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Assessing public knowledge of clinical and social issues of sickle cell disease: A study in the Kumasi metropolis of Ghana

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ABSTRACT

Sickle cell disease (SCD) is a major health concern in Ghana, but little has been carried out to evaluate its clinical characteristics. This study therefore assessed knowledge of SCD in Kumasi, Ghana. A descriptive cross-sectional study was carried out on 405 individuals randomly selected from the metropolis using the quota sampling technique to ascertain knowledge of SCD, sickling status, disease complications, and choice of drug management. The results showed that 65.4% of the respondents knew that SCD is genetic in origin, but 65.1% had no idea what sickle cell crisis was. Educational level influenced the knowledge of the cause of SCD ($p \leq 0.001$), but gender, age, employment, and marital status had no significant correlation ($p > 0.05$). Most (67.5%) of the participants had no idea of their sickling status, with individuals aged 18–30 years (i.e., 69.3%) being the majority. Education ($p \leq 0.001$) and age ($p \leq 0.001$) did not influence knowledge of sickling status. Many (56.9%) regarded sickle cell as a burden on society. Most (69.3%) opted for orthodox management, while 28.5% chose herbal treatment giving reasons such as "no side effects," tradition, affordability, and efficacy. The majority (52.5%) indicated very poor public sensitization, and 69.4% did not have an idea of the availability of sickle cell centers in hospitals. Findings suggest the need for more effort to promote SCD awareness campaigns in Ghana.

INTRODUCTION

Sickle cell disease (SCD), characterized by episodes of acute illness and body organ damage, is one of the most common forms of hemoglobinopathies worldwide (Mortality and Collaborators, 2014; Weatherall *et al.*, 2005). Although globally SCD contributes a significant disease burden, it is not amply addressed (Weatherall, 2010). Per the systematic analysis of the global disease burden in 2015, about 3.2 million people live with SCD, 43 million people have sickle cell trait, and 176,000 people die of SCD-related complications annually (Mortal, 2015). In sub-Saharan Africa, 300,000 infants were born with major hemoglobin disorders with about 2% of all children having SCD (WHO, 2006). The occurrence of the sickle cell trait is between 15 and 30% in West Africa and about 2% in Ghana (Kyerewaa *et al.*, 2011). As the global burden of SCD is increasing, especially in low- and middle-income countries, there is a need for appropriate knowledge improvement to help enhance health policies (Piel *et al.*, 2013). The manifestations and complications of SCD include episodes of pain in the bones and joints, chronic hemolytic anemia (sickle cell anemia), and cerebrovascular events such as thromboembolic disorders and priapism. Others like recurrent microbial infections, retinopathies, vision issues, and progressive organ damage (Hoppe *et al.*, 1998) are devastating. Knowledge of clinical and social issues of SCD, that is, having information on the etiology of the disease, its possible complication, and subsequently knowing one's sickling status, is really relevant in preventing the disease and contributing to its management. There is therefore a need to bridge the gap in the literature with regard to increasing knowledge and awareness of SCD among the general public. This study therefore sought to assess knowledge of clinical and social issues regarding SCD among the Ghanaian populace.

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METHODOLOGY

Study area

This study was carried out in the Kumasi metropolis of the Ashanti Region of Ghana (latitude 6.35° N and 6.40° S and longitude 1.30° W and 1.35° E). It is among the largest metropolitan areas in Ghana. Kumasi, the second largest city in Ghana, covers an area of about 299 sqkm, and harbors 209 communities. It is the administrative capital of the Ashanti Region (Ghana Statistical Service, 2014). The metropolis, which is located in the central portion of the Ashanti region, has been divided into five submetros, namely, Asokwa, Bantama, Manhyia South, Manhyia North, and Subin, by the Ghana Health Service for the purpose of healthcare delivery. It has several colleges and universities, and it is a major trading center in Ghana. The metropolis inhabits Ghanaians from so many tribes and several religious groups, including Christians, Muslims, Traditionalists, and Pagans. This metropolis was chosen for the study because it would offer a variety of opinions due to its cosmopolitan nature with individual participants having varied views and beliefs.

Study population

The study populations were males and females aged 18 years and above and were residents of the metropolis. Individuals below 18 years were excluded from this study as by law these individuals cannot give consent on their own.

Sample size used

In calculating the sample size required (n) for the study, the following equation was employed:

$$n = \left(\frac{No}{\frac{1+(No-1)}{N}} \right),$$

where N_0 is Cochran's sample size recommendation calculated as

$$N_0 = [Z^2pq]/e^2,$$

where n is the sample size, the Z-value as found in a Z table (at the confidence limit of 95%) = 1.96, "p" is the estimated proportion of the population which has the attribute in question, "q" is $(1 - p)$, and "e" is the desired level of precision (i.e., the margin of error), which was selected to be 5% for this study.

