 80(80.0%).

Table 2: showing the knowledge about SCD

Ever heard about SCD	Frequency	Percentage (%)
Yes	84	84.0
No	16	16.0
Total	**100**	**100.0**

As sown above in the table, 84(84%) of the respondents had ever heard about sickle cell disease while 16(16.0%) had never heard about sickle cell disease.

Table 3: showing where they heard the information about SCD

Source of Information	Frequency	Percentage (%)
Parents	18	18.0
Relatives	21	21.0
Health Unit	39	39.0
Talk Show, Radio or TV	22	22.0
Total	**100**	**100.0**

As shown in the table above, most of the respondents 39(39%) got the information about sickle cell disease from the health unit, followed by 39(39.0%) who got the information from talk show, radio or TV, 18(18.0%) from parents while the least 21(21.0%) got the information from the relatives.

Table 4: showing the Age period

Age group	Frequency	Percentage (%)
While below 18 years	22	22.0
Above 18 years, specify	78	78.0
Total	**100**	**100.0**

As shown above in the table, 78(78.0%) of the respondents heard the information about SCD while they were above 18 years of age and 22(22.0%) heard it while below 18years of age.

Table 5 showing the Knowledge about SCD (awareness)

Opinion of respondents	Frequency	Percentage (%)
A bone disease that makes a person feel very cold	6	5.0
A bone disease, with thinness	15	15.0
A bone disease that causes pain in the bones, joint pain	16	16.0
A bone disease that causes joint pain and general body weakness	**21**	**21.0**
A bone disease that affects the red blood cell and causes slimming	**28**	**28.0**
A bone disease of genetic origin that causes pain in the body	**5**	**6.0**
A bone disease that causes fever, body weakness and yellow eyes	**9**	**9.0**
Total	**100**	**100.0**

As shown in table above, 28(28.0%) of the respondents said SCD is a bone disease that affects the red blood cell and causes slimming, followed by 21(21.0%) of the respondents who said SCD is a bone disease that causes joint pain and general body weakness, 16(16.0%) of the respondents who said SCD is a bone disease that causes pain in the bones and joint pain, 15(15.0%) said SCD is a bone disease with thinness, 9(9.0%) said SCD is a bone disease that causes fever, body weakness and yellow eyes and the least 6(6.0%) said SCD is a bone disease of genetic origin that causes pain in the body.

Table 6: showing how sickle cell is acquired

How sickle cell is acquired	Frequency	Percentage (%)
Through direct contact with SC carrier	2	2.0
Through insect bites	2	2.0
Through parents who are SC carriers	95	95.0
Through blood transfusion	1	1.0
Total	**100**	**100.0**

As shown in the table above, most of the respondents 95(95.0%) said SCD is acquired through parents who are sickle cell carriers, 2(2.0%) of the respondents said SCD is acquired through insect bites and through direct contact with sickle cell carrier while the least 1(1.0%) of the respondents said they are acquired through blood transfusion.

