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Knowledge, Beliefs and Attitude towards Sickle Cell Disease among Students of Kampala International University Jinja Teaching Site Uganda

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ABSTRACT

Sickle cell disease (SCD) is one of the most widespread hereditary disorders among the African lineage. SCD is associated with recurrent severe pain, increased morbidity and mortality yet has received less recognition in the public domain. Evidence of the need to increase awareness to reduce the disease incidence is increasing due to the rising incidence of this preventable disease. This study aimed to describe the knowledge, beliefs and attitude towards SCD of students at Kampala international university. A descriptive cross-sectional study design was employed. A total of 384 university students participated in the study, and using a semi-structured questionnaire, information was collected from participants on demographic characteristics, general knowledge of SCD, and beliefs and attitudes of students towards SCD. Nearly all the students were aware of SCD (99.2%). Knowledge level of respondents on SCD based on scores revealed a mean score of 9.7± 4.5 with 65%, 30%, and 5% for poor, moderate and excellent respectively. Most of the respondents strongly agreed that they feel worried (52.9%) and sympathetic (51.3%) for people affected with SCD. Participants had the belief that it is an inherited disease acquired from parents (48.2%) but not a punishment from God (76.3%). In general, there was a limited understanding and inadequate knowledge of SCD among the students particularly on the pattern of inheritance. Results from the study highlights the need for effective public health education on SCT/SCD in trusted sources such as schools, media (radio/Television), health centres and churches. This is necessary to address misconceptions and increase knowledge level as well as an understanding of the risks of having a child with SCD to influence personal reproductive options.

Keywords: Sickle cell disease, Parents, Students, Child, Preventable disease.

INTRODUCTION

Sickle cell disease (SCD) refers to a group of inherited haemoglobin disorders characterized by a predominance of abnormal sickle haemoglobin in erythrocytes [1]. This genetic disorder (SCD) is a result of an abnormality in the synthesis of the B-globin chain of the haemoglobin molecule that results from the substitution of a polar amino acid, glutamic acid, with a non-polar amino acid, valine, in the 6th position of on chromosome11 [2], [3], [4]. Sickle cell anaemia, which results from homozygous inheritance of sickle-haemoglobin from both parents, is the most common and severe form of sickle cell disease which on deoxygenation, sickle haemoglobin undergoes a conformational change that promotes intracellular polymerization, that leads to distortion of the normal biconcave erythrocyte disc into the distinctive and pathological crescent shape [5]. The resulting hemolytic anaemia manifests as recurrent vas occlusion and organ damage that together cause substantial morbidity and early mortality

[6]. The impact of SCD threatening the life of people suffering from its effects results in an average lifespan of around the mid to late 40s [1]. For instance, SCD results in anaemia that may present with symptoms of fatigue, jaundice, and shortness of breath; continuous tissue and organ damage; pulmonary disease; and stroke [7]. Pain crises, caused by vas occlusion, are the trademark of SCD and affect most people with the disease (Novelli & Gladwin, 2016). Vasoocclusion occurs when the sickled red blood cells (RBC) obstruct the other blood cells resulting in an inadequate supply of blood to the organs [8]. The initial pain episode generally occurs as swelling in the hands and feet (hand-foot syndrome or dactylitis) resulting from decreased oxygen caused by blocked blood vessels. Moreover, almost 50% of children with SCD get dactylitis by the age of two. For children with SCD, approximately 50 to 60% of all emergency room visits and 60 to 80% of hospitalizations are due to pain crises [2]. Additionally, studies indicate that acute pain is the main cause of hospitalization for people with SCD of all ages; however, it occurs more often in teens and young adults [9]. Furthermore, frequent reoccurrences of acute pain are related to premature death in SCD patients over 20 years old [10]. Several factors including dehydration, extreme temperatures, infection, and low oxygen levels (high altitudes) can trigger SCD crises [11]. Another severe complication of SCD is acute chest syndrome (ACS). ACS results from infiltrates in the lungs or can also result from infections. Besides, ACS may also result in fever, chest pain, wheezing and cough symptoms following or accompanied by other acute symptoms [12]. There are numerous causes for ACS including infection, sickling, fluid overload and atelectasis caused by hypoventilation from over sedation or inadequate pain control [13].