"N" is the population size of the metropolis, which is 834,066 (based on the 2010 population census in Ghana).

$$n_0 = [(1.96)^2 \times 0.0.5 \times 0.5] / 0.05^2 = 385.$$

Sampling technique

Quota sampling was used in determining the number of participants to be selected from each submetropolitan area after obtaining the total sample size required. Applying this technique, 110 and 109 participants were randomly sampled from the Asokwa and Bantama submetropolitan areas, respectively, while 69, 68, and 47 participants were sampled from the Manhyia South, Manhyia North, and Subin submetropolitan areas, respectively.

Data collection tool

Data were collected by means of a well-structured questionnaire developed with both closed and open-ended questions on the subject matter. The questionnaire was pretested by the administration to assess and ascertain its ability to capture relevant information for this study. Sociodemographic characteristics, knowledge of SCD, knowledge of sickling status, preferred treatment choices for SCD, and the disease in relation to selecting reproductive partners, among others, were asked for documentation.

Study design and data collection

Between July and December 2018, questionnaires were administered to 405 individuals from marketplaces, offices, transport stations, fitting and mechanic shops, educational institutions, and roadsides, among others with the submetropolitan areas. The questionnaire was explained vividly to participants who were then made to fill it and submit it there and then. Participants who could not read and write however were assisted in filling the questionnaire by explaining the questions in the language they could understand, and their opinion was filled on the questionnaire for them.

Data analysis

Responses from the questionnaire were collated using Statistical Package for Social Scientists (SPSS version 20, IBM). Quantitative data analysis involving quantification and calculating percentages and qualitative analysis involving the use of Chi-square to determine the significant association, or otherwise between variables, were employed. p-values ≤ 0.05 were considered significant changes. Graphs were drawn with GraphPad Prism version 6.

Ethical consideration

Prior to the commencement of the study, its purpose, benefits, and risks were provided to individuals. Individuals who agreed to partake filled the consent form. They were made to understand that their participation in the study was voluntary. Anonymity and confidentiality of information given were assured. There was no remuneration for participants.

Ethical approval (CHRPE/AP/196/19) for the study was given by the Committee on Human Research, Publication, and Ethics of the School of Medical Sciences and Komfo Anokye Teaching Hospital.

RESULTS

Sociodemographic characteristics

Of the 405 respondents, 257 (63.5%) were male, while 148 (36.5%) were females. Most of the respondents (205 (50.9%)) were aged 18–30 years, with the majority (342 (84.4%)) being Christians. The majority of participants (305 (75.3%)) were employed, while 228 (56.4%) had never married before, and 159 (39.5%) had secondary education (Table 1).

Knowledge of SCD

Of the 405 respondents, 251 (65.4%) knew SCD to be a genetic disorder which has several complications associated with

Table 1. Sociodemographic characteristics of 405 participants in the study on public knowledge of SCD in the Kumasi metropolis of the Ashanti Region of Ghana.

Sociodemographic factors	Frequency	Percentage
Age		
18–30	205	50.9
31–45	147	36.5
46–60	49	12.2
Above 60	2	0.5
Religion belief		
Christian	342	84.4
Islamic	54	13.3
Nonaligned	9	2.2
Marital status		
Single	228	56.4
Married	168	41.6
Widowed	4	1.0
Divorced	4	1.0
Employment status		
Employed	305	75.3
Unemployed	27	6.7
Student	67	16.5
Retired	5	1.2
Level of education		
Nil	17	4.2
Primary	12	3.0
BECE/MSLC	116	28.8
WASSCE/GCE A&O level	159	39.5
Tertiary	99	24.6

Data are presented as the number of individuals with percentage distribution.

SCD: sickle cell disease, BECE/MSLC: Basic Education Certificate Examination/Middle School Leavers Certificate, and WASSCE/GCE A&O level: West Africa Senior High School Certificate Examination/General Certificate of Examination Advanced and Extra Ordinary level.