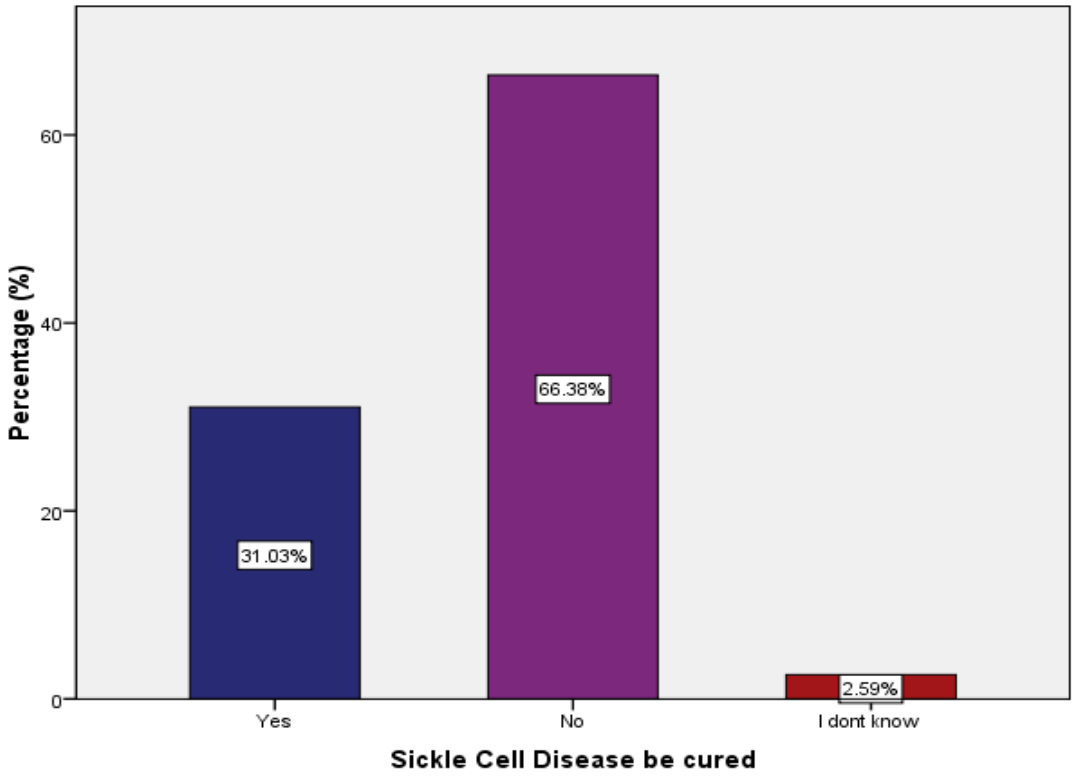

Figure 1: showing can SCD be cured

As shown in the figure above, 66.38% of the respondents said SCD cannot be cured, 31.03% who said SCD can be cured while 2.59% said they don't know whether it can be cured or not.

Table 7: showing the Cure for sickle cell disease

Cure for sickle cell disease	Frequency	Percentage (%)
Medical Treatment	92	92.0
Herbal Treatment	6	6.0
Both	2	2.0
Total	**100**	**100.0**

As shown above in the table, 92(92.0%) of respondents agreed that sickle cell disease can be treated by medical treatment, 6(6.0%) of the respondents agreed sickle cell disease can be treated

by Herbal treatment while 2(2.0%) of the respondents said sickle cell disease can be treated by both medical and herbal treatment.

