Sickle Cell Disease Awareness, Depth of Knowledge and Attitude Towards Premarital Screening Among Students in Ghana

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Abstract

Background: Sickle cell disease (SCD) is a genetic disease that results when an individual inherits two abnormal haemoglobin genes, one from each parent. It has been estimated that about 15,000 babies (2% of births) are born yearly with SCD in Ghana, thus SCD is a major public health issue. This study explored the awareness of SCD among students of a second cycle institution in Ghana's most populous city, Accra, as well as their knowledge about the disease and attitudes towards premarital counselling and premarital screening. Responses to a self-administered questionnaire were received from 115 randomly selected respondents. Findings show that 71.3% of respondents were aware of SCD. The proportion of females who were aware of SCD was higher than males. An interesting source from which a good proportion of respondents received information about SCD is social media. Of those who were aware of SCD, only 54.9% knew that it is a hereditary disease. Virtually all respondents did not have adequate knowledge on the presentation of the disease. As many as 65.9% of those aware of SCD thought it has a cure. While a majority of respondents were aware that pre-marital screening has something to do with prevention of the disease, only a little over a quarter of those aware of SCD knew precisely what pre-marital screening for SCD is about. Respondents were generally pre-disposed to pre-marital screening however. The study concludes that more intensive education on SCD early in the life of the youth, particular about pre-marital screening, would help in reducing the incidence of SCD in Ghana. More widespread studies along the dimensions of this study are recommended.

Keywords: Sickle cell disease, awareness, knowledge, Premarital screening, Attitude.

INTRODUCTION

Sickle cell disease (SCD) belongs to the group of inherited red blood cell disorders. Red blood cells are found in the blood and are responsible for exchange of gases. Normal red blood cells are shaped round and carry oxygen to various parts of the body. Their round and malleable shape enables them to move easily through small blood vessels. However, when one has SCD the red blood cells, under certain conditions, are unable to maintain the round and malleable shape. They become hard, sticky and sickle shaped, hence the phrase sickle cell disease. SCD negatively affects the oxygen carrying ability of the haemoglobin located in the red blood cells. Sickled cells have reduced lifespan, from 120 days in normal blood to about 30 days. Sickled cells adhere readily to the small blood vessels which disrupts the supply of blood to distal organs. This presents as pain to SCD patients.

Pain is the commonest clinical manifestation of this disease and results in tremendous suffering, prolonged absence from regular duties such as work, school, etc. Individuals with SCD experience chronic pain compounded with acute pain episodes. In a six-month study of adults with SCD, half of the respondents reported experiencing some level of pain for half of the days, while nearly a third noted having pain majority of the time, Isah, Musa, Mohammed, Ibrahim, Awosan and Yunusa (2016).

SCD causes severe lifelong morbidity that requires prolonged hospital exposure. Isah *et al.* (2016) document that this disease affects almost every organ in the body. Consequences include acute renal failure, gallstones, jaundice, asplenia, strokes, and acute chest syndrome among others. The many complications of SCD can make every stage of life extremely challenging for individuals with the disease. For example, approximately 10 percent of children with SCD present with obvious symptoms of stroke, which result in difficulty in learning and lifelong disabilities. This disease is also associated with high early life mortality of 50 to 90%, Grosse, Odame, Atrash, Amendah, Piel and Williams (2011).

In addition, Asare *et al.* (2018) report that, SCD also results in high rates of mortality especially in the first five years of life. Reported mortality rates in this age group range from 2% to 30%. In the second six months of life, the rates have been found to be higher due to the common complications that arise at that age. Pathological features of SCD are many. They include, delayed growth and development , growth retardation, congestive heart failure, pulmonary infection, fat or bone marrow embolism, sickle cell lung disease, pulmonary hypertension, iron overload, viral hepatitis, acute and chronic renal failure, and retinal detachment.

The World Health Organisation (WHO, 2011) and the United Nations (2015) have designated SCD as a global health problem. SCD is further designated as a major public health concern in West Africa including Ghana. The average prevalent rate is 2 percent of the population in this region, while 10 to 30 percent of the population is estimated to carry the sickle cell trait. That is, they have the capacity to donate an abnormal haemoglobin gene to an offspring. Worldwide, WHO (2011) reports that approximately 5% of the world's population carries trait genes for haemoglobin disorders of which SCD

is one. WHO further reports that over 300,000 babies are born worldwide each year with severe haemoglobin disorders of which the majority are in low and middle income countries. The medical cost of living with SCD too is high. While African data is not readily available, United States cost data suggest that in 2005 medical expenses on children with SCD averaged US$ 11,702 per child, Centers for Disease Control and Prevention (2018).