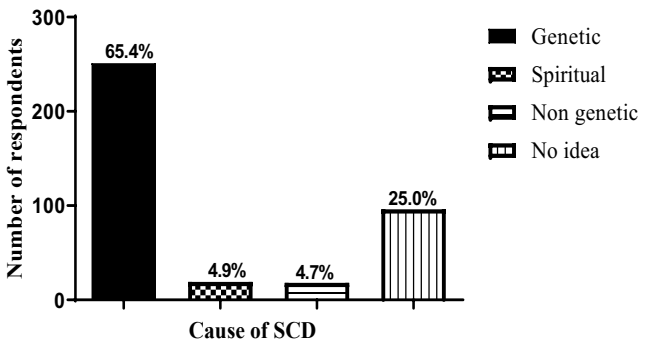

Figure 1. Causes of sickle cell disease (SCD) as stated by respondents in the survey on the knowledge of SCD in the Kumasi metropolis. The percentage with respect to the total response is as shown on the bars.

it, although others had other ideas (Fig. 1). However, the majority (244 (65.1%)) had no idea what sickle cell crisis was. The study revealed that education influences an individual's knowledge of the cause of SCD since there was a positive association ($p \leq 0.001$) between educational level and knowledge of SCD. Gender, age, employment, and marital status showed no significant correlation ($p > 0.05$) (Table 2).

Knowledge of sickling status

Interestingly, most participants [260 (67.5%)] had no idea of their sickling status, even though some knew the causes of SCD. Most of the respondents [210 (51.9%)] expressed their wish to have known their sickling status but cited a number of reasons why they have not been able to do so. The majority of them gave a lack of time as a reason why they have not checked their sickling status (Fig. 2). There was a negative association between education ($p \leq 0.004$) and age ($p \leq 0.001$) and individual's knowledge of sickling status (Table 3).

SCD management

Most respondents [214 (56.9%)] regard SCD patients as a burden on society. On the choice of management, 253 (69.3%) opted for orthodox management citing reasons. For example, some are of the view that practitioners in the orthodox system have the requisite knowledge and skill to thoroughly investigate and manage the disease and that it is a scientific, effective, and reliable form of management, among others (Fig. 3). However, 104 (28.5%) chose the herbal form of management, explaining that this form of management has no side effects, it is our tradition, and it is cheap and cures the disease (Fig. 4). They also mentioned several plants, of which the 10 most common ones have been documented (Table 4). Eight participants (2.2%) opted for prayers for management as they saw the SCD to be spiritual in origin.

Marriage/pregnancy and SCD

The majority of respondents [313 (82.6%)] declined to marry a sickle cell patient explaining that people with SCD will be a burden on them. Furthermore, 114 (30.6%) participants chose to abort a sickle cell pregnancy, while 259 (69.4%) said they would still keep a sickle cell pregnancy as they were of the view that abortion meant the destruction of an innocent child.

Knowledge of SCD management centers

The majority of the participants [259 (69.4%)] had no idea that there are available sickle cell units/centers in hospitals where they could walk in for either treatment or relevant information on the disease.

Public education

The majority of the participants (Fig. 5) believed that the sensitization and public education with regard to SCD are poor.

DISCUSSION

This study assessed knowledge of SCD among individuals living in the Kumasi metropolis of Ghana as a way of providing baseline data on the awareness of the public with regard to SCD. Most participants knew that SCD is a genetic

Table 2. Association between sociodemographic factors and knowledge of the cause of SCD among participants in a survey on the public knowledge of SCD in the Kumasi metropolis.

Demographics	Causes of SCD				Total	*p*-value
	Genetic	Spiritual	Nongenetic	No idea		
Age group						
18–30	130 (66.7%)	8 (4.1%)	8 (4.1%)	49 (25.1%)	195 (100.0%)	
31–45	93 (67.4%)	10 (7.2%)	5 (3.6%)	30 (21.7%)	138 (100.0%)	0.306
46–60	25 (53.2%)	1 (2.1%)	5 (10.6%)	16 (34.0%)	47 (100.0%)	
Above 60	1 (50%)	0 (0%)	0 (0%)	1 (50%)	2 (100.0%)	
Employment status						
Employed	175 (61.2%)	14 (4.9%)	14 (4.9%)	83 (29.0%)	286 (100.0%)	
Unemployed	19 (73.1%)	0 (0.0%)	2 (7.7%)	5 (19.2%)	26 (100.0%)	0.071
Student	53 (80.3%)	4 (6.1%)	1 (1.5%)	8 (12.1%)	66 (100.0%)	
Retired	3 (60.0%)	1 (20.0%)	1 (20.0%)	0 (0.0%)	5 (100.0%)	
Marital status						
Single	146 (67.0%)	13 (6.0%)	8 (3.7%)	51 (23.4%)	218 (100.0%)	
Married	102 (64.6%)	6 (3.8%)	9 (5.7%)	41 (25.9%)	158 (100.0%)	0.169
Widowed	3 (75.0%)	0 (0.0%)	0 (0.0%)	1 (25.0%)	4 (100.0%)	
Divorced	0 (0.0%)	0 (0.0%)	1 (25.0%)	3 (75.0%)	4 (100.0%)	
Level of education						
Nil	4 (25.0%)	4 (25.0%)	0 (0.0%)	8 (50.0%)	16 (100.0%)	
Primary	5 (45.5%)	2 (18.2%)	3 (27.3%)	1 (9.1%)	11 (100.0%)	0.001
BECE/MSLC	54 (50.9%)	5 (4.7%)	8 (7.5%)	39(36.8%)	106(100.0%)	
WASSCE/GCE A&O level	101(66.9%)	5 (3.3%)	4 (2.6%)	41 (27.2%)	151 (100.0%)	
Tertiary	85 (86.7%)	3 (3.1%)	3 (3.1%)	7 (7.1%)	98 (100.0%)	

