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Knowledge, Beliefs and Attitude towards Sickle Cell Disease among University Students

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Abstract

Background: Sickle cell disease (SCD) is one of the most prevalent genetic disorders among the African descent. SCD is associated with intermittent excruciating pain, increased morbidity and mortality yet has received less recognition in the public domain. There is growing evidence on the need to increase awareness to reduce the disease incidence. This study aimed to elicit student's knowledge, beliefs and attitude of SCD.

Method: A descriptive cross-sectional study design was employed. A total of 380 university students at all levels were invited to participate in the study. Of these, 350 successfully completed the study (response rate, 92.10%). A semi structured questionnaire was used to collect information on participant's demographic characteristics, general knowledge of SCD, beliefs and attitudes of students towards SCD.

Results: Almost all the students were aware of SCD (98.6%) with the main source of information being school (84.6%) and the media (12.6%). Knowledge level of respondents on SCD based on scores revealed a mean score of 9.8 ± 4.2 with 45.1%, 47.8%, and 7.1% for poor, moderate and excellent respectively. Most of the respondents strongly agreed that they feel worried (52.9%) and sympathetic (51.4%) for people affected with SCD. Participants had the belief that it is an inherited disease acquired from parents (48.3%) but not a punishment from God (76.3%). Higher level of education and knowing a relative with sickle cell trait (SCT) or SCD was significantly associated with high knowledge of SCD ($p<0.05$).

Conclusion: 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 highlight the need for effective public health education on SCT/SCD in trusted sources such as schools, media (radio/Television), health centers and churches. This is necessary to address misconceptions and increase knowledge level as well as understanding of the risks of having a child with SCD to influence personal reproductive options.

Keywords: Sickle cell disease; Knowledge; Attitudes; Beliefs; Hemoglobin

Introduction

Sickle cell disease (SCD) remains one of the most common genetic blood disorders among the African populace. It is estimated that about 400,000 children with SCD are born globally each year with almost 300, 000 children in the Africa continent alone [1]. About 25% of Africans are carriers of the abnormal hemoglobin gene and estimated 2% of neonates are born with SCD annually in Ghana [2]. Sickle cell trait is known to show a protective effect against malaria, and this may be the reason why SCD is highly prevalent among the Africa populace [3]. This genetic disorder (SCD) is as a result of abnormality in the synthesis of B-globin chain of hemoglobin molecule. This abnormality results from the substitution of a polar amino acid, glutamic acid, with a non-polar amino acid, valine, in the 6th position of on chromosome 11 [4]. Under low oxygen tension, this single point mutation causes red blood cells to assume the shape of a "sickle" and leads to complications including tissue infarction, anemia, priapism, splenomegaly and reduced dietary intake [5]. Marriage is a lifetime commitment between partners with the sole aim of companionship, support and procreation [6]. The process of choosing a partner is sometimes challenging especially when considering their health status. Bearing children in marriage brings great joy but also compelling responsibility that places great demand on couple's time and finance especially when coupled with chronic disease conditions such as SCD. Studies [7-9] have reported that more than half of married couples enter into marriage unaware of their haemoglobin genotypes. This may account for the reported 2% annual births of children with SCD in most developing countries. Children are born with SCD possibly because parents may have entered into marriage without prior knowledge of their sickling status. Knowledge about SCD prior to marriage is essential especially in tertiary institutions where many young adults are in the reproductive age and consider campus as a domain for choosing their life partners. This is also important to make the students aware of the possible genotypes of their children so as to reduce incidence of SCD. Student's attitude and beliefs towards SCD is one of the contributing factors that is important to plan educational programme as well as determine level of stigmatization towards patients affected with SCD. This study therefore sought to determine the knowledge, beliefs and attitudes of students in University of Ghana campus.

Methodology

The study is a descriptive cross-sectional survey involving students at the University of Ghana campus. Five halls of residence (Akuafo, Legon, Mensah Sarbah, Jubilee, Volta hall) were conveniently selected for the survey. A total of 380 students were approached in these halls to complete the questionnaire.

The purpose of the study was explained to participants and those who volunteered to participate were enrolled in the study. Of these, 350 successfully completed the questionnaire giving a response rate of 92.10%. The initial version of the questionnaire was pretested on 10 students at University for professional studies (UPSA), a nearby university and modified thereafter. Validity of the questionnaire was checked using Cronbach's alpha (r=0.7).

The questionnaires captured 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. Questionnaires were filled in the presence of the researcher to avoid any external source of information such as the internet.