History of SCD and Importance of SCD to the Youth

This disease was discovered by Dr. J.B. Herrick in 1904 and published in 1910 (Isah *et al.*, 2016). Olubiyi, Umar, Ajiboye, Olubiyi and Abioye (2013) report that SCD is one of the most common single-gene disorders. They add that, it is commonest among the black race. The highest incidence occurs in equatorial Africa – 75% of 300,000 world annual births, (Makani *et al.*, 2011). One of the reasons for this preponderance in equatorial Africa is that, sickle haemoglobin gene is believed to have developed in response to severe malaria endemicity. Gbeneol, Brisibe and Ordinioha (2015) report that, the sickle cell gene in heterozygous individuals has been found to be protective against malaria, but not so in homozygous individuals. SCD is also common in communities with consanguineous marriages such as among Arabs and in Indians.

Every individual carries two haemoglobin chains. In an SCD carrier, one haemoglobin is normal, while the other is a sickled haemoglobin. In SCD patients, both haemoglobin genes are sickled. An offspring becomes infected with SCD when both parents donate abnormal haemoglobin genes to it. Careers do not show signs of the disease. SCD can be detected through various tests including blood tests when the child is born or through prenatal diagnostic testing. Countries such as the United States have included SCD testing as part of their newborn health screening programs (WHO, 2011).

The main point about SCD lies in the fact that it is a common, chronic and incurable condition with associated significant morbidity and mortality. Prevention is key in this fight to avoid the cycle of problems that come with SCD. Limitations to this process include availability of genetic testing resources and genetic counselors. Specifically, WHO (2011) says the international body has resolved to shed more light and raise the awareness of the international community on the global impact of haemoglobin disorders. WHO also seeks to promote and support heavily burdened countries by investing more into research to improve quality of life and also to provide technical and equitable health services to support countries in their management and prevention strategies of SCD.

To this end, it is noted that, in their investigation of whether the general population appreciates how SCD is passed on to off-springs, Abioye-Kuteyi *et al.* (2009) found that a fourth of the married and engaged respondents in Ile-Ife (Nigeria) did not know their partner's sickling status. One-third to two-thirds of the study subjects said that they would continue the relationship with their partner no matter the results of any premarital screening. For Ghana, Boadu and Addoah (2018) analysed responses from 350 university students and found that almost all were aware of SCD. 48%

of respondents believed that it was an inherited disease acquired from parents. The authors also found that higher level of education and knowing a relative with SCD was significantly associated with high knowledge of SCD.

Guttmacher Institute (2016) found that the risk of unintended pregnancy rate among sexually active adolescent women aged 15 – 19 in the US was highest among all age groups. One interpretation of this finding is that sexual partners may not have taken precautions such as premarital screening for SCD. Assuming the same behavior among 15 – 19 women in Ghana, the implication for Ghana is a high risk of many children with SCD, giving that the pregnancies are carried to term. For, women aged 15 – 19 constitute 5% of Ghana's population, (CIA World Factbook, 2018). Also, the 15 – 19 year olds are mostly in second cycle institutions in Ghana, so the finding by Abioye–Kuteyi, so the finding by Oyegbade, Bello and Osakwe (2009) that tertiary education promotes positive sexual attitudes and less unintended pregnancies would mostly not apply. Also worth mentioning is Edwin, Edwin and Etwire (2011) who stress the importance of self-awareness and prenatal diagnosis in curbing this disease in Ghana. Thus, it is important that this segment of the population (adolescents) is thoroughly schooled on issues relating to SCD in an SCD endemic area such as Ghana.

This study aims to assess awareness of SCD among students of second cycle institutions, their knowledge of sickle cell related issues, and their attitude to premarital screening for SCD. Following this introduction is a presentation of aspects of relevant literature. Then, the methodology adopted in this study is presented, followed by findings and discussions, then limitations and conclusions.