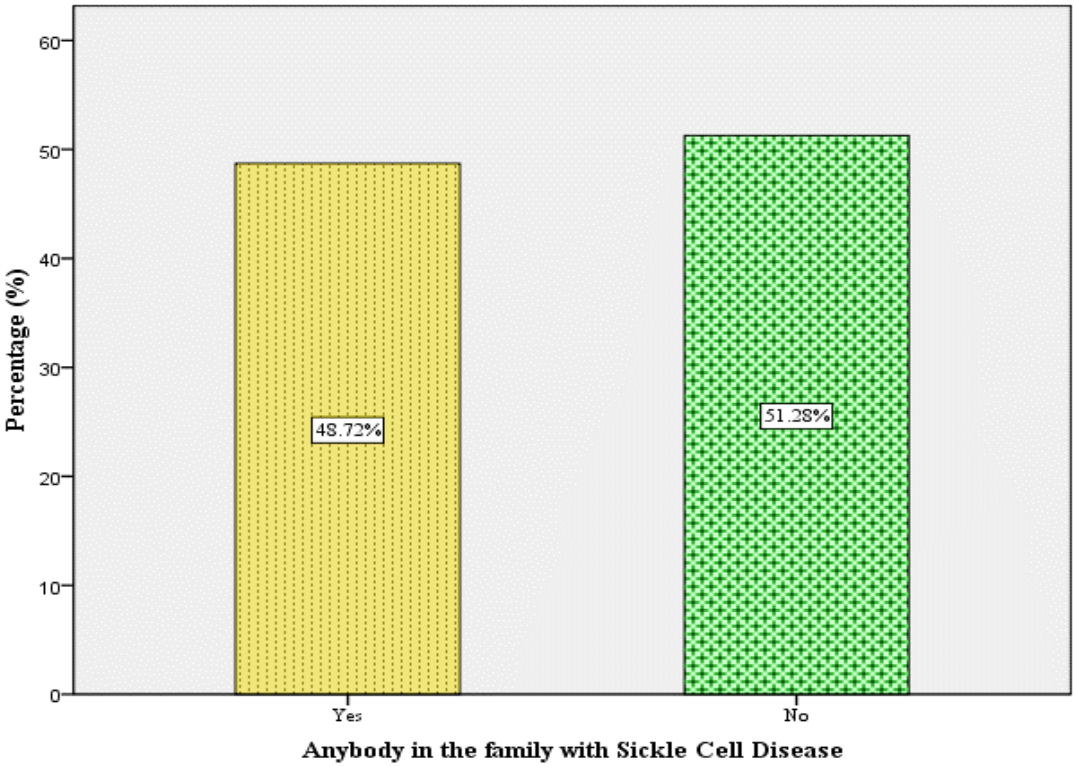

Figure 2: showing the prevalence of sickle cell disease

As shown in the figure above 51.28% respondents said their relatives don't have SCD while 48.72% said their relatives had SCD.

Table 8: showing those being treated of sickle cell disease

Treatment Recode	Frequency	Percentage (%)
Yes	90	90.0
No	6	6.0
I Don't Know	4	4.0
Total	**100**	**100.0**

As shown in the table above, 90(90.0%) of the respondents said their relatives were being treated for SCD, 6(6.0%) said their relatives not treated of SCD and 4(4.0%) said they don't know whether their relatives were being treated of SCD or not.

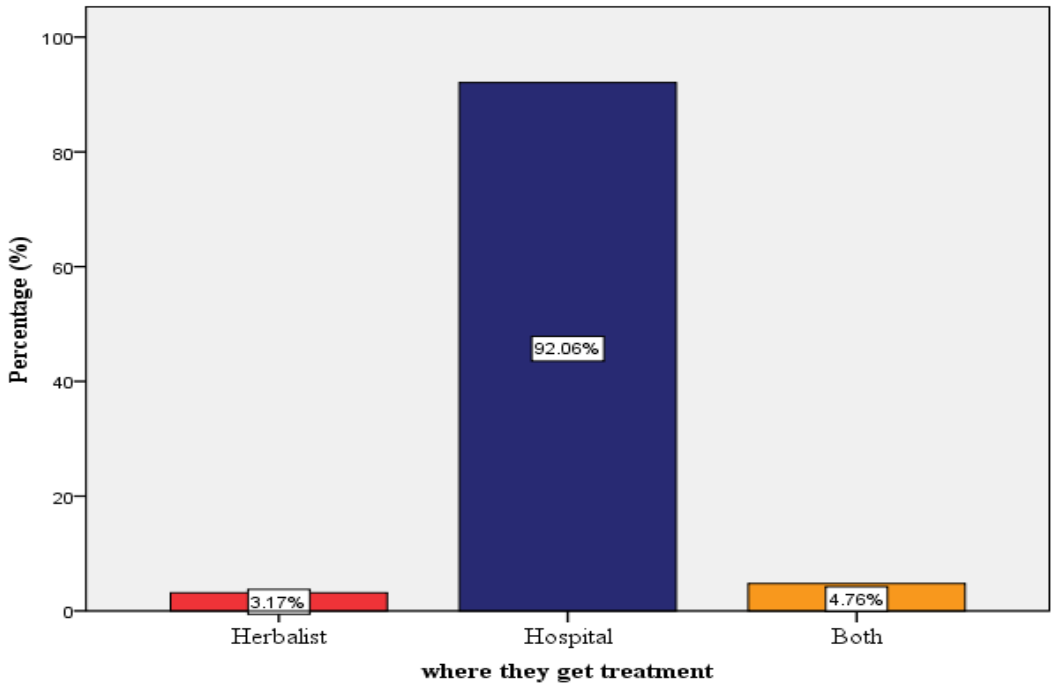

Figure 3: showing where they get their treatment

From the figure above, 92.06% of respondents got their treatment from the hospital, 3.17% got from herbalist while 4.76% of the respondents got their treatment from the both hospital and herbalist.

Table 9: showing the respondent who had Ever tested for sickle cell disease

Ever Tested	Frequency	Percentage (%)
Yes	15	15.0
No	85	85.0
Total	**100**	**100.0**

From the table above, 15 (15.0%) had ever tested for sickle cell disease while 85(85.0%) of the respondents have never tested for sickle cell disease.