Data analyses

Data were entered using SPSS version 22 (SPSS Inc., Chicago, Ill., USA) and imported to R. All analyses were performed using R (version 3.4.1). To categorize knowledge of respondents, a score of 2 and 1 were 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 is 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% were considered excellent. Demographic characteristics and sickle cell information was summarized in frequencies and proportions. Relationship between demographic characteristics, sickle cell information and participant's knowledge scores was performed using unpaired t-test. Significance level was determined at $p<0.05$.

Results

Demographic characteristics and sickle cell information of participants

The study involved 350 participants with 55.1% females (Table 1). About half (45.1%) of the participants were within the age range of 18-20 years and were mostly (81.4%) undergraduates. Almost all (94.9%) the participants were single and Christians (92.6%). Approximately all the participants (98.6%) were aware of SCD but most (60.9%) had not ever tested for the genetic disorder (SCD). Of those who had had test for SCD (39.1%), only 30.3% knew their genotype. The prevalence of self-reported sickle cell trait (SCT) and SCD was 16.9% and 0.9% respectively.

Characteristics	Frequency	Percentage (%)
Age (years)		
18-20	158	45.1
21-24	136	38.9
25-27	43	12.3
28-30	8	2.3
>30	5	1.4
Sex		
Males	157	44.9
Females	193	55.1
Educational level		
Undergraduate	285	81.4
postgraduate	65	18.6
Marital status		
Single	332	94.9
Married	15	4.3
separated	3	0.9
Religion		
Christian	324	92.6
Moslem	19	5.4
Traditionalist	7	2
Sickle cell information		
Aware of SCD		
Yes	345	98.6
No	5	1.4
Test for SCD		
Yes	137	39.1
No	213	60.9
Knows genotype		
Yes	106	30.3
No	244	69.7
Genotype		
AA	87	82.1
AS	18	16.9
SC	1	0.9

Table 1: Demographic characteristics and sickle cell information of participants.

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 9.8 ± 4.2 indicating a poor general knowledge of participants. Of the 350 participants, approximately 45.1%, 47.8% and 7.1% respectively had poor, moderate and excellent knowledge of SCD.

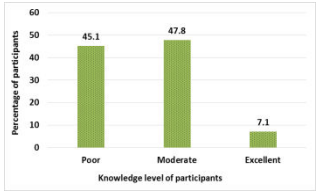

Figure 1: Knowledge of participants of SCD.

Beliefs and attitudes of SCD

Almost half of the participants (47.5%) strongly belief that SCD is an inherited disease but not evil disease or punishment from God to sinners. Most of the participants (64.1%) belief 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 (34.7%) 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 (32.8%) could not decide whether they would choose not to have a child than to give birth to a child with SCD (Table 2).

Relationship between demographic characteristics, sickle cell information and knowledge scores

Postgraduate students significantly had higher knowledge scores compared to undergraduates (10.02 *vs.* 8.78, p=0.03) (Table 3).

Beliefs	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
	0	3	19	81	247
SCD is an evil disease	0	-0.9	-5.4	-23.1	(70.6)*
	169	134	18	14	15
SCD is an inherited disease acquired from parents	-48.3	-38.3	-5.1	-4	-4.3
	0	0	17	66	267
SCD is a punishment from God to sinners	0	0	-4.9	-18.9	-76.3
	12	9	26	79	224
SCD cannot run in a family who believe in God	-3.4	-2.6	-7.4	-22.6	-64
	0	3	18	96	233
Subjecting oneself to genetic counseling before marriage shows lack of faith in God	0	-0.9	-5.1	-27.4	-66.6
Attitudes					
	14	9	19	123	185
We should worry less about people with SCD since they may die soon	-4	-2.6	-5.4	-35.1	-52.9
	180	121	24	19	6
I feel sympathetic for people with SCD	-51.4	-34.6	-6.9	-5.4	-1.7
	99	97	89	48	17
Irrespective of my genotype I will not marry someone with SCT/SCD	-28.3	-27.7	-25.4	-13.7	-4.9
	125	81	88	33	23
I will end my relationship if I discover that our genotypes predispose us to having children with SCD	-35.7	-23.1	-25.1	-9.4	-6.6
	62	56	117	61	52
I will choose not to have a child than to give birth to a child with SCD	-17.7	-16	-33.4	-17.4	-14.9

Table 2: Beliefs and attitudes toward SCD *n (%).

Knowing a family member with SCT/SCD was also significantly associated with increased knowledge scores of participants (p=0.01). All other variables were not significantly different from each other (p>0.05).