LITERATURE REVIEW

SCD is particularly common among people whose ancestors are from Sub-Saharan Africa, South America, Cuba, Central America, Saudi Arabia, India, and Mediterranean countries such as Turkey and Italy. It is estimated that in sub-Saharan Africa, SCD affects 2% of annual births, but lack of compiled reliable data makes it difficult to obtain accurate statistics in the general sub-Saharan African population. However, cohort and cross-sectional studies by Grosse *et al.* (2011) puts early life mortality at between 50 to 90%. More importantly also, it is estimated that up to 30% of Ghanaians are SCD carriers, (Konotey-Ahulu, 2011).

SCD is called various names in different communities in Ghana. It has been known for centuries in West Africa, where the recurrent seasonal nature of biting limb pain gave rise to such onomatopoeic local names as: Chewechechwee in Ga, Nuinnui in Fante, Nuiduidui in Ewe, Ahututuo in Twi (Riddington and Owusu-Ofori, 2002). These labels reflect the pain that sufferers endure.

Management of Sickle Cell Disease

Current strategies to control SCD include prenatal diagnosis, selective abortion, pre-marital/preconception counselling and testing, holistic management of SCD positive patients. The management of SCD can be expensive. Edwin *et al.* (2011) suggest that a multi-disciplinary approach is also

needed to aid the complete management of the patient.

An important aspect of SCD management involves prevention of the disease. The disease currently has no cure except for stem cell transplantation which was done for a French teenager in France thereby causing this individual to escape the effects of the disease (Ribeil *et al.*, 2017).

Reducing the Spread of SCD

Premarital medical screening is a panel of tests that couples preparing to get married undertake so as to detect any genetic and infectious diseases that may be transmitted to each other, or off-springs. This forms an integral part of genetic counseling by which couples and individuals obtain necessary information that affects their lives as couples so that they can make informed decisions about their health. Two important ones are SCD and human immunodeficiency virus (HIV). Premarital screening remains one of the most important strategies for preventing genetic disorders and congenital anomalies (Rahman, Naznin, Giti, Islam and Khatun, 2014). The history of premarital screening dates back to the 1970s in countries such as the United States of America for diseases such as SCD. It has also been successfully implemented in countries like Canada, United Kingdom, Greece and Italy with a variety of diseases that are peculiar and endemic to those regions (Rahman *et al.*, 2014).

In Ghana, premarital counseling on many aspects of married life is an integral part of the process leading to marriage. However, pre-marital counselling on SCD has not been an integral part of traditional pre-marital counselling. It is only in recent times that some religious denominations and public health authorities are making pre-marital counselling on SCD mandatory, Konotey-Ahulu (2011).

Empirical Studies

Olubiyi *et al.*, (2013) conducted a study to determine the knowledge and attitude among undergraduate students of Ekiti State University in Nigeria towards SCD and premarital counseling for early detection of carrier genes to help reduce the incidence of sickle cell disease. A self-administered questionnaire was used to collect data from 93 randomly sampled respondents (from six residential hostels). Majority of the students were between 21-25 years of age with females forming the predominant gender of 62.4% of the respondents.

Result showed 91 out of 93 respondents (97.8%) had heard about sickle cell disease previously, a very high level of awareness. The study also reports that 90.3% of respondents knew their genotype. The rest did not. Further, 64.5% of the respondents believed that sickle cell disease was a major public health challenge in Nigeria due to the high incidence of the condition. Majority of the respondents (89.2%) thought genetic counseling was a means of prevention. The increased level of knowledge transformed into a positive attitude towards premarital counseling. 94.6% were in favour of pre-marital counselling. This suggests that increasing public health education, seminars and media will propagate the message and help reduce SCD prevalence in that country, the authors concluded.

Another Nigerian study conducted by Abioye–Kuteyi *et al.* (2009) assessed the

knowledge and attitudes of local government workers in Ile-Ife. They conducted a cross-sectional descriptive study of knowledge of SCD and attitudes towards premarital screening using a self-administered questionnaire. They reported that 69% of their study subjects had poor knowledge of sickle cell, even though attitudes towards premarital screening was positive. Further, they reported that good knowledge and positive attitudes among those who had tertiary education. Most of the respondents (86.7%) said they and their sexual partners had undergone premarital screening for sickle cell disease. However, authors also reported that one quarter of married and/or engaged respondents did not know their partners' sickling status.