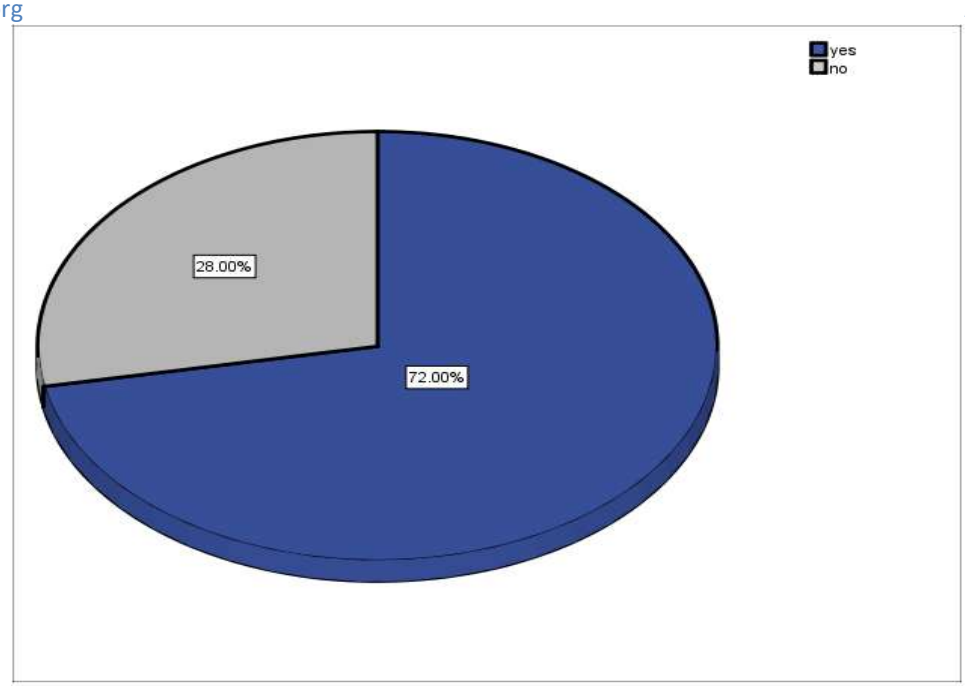

Figure 4: showing those willing to test

As shown in the figure above, 72% of the respondents were willing to test for SCD while 28% were not willing to test for SCD.

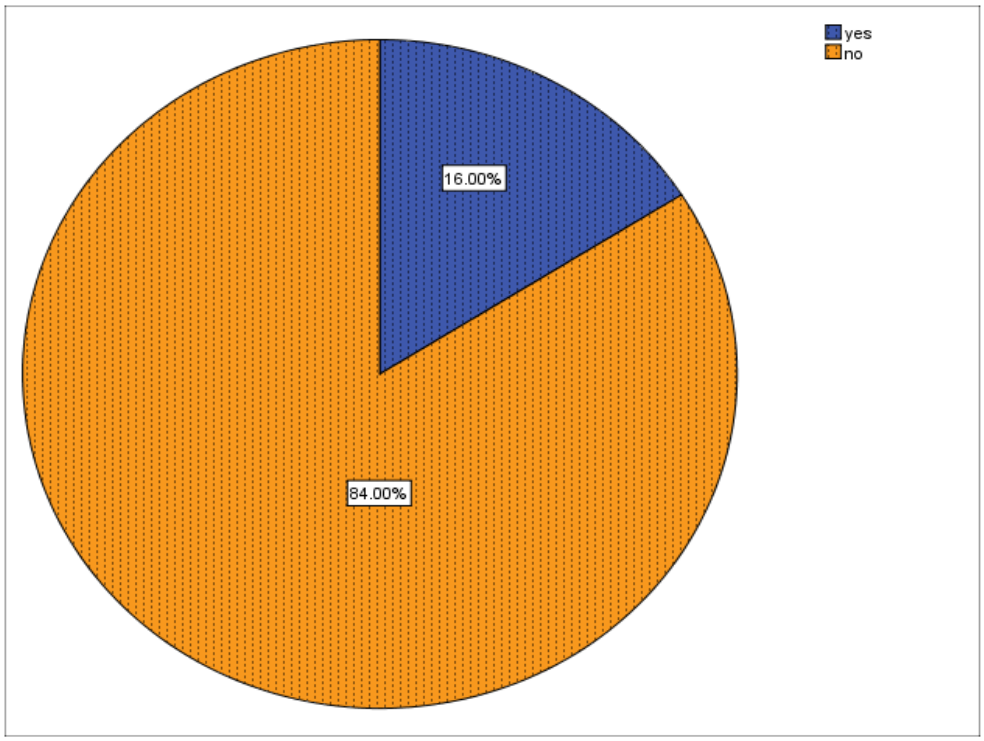

Figure 5: showing marrying someone who tested positive of sickle cell disease

The figure above showed that 84% of the respondents said they cannot marry someone who tested positive of SCD while 16% said they can marry someone who tests positive of SCD.

