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Assessing Knowledge, Attitudes, and Practices Regarding Sickle Cell Disease among Outpatients at Jinja Referral Hospital

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ABSTRACT

Sickle cell disease (SCD) is one of the most common genetic causes of morbidity and mortality in the world. In resource-limited settings, SCD prevention through public education and screening could be a significant strategy to curb its prevalence. The study aimed to determine the knowledge, attitude, and practices among the respondents at the OPD towards SCD. A community-based, analytic, cross-sectional study was conducted within the Jinja referral hospital at the OPD. Data was collected from 410 respondents using self-administered questionnaires. The data was analysed using the statistical software Epi Info Version 7 (51.5%) of the 410 respondents were female. The modal age range was 18-21 years (46.8%), and 60.4% had tertiary education. Less than one-quarter (20.5%) had good knowledge of SCD. Only 13.2% knew their genotype, and 59.3% were willing to avoid carrier marriages. Most of the respondents had moderate knowledge of SCD. The promotion of preventive methods like public education and genetic screening was recommended to reduce the burden of SCD.

Keywords: Sickle cell disease, Public education, Screening, OPD, Genetic screening.

INTRODUCTION

Sickle cell disease remains one of the most common genetic autosomal disorders among the African population. Sickle cell disease (SCD) is an inherited blood disorder caused by abnormal haemoglobin [1,2]. Sickle cell disease limits the oxygenating role of haemoglobin, resulting in the damaging or "sickling" of the red blood cells [3]. It is said to occur as a result of a single-base mutation of adenine to thymine, which produces a substitution of valine for glutamic acid at the 6th codon of the β-globin chain [4]. In the homozygous state (HBSS), commonly known as sickle cell anaemia, both genes are affected, whereas in the heterozygous state (HBAS), commonly known as sickle cell carrier, only one gene is affected. Children who inherit sickle cell genes from just one parent receive the sickle cell trait; they have no symptoms but can pass the gene on to their kids. Thalassemia, haemoglobin C, and haemoglobin D are other inherited haemoglobin subtypes. The combination of inherited genes determines the clinical presentation of disease among affected individuals [5]. This disorder affects all parts of the human body and differs widely among individuals [6]. In 1910, Dr. James Herrick, a Chicago physician, was the first American to formally report and identify elongated, sickle-shaped haemoglobin in an anaemic Grenadian student's blood smear. Herrick coined the now-familiar term "sickle cell" [7]. The inability of the crescent-shaped red blood cells to pass through the blood vessels decreases the level of oxygen carried from the lungs to the rest of the body. The sickle shape causes red blood cells to deteriorate early, which leads to anaemia [8]. The long-term effect of SCD over time leads to a progressive and systemic weakening of multiple organs. The resulting symptoms include repeated occurrences of severe pain, anaemia, organ damage, and infection [9]. SCD is impacting millions of people around the world. Nevertheless, it is the most popular among people with ancestors from Sub-Saharan Africa, South America, Cuba, Central America, Saudi Arabia, India, and Mediterranean countries like Turkey, Greece, and Italy. SCD affects approximately 72,000 people in the United States of largest burden of SCD occurs, more than 75% of SCD [8], around 200,000 cases of SCD occur; in Nigeria, about 150,000 children are born with the disease annually [10]. 0.7% of children in Uganda had SCD in 2016 and 13.3% had the sickle cell trait [11]. WHO identified SCD as an important public health disease in 2006 and urged Member States to create, introduce, and strengthen robust national integrated SCD prevention and management systems [12]. Objectives and goals for 2020 for the African region are established with guidelines and objectives that should have been tailored to local settings. Such interventions as increased understanding, disease prevention, and early detection are expected to improve the quality of life and life expectancy of SCD-affected people to lead more productive lives[10].Uganda has a varying distribution of SCD by state and district, with an overall disease incidence of 0.7% and an SCT rate of 13.3%, with an estimation that at least 15,000 babies are born with sickle cell disease each year in Uganda [11] and that 80% of these babies die before they reach the age of 5. Overall, SCD contributes 15% to the under-five mortality rate in Uganda, which is 64/1000 live births; the infant mortality rate is 43/1000 live births. Ssali, Northern Uganda has the highest sickle cell prevalence of 18.6%, the East-Central region of 16.7% second, the Mid-Eastern 16.5%, and the South Western region of 4.1% second. A maximum of 47 per cent of Uganda's fourteen districts have the largest burden of sickle cell disease: Kampala, Gulu, Lira, Jinja, Tororo, Luweero, Wakiso, Apac, Iganga, Mayuge, Buikwe, Oyam, Masaka, and Masindi. The highest prevalence of sickle