Statement of Problem

SCD and Thalassemia are measured as the two major Hemoglobin Disorders, and have recently been declared a global health problem by the World Health Organization [14]. Despite SCD being a global health issue, in Uganda and many other African countries, more focus is paid on treatment and management of the disease rather than prevention, this focus on treatment and management is mostly on the physical effects; the psychosocial impact of the disease on the person affected and his/her family and support system is all but forgotten. Key to prevention is an understanding of how SCD and are inherited from parents in the same way as blood type or any physical traits. Since it is inherited genetically, a major approach to prevention should be education about the reproductive implications of the disease. The literature on informed reproductive decisions among people with SCD is limited. The current literature suggests that there is a lack of knowledge about SCD, carrier status (includes both Sickle Cell Trait (SCT) and reproductive implications of the disease among high-risk populations. The gaps in knowledge indicate the need for adequate education of at-risk individuals; particularly, prevention needs to be aimed at young people who are starting to plan their long-term relationships and reproductive decisions. Prevention and intervention programming should be geared towards increasing knowledge, changing false beliefs, and attitudes about the disease well as its reproductive implications. [15], carried out a study on university students regarding SCD and suggested that university level students should be a focus for the prevention of SCD because they are engaged in dating and relationships, therefore SCD trait screening and increase in education, and awareness among them is essential to reduce on the incidence of the disease. However, no study of this nature has been carried out among students of Kampala International University, Jinja teaching site, hence this study will seek to find out the knowledge, beliefs and attitude of students towards sickle cell disease in Kampala International University, Jinja teaching site.

Aim of the study

The main objective of this study was to describe the knowledge, beliefs and attitude towards sickle cell disease among

Kampala international university students of Jinja teaching site.

Specific objectives

- To describe knowledge of sickle cell disease among students of Kampala International University, Jinja teaching site.
- To describe the beliefs of students regarding sickle cell disease in Kampala International University, Jinja teaching site.
- To describe the attitude of students towards sickle cell disease in Kampala International University, Jinja teaching site.

Research questions

i. What is the knowledge regarding sickle cell disease among students in Kampala International University, Jinja teaching site?
ii. Which beliefs regarding sickle cell disease do students in Kampala International University, Jinja teaching site have?
iii. What is the attitude of students towards sickle cell disease among students in Kampala International University, Jinja teaching site?

METHODOLOGY

Study design

The study was a descriptive cross-sectional study [16] involving students of Kampala International University at Jinja teaching site, to describe their knowledge, belief and attitude towards sickle cell diseases.

Area of Study

The study took place at KIU- Jinja teaching site. The site is located in the center of Jinja not far from the source of the Nile. It is in the Jinja regional referral hospital located approximately 84 kilometres east of Mulago national referral hospital. The coordinates of Jinja regional referral hospital are 00°25`52.0" N, 33°12'18.0" E (Latitude; 0.431111; Longitude: 33.20500).

Study population

The study involved all KIU students Jinja teaching site.

Inclusion criteria

All students of KIU Jinja teaching site were included in the study.

Exclusion criteria

Students who refuse to give consent for the study will not be included, and students who are on holidays not be included in the study.

Sample size determination

The sample size was determined by using Kish's formula [17] which states that,

$$N = \frac{Z^2(p(1-p))}{\varepsilon^2}$$

Where;
N = the required sample size
p= Proportion of students with knowledge about sickle cell disease. For unknown population, 50% is taken [18].
ε = margin of error on p (set at 5%)
z= standard normal deviate corresponding to 95% confidence level (=1.96)

$$N = \frac{1.96^2(0.5(1-0.5))}{0.05^2} = 384.$$

Sampling Procedures

The researcher used consecutive sampling to get the 384 students needed for the study.