Variables	N	Mean ± SE	p-value
Age (yrs)			
18-24	294	9.93 ± 0.23	
≥25	56	9.05 ± 0.73	0.15
Sex			
Male	157	9.25 ± 0.30	
Female	193	10.46 ± 0.33	0.08
Marital status			
Married	332	9.76 ± 0.23	
Single	18	8.78 ± 0.69	0.5
Educational level$			
Undergraduates	285	8.78 ± 0.69	
Post graduates	65	10.02 ± 0.23	0.03
Had SCD test*			
Yes	137	9.75 ± 0.34	
No	213	9.82 ± 0.29	0.88
Knows genotype			
Yes	106	10.15 ± 0.41	
No	244	9.63 ± 0.27	0.296
Knows relative with SCT/SCD			
Yes	14	12.64 ± 1.18	
No	336	9.67 ± 0.23	0.01

Table 3: Relationship between demographic characteristics, sickle cell information and knowledge scores.

Discussion

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 decision(s) regarding reproductive options. In this study, almost all the students (98.6%) were aware of SCD. Source of information was mainly from school (84.6%), media (radio/Television) (12.6%), health centre/family and friends (2.9%). This finding is not different from earlier report by other authors [9-12]. This shows that schools and the media can be an effective institution and platforms for educating people on SCD. It was quite surprising that although almost all the students were aware of SCD, less than half had ever tested for SCD. This may be due to the fact that medical examination at the senior high school and universities do not include SCD test. In Ghana 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. Of those who had had SCD test, only 30.6% reported to know their haemoglobin genotype. This is not different from findings by Ameade et al. [9], where more than half of the public servants interviewed in the Northern part of Ghana did not know their sickling status. Again, this is similar to the findings of Moronkola et al. [6] and Bazuaye et al. [13] where more than a third (36.4%) and more than half (55.1%) of university and senior high school students respectively did not know their genotypes. Others who had SCD screening were unaware of their genotype possibly because Hb-Electrophoresis test may be expensive than usual microscopy (positive/negative) test in Ghana. Self-reported genotypes include 82.1% normal haemoglobin (AA) and 16.9% carriers (AS). Only one person reported to have SCD (SC).

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. Knowledge assessment in the questionnaire ranged from SCD diagnosis, symptoms, pattern of inheritance, and management as were as cure options of SCD. Almost half (45.1%) of the participants had poor knowledge, moderate knowledge (47.8%) and excellent knowledge (7.1%) of SCD. Most participants had inadequate knowledge particularly on the pattern of inheritance of SCD or trait. This is consistent with previous published US data that demonstrated low knowledge of SCD [14-16]. In a study among adults who themselves were sickle cell carriers or who had a child with SCT, Acharya et al. [8] reported significant misunderstanding about how SCD is inherited. Similar poor knowledge among tertiary students have been concluded by other authors in Nigeria [11,17-19]. In addition, in a study by Dyson (1997), 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 Gabriel and Mathew [20] in their study to investigate the knowledge, attitude and practice of premarital counseling for SCD among youth in Yaba, Nigeria. Other studies in the UK [21], US [22] and Nigeria [23] have reported good knowledge of participants regarding SCD. 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. High educational level has been correlated with comprehensive and good knowledge of SCD. In this study, high educational level and knowing a family member with SCT/SCD was significantly associated with good knowledge of SCD. This is not unique from the study by Treadwell and colleagues [24] where respondents who received information from friends and family were three times more likely to know their trait status, signifying the possible benefit of family discussions about SCD.

Despite poor knowledge of SCD among the students, majority (85.4%) 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 Laskey et al. [25] where a vast majority of students interviewed supported genetic testing for preventive care and presymptomatic 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 (48.3%) and not a punishment from God (76.3%). This is similar to the findings of Olakunke et al. [26] and Treadwell et al. [24] where majority of the respondents correctly believed that sickle 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]. In general, most participants demonstrated positive attitude towards people affected with SCD. Most strongly expressed worry (52.9%) and felt sympathetic (51.4%) for sufferers of the genetic disorder. This positive attitude is similar to the work of Olatona et al. [18], Ameade et al. [9]. Contrast to the positive attitudes by most of the respondents, close to one third strongly agreed (28.3%) and agreed (27.7%) 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. Similar report has been reported in Ghana where 78.0% of public servants agreed to call off marriage if they become aware of genetic incompatibility [9]. This could possibly be due to the fact that respondents maybe aware of the associated painful and psychosocial trauma affected children go through and would not want to put themselves into such dilemma. A limitation of this study is the small sample size which may make generalizability questionable. However, the results from this survey points to the inadequate knowledge and misunderstanding of SCD among the students.

Conclusion

Almost all the students were aware of SCD with the main source of information being schools and the media (radio and Television). 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. To reduce the incidence of SCD, we suggest effective public health education for SCT and SCD in strategic places such as schools, media (radio/Television), health centres 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.

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