Data are presented as the number of individuals with percentage distribution in brackets.

SCD: sickle cell disease, BECE/MSLC: Basic Education Certificate Examination/Middle School Leavers Certificate, and WASSCE/GCE A&O level: West Africa Senior High School Certificate Examination/General Certificate of Examination Advanced and Extra Ordinary level.

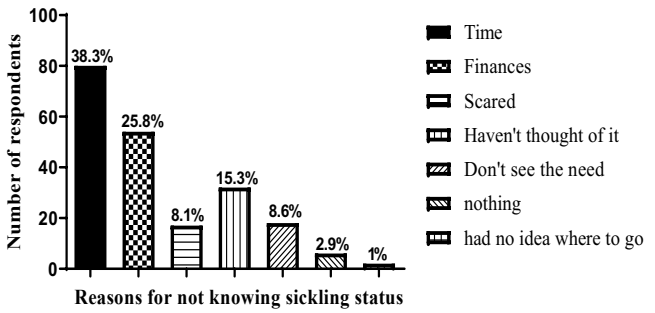

Figure 2. Reasons why participants involved in the study on knowledge of SCD had no idea of their sickling status. The percentage with respect to the total response is as shown on the bars.

disease, although a few individuals think that it is spiritual and not genetically related. This indicates that access to information about SCD is relatively good. This could be due to easy access to the Internet and educational materials. Internet access has been reported to be effective for education (Boadu and Adoah, 2018). The minority who had no idea of the cause of SCD indicates that there is still a knowledge gap that has to be filled by further enhancing education campaigns in Ghana. In 2010, WHO adopted a strategy recommendation that sought to increase the awareness among the populace coupled with strengthening primary prevention with the hope that it will help reduce the incidence of SCD and its related morbidities (OMS, 2011). In Ghana, the implementation of these recommendations is still very little noticeable, and our result

Table 3. Association between sociodemographic factors and knowledge of sickling status among participants in a study on public knowledge of SCD.

Sociodemographic data	Knowledge of sickling status			
	Yes	No	Total	*p*-value
Age group				
18–30	49 (25.0%)	147 (75.0%)	196 (100.0%)	
31–45	60 (43.5%)	78 (56.5%)	138 (100.0%)	0.004
46–60	15 (31.9%)	32 (58.1%)	47 (100.0%)	
Above 60	0 (0%)	2 (100.0%)	2 (100.0%)	
Marital status				
Single	56 (25.6%)	163 (74.4%)	219 (100.0%)	
Married	65 (41.1%)	93 (58.9%)	153 (100.0%)	0.100
Divorced	2 (50.0%)	2 (50.0%)	4 (100.0%)	
Widowed	2 (50.0%)	2 (50.0%)	4 (100.0%)	
Employment status				
Employed	100 (34.7%)	188 (65.3%)	288 (100.0%)	
Student	15 (23.1%)	50 (76.9%)	65 (100.0%)	0.210
Unemployed	7 (26.9%)	19 (73.1%)	26 (100.0%)	
Retired	3 (60.0%)	2 (40.0%)	5 (100.0%)	
Level of education				
Nil	3 (18.8%)	13 (81.2%)	16 (100.0%)	
Primary	3 (27.3%)	8 (72.4%)	11 (100.0%)	0.001
BECE/MSLC	29 (27.4%)	77 (72.6%)	106 (100.0%)	
WASSCE/GCE A&O level	38 (24.8%)	115 (75.2%)	153 (100.0%)	
Tertiary	50 (51.5%)	47 (48.5%)	97 (100.0%)	

Data are presented as the number of individuals with percentage distribution in brackets.

SCD: sickle cell disease, BECE/MSLC: Basic Education Certificate Examination/Middle School Leavers Certificate, and WASSCE/GCE A&O level: West Africa Senior High School Certificate Examination/General Certificate of Examination Advanced and Extra Ordinary level.