Memish and Saeedi (2011) conducted a study in Saudi Arabia on the outcome of six years (2004 to 2009) of premarital and genetic counseling for SCD and B-thalassaemia. The Arabs are known for consanguineous marriages, hence high rates of the disease due to its autosomal recessive nature. They concluded that over the six year period, the number of at-risk marriages reduced, which could translate into a decrease in the burden of this genetic disease over the next decades. They also asserted that premarital screening gives more advantage than neonatal screening because the former is primary prevention while the latter is secondary or tertiary prevention

Impact of Sickle Cell Disease

Though SCD can be managed medically, it still poses a big toll on family life, relationships and is in constant competition with economic activities of the family. A study done in Nigeria showed a significant correlation between total burden scores on families with SCD and frequency of crisis, (Famuyiwa and Akinyanju, 1998). The financial burden of SCD was found to be enormously high especially during crisis as compared to their steady state. This burdens the family and disrupts family life with as many as 58% of caregivers experiencing some level of difficulty coping with SCD. They suggested that this burden could be reduced significantly by reducing the frequency and duration of crisis as well as giving families adequate information and socio-economic support. The primary determinant of family burden in SCD is the frequency of sickling crisis. A holistic approach to managing SCD through the appropriate measures can greatly reduce the burden that is associated with the disease.

There is no doubt that SCD is a major public health concern that should receive serious attention from the health authorities. A number of studies on the subject using Nigerian subjects have been identified here. However, not nearly as many Ghanaian studies have been documented. This study provides a Ghanaian dimension that has not yet been investigated.

METHODOLOGY

Given that this study sought to investigate a group of people within a particular place at a particular period of time, a cross-sectional descriptive design was employed. A multi-stage sampling method was used in selecting the respondents. The first stage consisted of selecting one programme out of the five programmes offered in a second cycle school by simple random sampling method. Programmes are designed to be

completed in three years. At the second stage, students at any stage of the three-year programme were randomly selected to participate in the study. The school itself was selected on the basis of its cosmopolitan and average working class location, its non-residential nature, and the fact that it admits students of both genders.

Sample Size Determination

For large populations, Cochrane (1963) developed the following equation for estimating the sample size, n, if the desired precision (significance level) is α, and p is the estimated proportion of an attribute that is present in the population.

$$\boldsymbol{n = \frac{Z^2 p(1-p)}{\propto}}$$

where, Z is the Z-statistic for the level of desired confidence.

For this study, the usual 95% confidence interval was invoked. Thus, α = 5%. The corresponding Z is 1.96 (from tables). Koonotey (2011) suggests a sickle-cell carrier rate of up to 30% among the Ghanaian population. Thus, p of 30% was used. The Cochrane formula suggested a sample size of 323. However, this study did not achieve a sample size of 323 due to time and financial constraints. 120 students were sampled to participate in the study.

Data Collection

A self-administered questionnaire was used. Prior to this, the informed consent of respondents was obtained. The questionnaire had both close-ended and open-ended questions and were based on the objectives of the study as described below. The questionnaire was pre-tested on some students of the University of Ghana Medical School. After the pre-test, the questionnaire was revised – some questions were dropped, new questions were added and ambiguous questions were reframed. The questionnaire was in English. The questionnaire approach was preferred for this research because it was flexible, affordable and easy to administer.

The questionnaire was in three sections: the first section focused on the socio-demographic characteristics of the respondents (age, sex, marital status and religion); the second section sought to establish respondents' awareness and knowledge about sickle cell disease; the third sought to establish the attitudes of the students towards premarital screening for sickle cell disease. It was conducted between March and April of 2017.

Ethical Consideration

The researchers approached the Headmistress of the second cycle institution with an introductory letter from the Department of Community Health of the University of Ghana Medical and Dental School, seeking her permission to administer the questionnaire to students in her school. She granted her permission. However, due to the ages of some of the students (less than 18, the legal age of maturity in Ghana), the Headmistress herself sought the approval of parents at the school's Parent-Teacher Association Meeting. The parents gave verbal consent.

Data Handling, Analysis and Presentation

Being a baseline study, this study reports responses provided by respondents, often expressed as percentages. The results were then discussed vis-à-vis findings in the literature. Finally, conclusions are drawn from the findings.