traits is observed in the districts of Alebtong, 24.3%; Buliisa,22.1%, Bundibugyo, 20%, Lira, Gulu, 19.6%, Tororo, 19.5%, and Jinja, 19.9% could reduce the number of new SCD neonatal births by 2050 in Africa [13]. The SCD burden is currently increasing three times in 2050. While SCT is asymptomatic and a person with it leads a normal life, scientific evidence is available that a woman who has SCT and conceives of a man who has SCT is likely to be 25% born with SCD, while 50% is born with SCT, and the child is only 25% non-carriers of SCT, indicating that the child has normal haemoglobin (CD) genes. Therefore, an increase in intermarrying between SCT individuals who do not have sufficient knowledge of SCD as a result of a lack of premature screening and genetic resources may lead to an increase in SCT and SCD prevalence. As a result, since 2013, the Uganda Sickle Cell Rescue Foundation has actively promoted awareness and prevention of sickle cell disease. Following the study by Ndeezi and others, the Ministry of Health, Uganda, has also made significant progress in addressing the burden of sickle cell disease by implementing a newborn screening programme in selected regions with the highest disease burden. This survey is therefore designed to determine attitudes, perceptions, and knowledge of sickle cell disease in Uganda at the Jinja Referral Hospital. This data will be important in identifying potential areas of intervention and change to encourage better outcomes in sickle cell prevention, sensitization, and management.

The prevalence of sickle cell trait in Jinja is high at 18.9% but this is above the national average of 13.3% for the trait [11]. The consequences of a high burden of sickle cell trait mean more people are at an increased risk of developing SCD, which is associated with serious morbidity due to vascular occlusion leading to extreme pain, severe anaemia, opportunistic infections, and damage to multiple organs. This results in slow growth and development, poor quality of life, and an increased risk of mortality, especially among children [14,11]. This is complicated by the fact that most of the diagnosis for SCD is done when clinical signs appear. On average, a family spends 111.67 U.S. dollars, equal to 402,102Ugandan Shillings per episode of a crisis involving SCD hospital admission [15]. While major campaigns are being undertaken by the Ministry of Health and NGOs in different districts to inform, monitor, and advise the different communities in Uganda about SCD, relatively few of the youths are aware of their sickle cell status. Jinja district, where this research was carried out, has a high prevalence of 18.9% of sickle cell traits and is one of the fourteen districts with a heavy incidence of sickle cell disease [15]. This research therefore tested the awareness and attitudes of the patients at Jinja Regional Referral Hospital about sickle cell disease. This information is important in identifying potential areas of intervention and changes to encourage better outcomes in sickle cell prevention, sensitization, and management. The research was designed to assess awareness about sickle cell disease among adults at Jinja Regional Referral Hospital OPD.

METHODOLOGY

Study Design

This was a descriptive cross-sectional study that assessed the level of awareness about sickle cell disease among the out-patients department at Jinja Regional Referral Hospital.

Area of Study

The study area was the OPD clinic of Jinja Regional Referral Hospital in eastern Uganda. Jinja Hospital is one of the thirteen (13) regional referral hospitals in Uganda and is located in the centre of Jinja, not far from the source of the Nile. It is the Regional Referral Hospital for the districts of Bugiri, Iganga, Jinja, Kaliro, Kamuli, Mayuge, Kayunga, and parts of Mukono, with an overall population of 3.5 million people. The coordinates of Jinja Hospital are 00 25 52 N, 33 12 18 E, with a bed capacity of 600.