Data collection methods and management

The questionnaire was used to capture information on participant's demographics, awareness and testing of SCD, and genotype status. A 5-point Likert scale ranging from 'strongly agree to strongly disagree' was used to explore respondent's knowledge, attitudes, and beliefs of SCT/SCD. A total of 10 questions were asked to ascertain respondent's knowledge of SCD which included general information of SCD (inheritance pattern, diagnosis, major signs and symptoms, and management/cure options) while 5 questions each were asked with respect to their beliefs and attitudes toward SCD.

Data Analysis

Data was entered and analyzed using IBM SPSS version 25. To categorize knowledge of respondents, a score of 2 and 1 was respectively assigned to strongly agree and agree on affirmative questions on the 5-point Likert scale while a score of 0 was assigned to otherwise. On the other hand,

if the correct answer was negative, a score of 2 goes for strongly disagree and 1 for disagree with 0 for other response (wrong answer). The maximum knowledge assessment score was 20. Participant's knowledge was categorized as poor when scores were below 10.0 or 50%, moderate for scores between 10.0 and 16.6 (50% to 80%) while above 16.6 or 80% was considered excellent. Demographic characteristics and sickle cell information were summarized in frequencies and proportions.

Quality control

The questionnaire was pretested on 10 students to check for relevance and ambiguity. The questions were modified accordingly. Results from pretest were not included in the final results. In addition, questionnaires were filled in the presence of the researcher to avoid any external source of information such as the internet.

RESULTS

Demographic characteristics of participants

The study involved 384 participants, half (50.5%) of the participants were within the age range of 21-29 years and were mostly male 269 students (70%), (98.9%) 380were undergraduates. Most of the participants were single (95.1%) and (88.1%) are Christians. Approximately all the participants (99.2%) were aware of SCD but most (96.1%) had not ever tested for the genetic disorder (SCD).

Table 1: Demographic characteristics and sickle cell information of participants

Characteristics	Frequency	Percentage (%)
Age (years)		
≤20	133	34.6
21-29	194	50.5
≥30	57	14.9
Sex		
Male	269	70.0
Female	115	30.0
Education level		
Undergraduate	380	98.9
Postgraduate	4	1.1
Marital status		
Single	365	95.1
Married	19	4.9
Religion		
Moslem	45	11.7
Christian	339	88.3
Aware of SCD		
Yes	381	99.2
No	3	0.8
Tested for SCD		
Yes	15	3.9
No	369	96.1

Knowledge of SCD among participants

The total knowledge score was 20. Knowledge levels were grouped as poor (score<10), moderate (score 10-16) and excellent (score>16) depending on the total score of participants (Figure 1). The

mean knowledge score was 9.7 ± 4.5 SD indicating a poor general knowledge of participants. Of the 384 participants, majority (65%) had poor while the rest30% and 5% respectively had moderate and excellent knowledge of SCD.