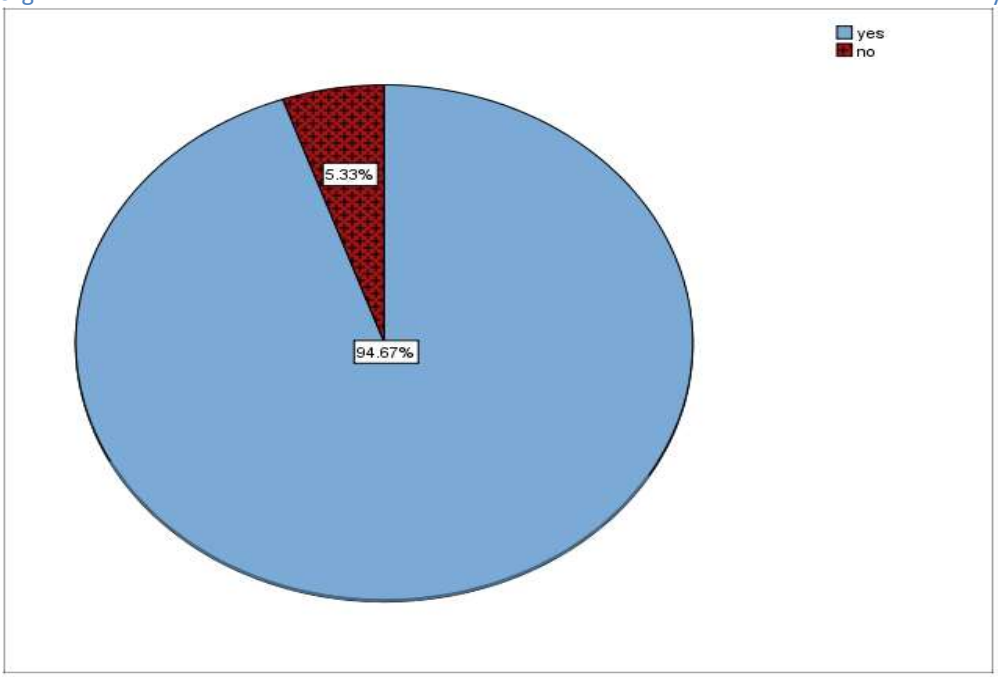

Figure 6: showing those who support idea of testing for sickle cell disease before marriage

As shown above in the table, 94.67% of the respondents agreed that it is a good idea to test for SCD before marriage while 5.33% didn't agree.

DISCUSSION

The study had the highest number of female respondents, 56 (56%) as compared to male gender 44 (44.0%), the age group of 21–30 had the highest number of 33 (32.4%), with the age group of 71–80 having the least number of 2 (1.9%). By tribe, the Langi dominated with the number of 97 (97.0%), most of the respondents were peasant farmers, 60 (59.4%), most of them had attained the primary level of education, 31 (31.0%), most of the respondents were Anglican by religion, 52 (51.0%), and the majority were married, 80 (80.0%).

Knowledge/awareness about SCD among adult patients attending general outpatient department at LRRH

The study revealed that most of the respondents (84.0%) had ever heard about sickle cell disease, while 16 (16.0%) had never heard about sickle cell disease. This interesting finding is in accordance with research done in Nigeria about knowledge, attitude, and practices, which found that most (98.4%) of the respondents had heard about sickle cell disease [14]. This study further showed that most of the respondents (39.0%) got the information about sickle cell disease from the health unit, followed by 22 (22.0%) who got the information from talk shows, radio, or TV, 18 (18.0%) from parents, and the least (21.0%) got the information from relatives. This suggested a good level of awareness about the disease. This is also in line with a study done by Adewoyin et al. [14] in Nigeria, which revealed that the main channel of information (45.9%) was health talks and mass media. However, 100 (83.5%) of the respondents heard the information about SCD while they were above 18 years of age, and 20 (16.5%) heard it while below 18 years of age.