Study Population

Adults attending OPD at Jinja Regional Referral Hospital in western Uganda.

Inclusion Criteria

Only adults attending OPD at Jinja Regional Referral Hospital who are over 18 years old.

Exclusion Criteria

All adults who did not consent to the study and all those receiving health care services from other hospitals. Adults who met the inclusion criteria but unfortunately were mentally ill, blind, or too sick at the time of the study were excluded.

Sample Size Determination

Using a 95% confidence interval and an allowable error (e) of 5%, the sample size (n) was computed using the following formula

Where Z = Z value at the 95% confidence level, p = proportion, expressed as decimal, and e = error margin, expressed as decimal

$n = 1.962 \times 0.912\ (1 - 0.912)\ 0.052$

$n = 126.536$

The sample size is **127.**

However, the respondents interviewed exceeded the above calculation. So, for purposes of this report, 410 respondents are referred to as the actual sample size.

Sampling Technique

Convenient sampling was employed by the researcher. Convenient sampling was used to select the participants during the day from 8 a.m. to 4 p.m., specifically on Mondays and Fridays, so that all individuals who met the inclusion criteria were included in the survey.

Data Collection Method

The study employed a quantitative approach for data collection. The measurement tool for the study was a self-administered questionnaire, available in English, and for those who do not speak English, it was translated into the Lusoga and Luganda languages.

Data Collection Tools

The questions were open-ended and closed-ended in nature.

Data Analysis

Data from the questionnaire was entered and analysed using SPSS software or Microsoft Excel, and the results were presented in a frequency table and descriptive analyses. The descriptive statistics were used to ascertain information about the awareness of SCD among adults. Tests of association and correlation between explanatory variables and the outcomes of interest were done using Chi-square tests and linear regression.

Quality Control Validity

The research assistants underwent training and were introduced to the research protocol and the questionnaire. In addition, interview simulations to polish up their skills were executed. This was important to familiarise them with the questionnaire administration and thus reduce inconsistencies and biases during the explanation. Each question was explained in English to ensure that participants understood clearly what the question needed. Furthermore, participants were encouraged to ask any questions. All questionnaires were collected from participants and checked for completeness, accuracy, and any irregularities. All the data collected was kept by the researcher for analysis and report writing. At the data analysis stage, the researcher again checked the data for completeness and consistency.

Ethical Consideration

Ethical approval was sought from the KIUTH Research Ethics Committee (REC). The approval letter will be forwarded to the office of the Executive Director of Jinja Regional Referral Hospital for acceptance to carry out research in the hospital. Great care was taken to protect the research participants. First, the purpose of the research was explained to the participants, allowing them to choose whether or not to participate. They were informed that since participation was voluntary, each individual was free to withdraw at any point during the study. Informed consent was obtained from all those who agreed to participate in the study. Participants were assured that no harm would come to them as a result of their participation or refusal to participate in the research. They were also assured about the confidentiality of all that they said in the study.

RESULTS

Socio-demographic characteristics of the study population

Of the 410 participants, 211 (51.5%) were females and 199 (48.5%) were males **(Table 1).** The overall mean age was 21 ± 3.4 years, and the age group of 18–21 was most represented (46.8%). Most participants (84.6%) did not have children, and the majority (99.5%) were Christians. Concerning their educational status, 4.9% had only primary education, 34.7% had secondary education, and 60.4% had tertiary education.

Table 1: socio demographic characteristics of respondents

18-21	192	46.8
22-25	149	36.3
26-30	42	10.2
31-35	27	6.6
Yes	63	15.4
Male	199	48.5
Female	211	51.5
Christianity	408	99.5
Islam	2	0.5
Level of education		
Primary	20	4.9
Secondary	142	34.7
Tertiary	248	60.4
Others	0	0.0

Awareness of Sickle Cell Disease

Most of the participants (89.8%) had heard about sickle cell disease, while the remaining 10.2% were not aware of the disorder. The main channel of information (41.7%) was through formal learning. Other sources of information included affected persons (21.0%), the media (20.2%), and health professionals (15.4%). About one-half (53%) of respondents claimed to have relatives or friends with SCD.