Eleven questions were used to assess knowledge of SCD of respondents. A respondent was classified as having good knowledge if he/she scored 6 and above. He/she was considered to have a poor knowledge if he/she scored 5 or less. For assessing attitude to pre-marital counselling, six questions on premarital screening attitudes were asked. The questions required respondents to choose "true" or "false" or, "yes" or "no". A correct answer scored one positive point in favour of positive attitude to pre-marital counselling, while an incorrect answer was scored zero. Respondents scoring 3 or more were graded as having positive attitude to pre-marital counselling. Those scoring less than 3 were classified as having poor attitude to pre-marital counselling.

RESULTS AND DISCUSSIONS

Background Characteristics of Participants

A total of 115 out of 120 questionnaires were completed and returned and judged to be usable. This translates to a response rate of 95.8%. From Table 1, one sees that majority of study participants were less than 18 years old; followed by those between 18 and 21 years. Females respondents were in the majority. As expected, almost all the students were not married. Majority of the participants were Christians. The rest were Muslims.

Table 1: Demographic characteristics of respondents

GENDER		
GENDER	Number of respondents	% of total
Male	52	45.2
Female	63	54.8
Total	115	100

AGE		
AGE (years)	Number of respondents	% of total
Below 18	66	57.2
18 - 21 years	47	40.9
22 – 25 years	2	1.9
	115	100

MARITAL STATUS		
STATUS	Number of respondents	% of total
SINGLE	113	98.3
COHABITING	2	1.7
TOTAL	115	100

RELIGION		
RELIGION	Number of respondents	% of total
CHRISTIAN	102	88.7
ISLAM	13	11.3
	100	100

Awareness of Sickle Cell Disease

The results in respect of awareness of Sickle cell disease (SCD) are illustrated in Table 2. Of the 115 total respondents, 82 were aware of the disease. The rest claimed they never heard about SCD. Probing further, their responses indicate that a higher proportion of females than males had heard about the disease.

The level of awareness in our sample is low compared to what was obtained in three studies in Nigeria: Olubiyi *et al.*. (2013), referred to earlier, 97.8% awareness; Olaweraju, Enwerem, Adebimpe and Olugbenga-Bello (2013) that was also conducted among secondary school students in Jos, Nigeria, showed 97.4% awareness level; and Omuemu, Obarisiagbon and Ogboghodo (2013) awareness among undergraduates at the Benin State University, 98.8%. Authors of the third study suggested that this high awareness level is probably due to the fact that Nigeria is known to be one of the regions where SCD is endemic, thus fuelling high awareness by the citizenry. In fact, DeBaun and Galadanci (2019) reports that, nearly 90% of the world's SCD population lives in Nigeria, India and the Democratic Republic of Congo, and that in Nigeria, the prevalence of SCD among newborns was 3 percent.

Table 2: Awareness of Sickle Cell Disease

	Yes, aware		Not aware		
Gender	Number	% of respondents	Number	% of respondents	Total Gender respondents
Female	48	76	15	24	63
Male	34	65	18	35	52
Total	82	71	33	29	115

Sources of SCD information

For those who had heard about the disease, an attempt was made to assess their sources of information. 50% of respondents claimed to have heard about SCD at school; 21% heard of it by way of social media; 13% heard about it from friends; 11% heard about it from health workers; while 5% heard about it from other internet sources. This finding is broadly consistent with that of Ameade, Mohammed, Helegbe and Yakubu (2015), who reported that their respondents indicated that the television, newspapers, radio and the internet were their initial sources of information about SCD. It must be noted that these two studies are pointing to social media, which works via the internet, is becoming an important source of information for the people.

Knowledge about How SCD is Contracted

54.9% of respondents who knew about SCD, knew that it is a hereditary disease; 28% thought it is acquired through blood transfusion; 12.2% knew nothing about how people get SCD; 2.4% thought that it is caused by bad weather conditions; 1.2% thought it is caused by a curse; and 1.2% thought it is acquired when people are bewitched. In the literature, Adewuyi (2000) reported that knowledge that SCD was a hereditary blood disorder was as high as 91% among African-American women in St. Louis, Missouri.

Knowledge of the Symptoms of SCD

To assess, their knowledge on the presentation of the disease, participants who responded that

they were aware of SCD were presented with a list of 11 symptoms and asked to choose which symptoms suggest SCD. Participants choosing four or more correct symptoms were classified as having adequate knowledge of the SCD symptoms. Those scoring less were judged as having inadequate knowledge. Responses of participants indicated that 98.8% of the sample had inadequate knowledge on the presentation of the disease. Only 1.2% have adequate knowledge.