Regarding the knowledge about SCD, 28 (28.0%) of the respondents said SCD is a bone disease that affects the red blood cells and causes slimming, followed by 21 (21.0%) of the respondents who said SCD is a bone disease that causes joint pain and general body weakness. 16 (16.0%) of the respondents who said SCD is a bone disease that causes pain in the bones and joint pain, 15 (15.0%) said SCD is a bone disease with thinness, 9 (9.0%) said SCD is a bone disease that causes fever, body weakness, and yellow eyes, and the least 5 (5.0%) said SCD is a bone disease of genetic origin that causes pain in the body. This finding is in accordance with a study by Al-Nasir and Niazi [15] regarding the general knowledge of 118 SCD patients, which found that 38% had little knowledge about SCD, 32% had moderate knowledge, and 30% had a high degree of knowledge.

Furthermore, the study revealed most of the respondents had knowledge about SCD, with most of the respondents (95.0%) saying SCD is acquired through parents who are sickle cell carriers; 2 (2.0%)

of the respondents said SCD is acquired through insect bites and through direct contact with sickle cell carriers; and the least 1 (1.0%) of the respondents said it is acquired through blood transfusion. The result indicated that 66.38% of the respondents said SCD cannot be cured, 31.03% said SCD can be cured, and 2.59% said they don't know whether it can be cured or not. This study revealed that 92 (92.0%) of respondents agreed that sickle cell disease can be treated by medical treatment, 6 (6.0%) of the respondents agreed sickle cell disease can be treated by herbal treatment, and 2 (2.0%) of the respondents said sickle cell disease can be treated by both medical and herbal treatment. Results showed that 51.28% of respondents said their relatives don't have SCD, while 48.72% said their relatives have SCD. These findings showed a sharp discrepancy, according to [16,17], who said the Bamba tribe in western Uganda has up to 40% trait prevalence, according to studies.

Attitude towards SCD among adult patients attending outpatient department at LRRH

In this study, 84% of the respondents said they could not marry someone who tested positive for SCD, while the least proportion, 16%, said they could marry someone who tested positive for SCD. This interesting finding also agrees with the finding according to a study conducted by Adewoyin et al. [14], which states that only a few (8.6%) of the respondents expressed willingness to marry another sickle cell trait carrier despite the risk of raising children with sickle cell disease. Most of the respondents (80.8%) were unwilling to take such actions, while the remaining 10.5% were undecided.

Practices about sickle cell disease among adults attending outpatients in Lira Regional Referral Hospital.

This study revealed that 90 (90.0%) of the respondents said their relatives were being treated for SCD, 6 (6.0%) said their relatives were not being treated for SCD, and 4 (4.0%) said they didn't know whether their relatives were being treated for SCD or not. And that 92.06% of respondents got their treatment from the hospital, 3.17% got it from herbalists, and 4.76% got their treatment from both hospitals and herbalists. This revealed that there is a good practice in that the community is fully certified that, in such cases, there is a need to seek medical intervention for the treatment. Results showed that a large proportion (94.67% of the respondents) agreed that it was a good idea to test for SCD before marriage, while 5.33% didn't agree. According to this study, 35 (29.3%) had ever tested for sickle cell disease, while 85 (70.7%) of the respondents had never tested for sickle cell disease. And in that higher proportion, 72% of the respondents were willing to test for SCD, while 28% were not willing to test for SCD. It showed that the community had a positive response to accepting the changes.

CONCLUSION

The results show that the respondents have heard of sickle cell disease mostly from health units. It was noted that the majority of the respondents were aware of and basically knowledgeable about sickle cell disease and had a positive attitude about the disease. Most of the respondents knew that SCD is inherited; however, a large proportion did not know the cause of SCD. However, more than two-thirds of the respondents said they could not marry a person with SCD.

Recommendations

There is a need for stakeholders to continue with sensitization and the integration of SCD prevention and control programs or services within the health and non-health sectors. Health education and genetic counseling both at the community and health center settings and levels, and implementation of the SCD Day Care Service Model in all centers. There is a need for more studies to be carried out to establish the knowledge and factors contributing to the high sickle cell prevalence among the patients attending the outpatient department of LRRH. There is a need for the formulation of strategies to encourage male involvement in the SCD campaigns and to continue implementing the already existing government policies and programs. Furthermore, there is a need for capacity building among healthcare personnel and the provision of more specialist centers.

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