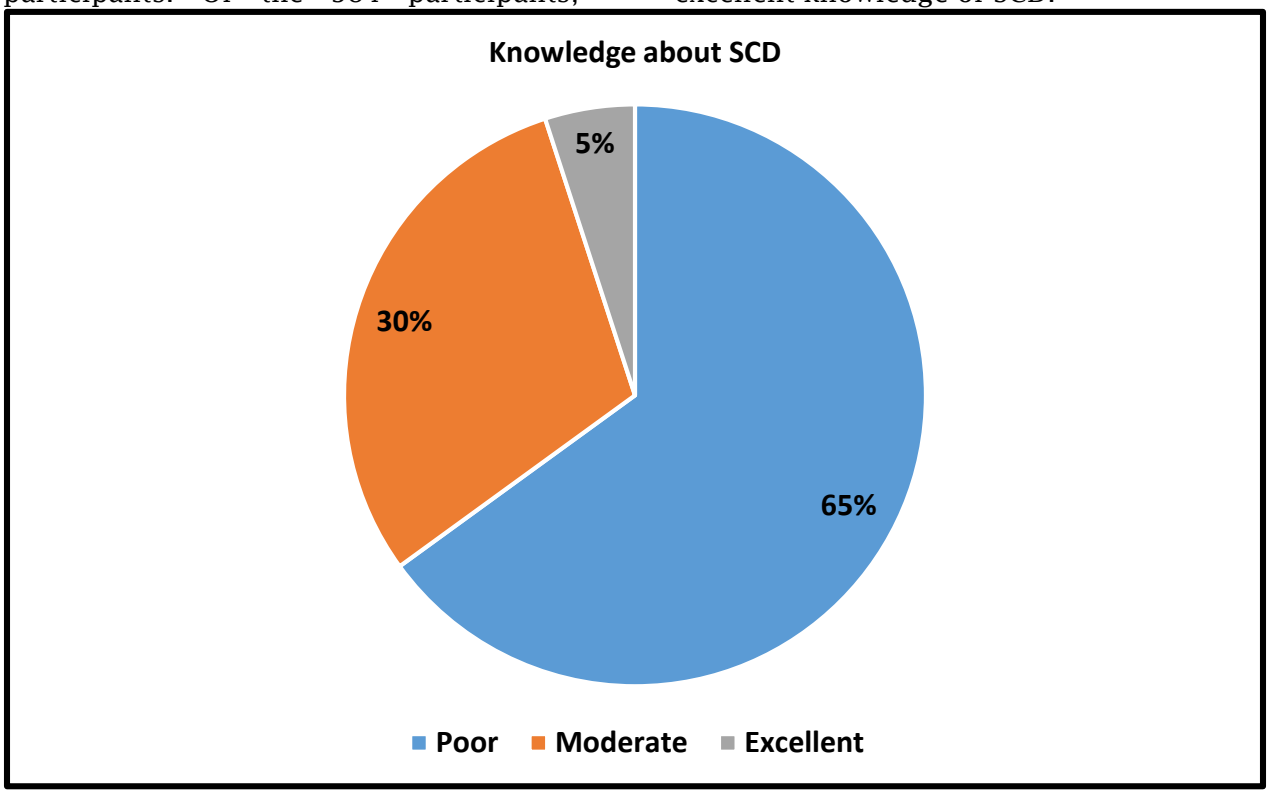

Figure 1: Knowledge of SCD among participants

Beliefs and attitudes about SCD

Almost half of the participants (48.2%) strongly believed that SCD is an inherited disease but not evil disease or punishment from God to sinners. Most of the participants (66.7%) believed that genetic counseling prior to marriage does not show lack of faith in God and that SCD can exist in families who believe in God. Majority of the participants showed positive attitude in terms of care and having sympathy for people with SCD. While more than one-third (35.7%) of the participants strongly agreed to end their relationships if they discover that their genotypes predispose them to having children with SCD, approximately one-third of the participants (33.3%) could not decide whether they would choose not to have a child than to give birth to a child with SCD (Table 2).

Table 2: Beliefs and attitudes about SCD

Beliefs	Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree
SCD is an evil disease	0	3	21	89	271
SCD is an inherited disease acquired from parents	185	147	20	16	16
SCD is a punishment from God to sinners	0	0	19	72	293
SCD cannot run in a family who believe in God	13	9	29	87	246
Subjecting oneself to genetic counseling before marriage shows lack of faith in God	0	3	20	105	256
Attitudes					
We should worry less about people with SCD since they may die soon	15	10	21	135	203
I feel sympathetic for people with SCD	197	133	26	21	7
Irrespective of my genotype I will not marry someone with SCT/SCD	109	108	98	53	16
I will end my relationship if I discover that our genotypes predispose us to having children with SCD	137	89	97	36	25
I will choose not to have a child than to give birth to a child with SCD	68	61	128	67	60
Should tertiary institution require students tested for their SCD genotype before being admitted to the institution	204	80	65	19	16