Isah *et al.* (2016) report that in a study among nursing (second cycle) students in Sokoto, one third (34.1%) of respondents were judged to have had adequate knowledge of SCD, just slightly lower than the 44% reported by students in three major universities in Nigeria, namely, Ahmedu Bello University, Zaria, University of Nigeria, Nsukka and University of Ibadan, Ibadan. Clearly, the knowledge of students of the Ghanaian second cycle institution woefully lags behind their Nigerian counterparts cited here. Although it is also low among Nigerians.

Knowledge of Chronicity and/or Cure of SCD

Regarding the chronicity and cure for Sickle cell disease, 65.9% of respondents of this study who aware of SCD thought it has a cure. Of those who thought SCD can be cured, 47.6% thought it can be cured through medical means; 22% thought it can be cured through herbal means; 2.4% said religious prayers can cure it; while 28 % said "other" means can be used to cure it.

It is unfortunate that as high a percentage as 65.9 of those aware of SCD thought it can be cured. This is finding is important in designing educational programmes about SCD, because in Ghana currently, there is no cure for SCD. However, advances in bone marrow transplantation in the Western world has shown the disease is curable in selected patients, (Edwin *et al.*, 2011). These authors also indicate that prenatal diagnosis and selective abortion have been suggested as means of primarily avoiding SCD in new born children but ethical issues in respect of selective abortion has made this method non-appealing to many.

Can SCD be Prevented?

Respondents who were aware of SCD were next asked to indicate by what means SCD can be prevented. They were to choose one out of a number of options. 63.4% of them thought testing before marriage is the way of prevention; 13.4% of respondents did not know how it can be prevented; 11% said it can be prevented by avoiding marriage to someone with SCD; 8.5% of the respondents said it can be prevented by taking medication; 3.7% thought it cannot be prevented.

This study observes that, it is a positive sign that as high a proportion as 63.4% has the sense that testing before marriage has something to do with prevention of off-springs of married couples from contracting SCD. However, responses of the remaining 36.6% are all problematic, since they suggest that respondents do not have any sense of how SCD might be prevented. The extent to which respondents understand what the testing before marriage is really bout is explored under pre-marital testing below. Suffice it to note here that Edwin *et al.* (2011) recommended that prevention of SCD should be targeted at three levels, namely, preconceptic genetic testing and strategic reproductive choices; education for carrier parents; and holistic management for those born with sickle cell disease.

Awareness of their Own Sickling Status

This section assessed the attitudes of students towards knowing their sickling status. 65.8% of the respondents who were aware of SCD did not know their sickling status. 34.2% knew. The respondents who knew their sickling status reported as follows: AA 50%; SC 21.4%; SS 21.4%; and AS 7.3%. Olubiyi *et al.* (2013) reported that in their study of students of three Nigerian universities 32% reported that they did not know their own genotype. This is half of our percentage

Attitude Towards Finding out Sickle Status

Of the Ghanaian 65.8% who did not know their sickling status, 59.3% indicated that they intended to find out before they got married. 40.7% did not intend to find out. 60% of those who did not intend to find out their sicking status before marriage said it was because they did not know much about the disease. 24% said they were prepared to face anything. 16% said they did not see the need to find out.

Pre-Marital Screening

To assess respondents' knowledge of pre-marital screening for sickling status, the 82 respondents who claimed to be aware of SCD were asked whether they knew what pre-marital screening for SCD was about. They were to choose one correct response out of four. Only 27.3% got it right. This poor knowledge of what pre-marital screening for SCD is contrasts with the finding of Olubiyi *et al.* (2013) in their Nigerian study which revealed that in a university, 57% of respondents knew what pre-marital screening was. One must note however, that the Ghanaian cohort being second cycle institution students are likely to be less knowledgeable than the Nigerian university students, whose educational level would be higher, (Boadu and Addoah, 2018).

Compulsory Pre-Marital Screening and Importance of Knowing their Sexual Partner's Status

Respondents who were aware of SCD were next asked whether they thought it was important to know the sicking status of their sexual partners 91.5% of them thought it was important to know their partners' sickling status. 8.5% did not think it was important to know. Then, they were asked whether they thought pre-marital screening for sickling status should be made compulsory for every couple. 76.8% of them said it should be made compulsory, while 23.2% did not think it should be so. It is heart-warming that such a high percentage thought it is important to know the sickling status of their sexual partners.