Knowledge of Sickle Cell Disease

Most of the respondents (44.9%) had moderate knowledge of SCD **(Table 2).** Interestingly 34.6%had poor knowledge of SCD. The mean knowledge score was 5.55 ± 3.08.

Table 2: Level of knowledge of SCD

Variable (n= 410)	Frequency	Percentage
Level of Knowledge		
0-4 (Poor)	142	33.6
5-8 (Moderate)	184	44.9
9-12 (Good)	84	20.5
Mean knowledge score=***5.5512 ± 3.0758***		

Attitude and Practices towards Sickle Cell Disease

The majority of participants (86.8%) did not know their haemoglobin genotype (SCD carrier status). A few of the respondents (13.2%) expressed willingness to marry another individual with sickle cell trait despite the risk of having children with SCD. More than half (59.3%) were unwilling to take such risks while 27.5% were undecided. Only 8.2% of participants will opt for termination of pregnancy compared to 43.2% who will allow the pregnancy to continue if they discover their unborn child had SCD. The remaining 48.6% were undecided at the time of the study. More than half of participants (50.8%) disagreed with the use of legislation against marital union between people with sickle cell trait to prevent further births of SCD babies.

Factors Associated with having Higher Knowledge of SCD

Having acquired a higher level of education and being exposed to formal learning about SCD were significantly associated with good knowledge of SCD.

DISCUSSION

In this study, the knowledge of SCD among the participants was found to be moderate. These results concurred with those of previous studies conducted in the USA, Nigeria, and Ghana [16,17]. However, these results were contrary to those of other studies, which either showed poor knowledge of SCD [18] or good knowledge of SCD [19]. Participants who had a higher level of education (secondary and tertiary education) and who had been exposed to formal learning on SCD had significantly higher knowledge scores ($p < 0.05$). This association compares with other studies done in Africa [19,16,18]. This is an expected association because SCD is probably taught in some courses in a number of secondary schools, high schools, and universities across Africa. About half (52.99%) of the participants knew someone who had SCD, implying that the disease is not uncommon. Concerning attitudes and practices towards SCD, in our study, only 13.2% of respondents claimed that they knew their haemoglobin genotype. This percentage (13.2%) is much lower compared to the 94.6% among 370 postgraduates in Nigeria [16] and the 25.0% among 320 youth workers in Ghana [19]. On the other hand, our study found a higher percentage compared to the 2.7% among 150 people in Ghana [20]. In our study, curiosity was observed to be the most common indication for carrier status checks. In a similar study in Nigeria [16], school entry and a doctor's request were the commonest indicators. More than half (59.34%) of respondents were averse to the union of trait carriers. This percentage is slightly higher than the 50% obtained among youth workers in Nigeria [18], but much lower than the 78% obtained among public servants in Ghana [17]. This difference in results could be explained by different levels of knowledge on SCD among the various respondents since knowledge on SCD could greatly influence one´s attitude towards it, as shown in a study in Sudan by [19] Less than half (43.7%) of respondents were averse to the termination of an affected pregnancy, while 8.2% agreed to selective abortion if permitted by law. Up to 38.1% of Nigerians [16] will agree to selective abortions. Less than half (28.5%) of respondents agreed that legislation against carrier marriages might be engaged in SCD control. This finding is lower than the 54.6% in Nigeria [16] who agreed to the use of legislation against carrier marriages. However, a study conducted in Greece showed that the use of punitive measures in the control of thalassemia gave disappointing results, as it led to increased anxiety, stigmatization, denial, and falsification of results.

CONCLUSION

This study illustrates that knowledge, attitude, and practices towards SCD among patients at the OPD at Jinja referral hospital are insufficient, as only a few respondents had good knowledge of SCD. With the presence of very few specialized centers with multi-specialist teams dedicated to the care of persons with SCD in Uganda, primary prevention through health education, population screening, genetic counselling, and the avoidance of carrier

marriages remain the most cost-effective methods of curbing the disease in Sub-Saharan Africa and Uganda in particular.

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