DISCUSSIONS

SCD is a debilitating chronic genetic blood disorder that places psychosocial, emotional and frequent painful burden on affected individuals as well as economic burden on affected families. Awareness of SCD is important for prospective couples to make informed decisions regarding reproductive options. In this study, almost all the students (99.2%) were aware of SCD which could be due to the fact that the study was carried out in a tertiary institution, moreover involving medical students with access to medical information. However, it was surprising that although almost all the students were aware of SCD, only less than half had ever tested for SCD. This may be due to the fact that medical examination at the secondary school and tertiary institutions does not include SCD test. In Uganda and many African countries, knowing one's carrier or sickling status mainly depends on free medical screening, compulsory medical screening prior to marriage or admission into an institution. This is not different from findings by [19], where more than half of the students interviewed in a Nigerian tertiary educational institution. Similarly, the findings of [20, 21] showed that majority (76.4%) and more than half

(95.1%) of university and secondary school students respectively did not know their genotypes. It is important that those who carry the SCT become knowledgeable of their carrier status and educated on how they can potentially pass the trait or disease on to their offspring. In general, participants had poor or inadequate knowledge of SCD. Almost half (65%) of the participants had poor knowledge, moderate knowledge (30%) and excellent knowledge (5%) of SCD. This is consistent with previous study in Ghana that demonstrated low knowledge of SCD [22]. Similar poor knowledge about SCD was reported by a study in Eastern and Western Uganda [23]. In addition, in a study by [12], only 25% of the participants correctly answered questions on the inheritance patterns of SCD. These results indicate that individuals are unaware that they could be carriers of this disease and could be at risk of producing children with SCD or the sickle cell trait. In contrast, good knowledge of SCD has been reported by [24] in their study to investigate the knowledge, attitude and practice of premarital counseling for SCD among youth in Nepal. The difference in knowledge level could be due to the groups studied and the knowledge assessment criteria. Beyond expectation, the poor knowledge of the participants in this study could be due to haste of answering the questionnaire without carefully reading and understanding them. Despite poor knowledge of SCD among the students, majority (66.7%) agreed to consider genetic testing before marriage. This indicates the realization of the potential importance and benefits of genetic testing as a preventive measure to control SCD. This supports earlier finding by [25] where a vast majority of students interviewed supported genetic testing for preventive care and pre-symptomatic detection of the genetic disorder. However, concerns such as fears and confidentiality were expressed by the students in relation to genetic counseling and testing. In this study, other students might have disagreed to genetic counseling and testing prior to marriage because of fear of losing prospective life partner by knowing their carrier/SCD status. Majority of the students had strong belief that SCD is not an evil disease (70.6%) but inherited disease (48.2%) and not a punishment from God (76.3%). This is similar to the findings of [19], [26] [31] [32] where majority of the respondents correctly believed that sickle cell was inherited from parents. Past experiences, beliefs, and attitudes have been reported to influence the way individuals approach new knowledge, learning, and decision making [27]- [32]. In general, most participants demonstrated positive attitude towards people affected with SCD. Most strongly expressed worry (52.9%) and felt sympathetic (51.3%) for sufferers of the genetic disorder. This positive attitude is similar to the work of [21]. Contrast to the positive attitudes by most of the respondents, close to one third strongly agreed (35.7%) and agreed (23.1%) not to marry someone with SCT/SCD irrespective of their genotype and that they will end their relationship if they discover their genotypes predispose them to having children with SCD.

CONCLUSION

Almost all the students were aware of SCD. Majority of the respondents demonstrated positive attitude towards SCD and had the belief that it is an inherited disease acquired from parents but not a punishment from God. In general, there was poor understanding and inadequate knowledge of SCD particularly on the pattern of inheritance.

Recommendations

To reduce the incidence of SCD, this study suggests effective health education for SCT and SCD in strategic places such as schools, media (radio/Television), health centers and churches to address misconceptions and increase knowledge level as well as understanding of the risks of having a child with SCD and influence personal reproductive decisions. Tertiary institutions should require students on their admission into the institution to test for their sickle cell trait so that they know their own trait before being enrolled into these institutions where they are likely to meet a life partner.

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