Next, respondents who said it was important to know their partners' sickling status were asked why they thought so. 54.7% of them said this was to prevent having children with SCD; 24% said it was to prevent SCD infections; 10.7% thought it was to know whether one's sexual partner has SCD; 5.3% said it was to determine who to marry; 4.0% said so that those with SCD can be treated; 1.3% thought it was because SCD can be transferred from one sexual partner to another. This question was an open-ended question which was imprecisely answered. For example, it is unclear what respondents meant by to prevent having children with SCD. Be that as it may, the take home from the responses to this question suggests that respondents do not know precisely the essence of testing for sickling status.

22 out of the 82 respondents who were aware of SCD had partners they intended to marry. For those with partners they intended to marry and who were aware of SCD, only two knew their partners' status. 20 did not. For the 20 who did not, 13 said they intended to find out before marriage. The rest would not bother to know the sickling status of their potential spouses, they reported.

Those who already knew their potential spouses' sickling status (2 of them) and those who expected to know by the time of marriage (13 of them) made up 15 out of the 22. That is, 68.2% of those who had potential spouses would know their partner's sickling status by the time of marriage, all things equal. This percentage falls far short of the 91.5% who responded earlier that it was important to know their sexual partners' status. Asked about encouraging their friends to go through premarital testing for SCD, 93.8% of those aware of SCD were willing to do so. 6.2% were not willing to do so.

DISCUSSION

It is clear that along may dimensions of SCD evaluated in this study, Nigeria has a higher awareness rate of SCD relative to Ghana. Omuemu's *et al.* (2013), not relating Nigeria to Ghana, explain that Nigeria's high awareness rate may be due to the fact that the country is within an SCD endemic region. Ghana, which is next door to Nigeria, also lies in and SCD endemic region. However, one notes that DeBaun and Galadanci (2019) report that Nigeria, India and Democratic Republic of Congo account for 90% of the world's SCD population. So there may be some truth to the statement by Omuemu *et al.* Indeed, DeBaun and Galadanci also report that three percent of births in Nigeria are SCD positive. The percentage in Ghana is two.

The following is noted about respondents who were aware of SCD in this study. Even though 63.4% of them thought testing before marriage is the way to prevent SCD (above), the more precise question about what pre-marital screening is reveals that respondents' knowledge is not up to scratch. Only 27.3% knew precisely what pre-marital screening for SCD was. Clearly, some respondents do not know the precise meaning, knowledge and purpose of pre-marital counselling. Thus, it would appear that many respondents have a sense that pre-marital screening has something to do with SCD prevention. Their knowledge is however imprecise. They must be given education about the correct essence of pre-marital screening.

Naturally, when testing reveals two careers of sickling genes who have plans to get married, they

would be counselled against marriage. This is bound to cause discomfort to the couple. It is suggested that SCD knowledge and pre-marital counselling be introduced early in school curriculum (second cycle) to prepare the minds of such young adults. This will also be consistent with the literature that more education is consistent with more knowledge of SCD.

On the bright side though, as many as 91.5% of respondents of this study, who are aware of SCD agreed that it is important to know their partners' sickle status. Also positive is that 93.8% of those aware of SCD said they would encourage their friends to go through premarital counselling and testing for SCD. Such positive pre-disposition towards pre-marital counselling should help in getting them to participate in pre-marital counselling sessions. Important as respondents say they perceive premarital screening, getting them to actually do so will not come easy, given that responses received in this study suggest that only about 68.2% expect to know their partners' sickling status by the time of marriage.

LIMITATIONS OF THE STUDY

Although the present research revealed a number of interesting findings, it is not without limitations. The research only focused on subjects from one second cycle school. Perhaps a different picture would have emerged if the study had been extended to individuals in the other secondary level institutions. Also, the sample size used in the study was small (due to lack of resources).

CONCLUSION

The outcome of the current study has a role to play in future health programme planning and evaluation for sickle cell disease services in Ghana. It is clear that there is need for increased awareness on sickle cell disease, how it is transmitted from carriers to their off-springs and therefore how its incidence may be reduced. Education on sickle cell disease will help orient the social behaviour of young individuals using social media as well as educational facilities. Policies are needed to ensure easily accessible community-wide sickle cell screening and premarital and genetic counselling services to achieve the desired decline in new births of children with SCD.

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