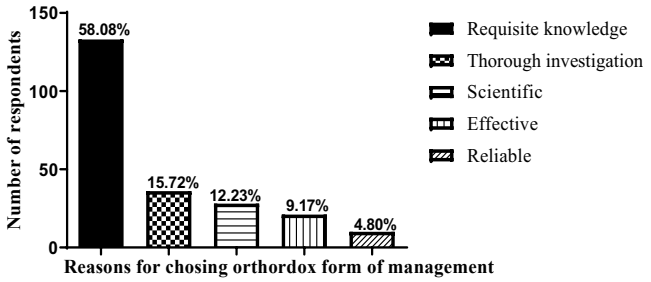

Figure 3. Reasons why participants involved in the knowledge of SCD study chose the orthodox form of management. The percentage with respect to the total response is as shown on the bars.

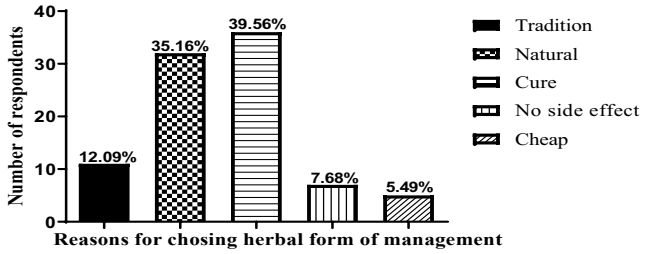

Figure 4. Reasons why participants involved in the knowledge of SCD study chose the herbal form of management. The percentage with respect to the total response is as shown on the bars.

reflects overall a still weak involvement of educational structures and healthcare workers in raising awareness, information, and education on SCD.

A higher proportion of respondents had no idea of their sickling status, a finding similar to that by Boadu and Adoah (2018). This finding may be a reflection of the socioeconomic status of the population. For this reason, most individuals, due to their low financial status, see no reason to undergo routine medical examinations unless they are in a critical situation that requires a test. For instance, in Ghana, an individual may know his or her sickling status only in situations where compulsory medical screening is required, for example, prior to marriage or admission into an institution (Boadu and Adoah, 2018). Also, the fear of the unknown and lack of motivation from health workers to educate the public on the need to know their sickling status may be a contributory factor.

Table 4. List of 10 commonly used plants mentioned by participants as useful in SCD management in Ghana.

Plant	Botanical name	Local name	Part used	Dosage form
Xylopia	*Xylopia aethiopica*	Hwentea	Fruits	Decoction
Fagara	*Zanthoxylum zanthoxyloides*	Okanto	Stem bark	Decoction
Pawpaw	*Carica papaya*	Bofere	Leaves	Decoction
Clove	*Eugenia caryophyllus*	Pepre	Fruits	Decoction
Ginger	*Zingiber officinale*	Akekaduro	Rhizome	Decoction
Moringa	*Moringa oleifera*	Moringa	Leaves	Decoction
Black pepper	*Piper guineense*	Soro wisa	Seeds	Decoction
Trilepisium	*Trilepisium madagascariense*	Okuri	Stem bark	Decoction
Sorghum	*Sorghum bicolor*	Durra	Leaves	Decoction
Neem	*Azadirachta indica*	Kuntunkuri	Stem bark	Decoction

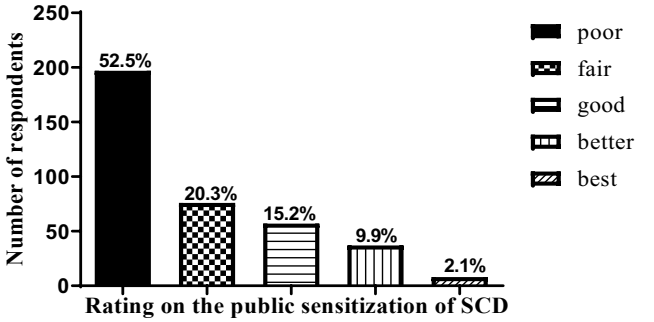

Figure 5. Respondents' idea on public sensitization on SCD. The percentage with respect to the totalresponse is as shown on the bars.

Most participants had no idea of a typical presentation of a sickle cell crisis. This reveals the low intensity of education by health workers and public health promoters with regard to SCD. The importance of education in the fight against this disease is highlighted in the study by Olatona *et al.* (2012), in Nigeria, who reported that health education has considerably improved the knowledge of the population studied about SCD and their attitude towards it. These findings indicated that education plays a positive role in one knowing the cause of SCD.

The knowledge of sickling status in the older population was higher as compared to the younger population, probably because most of the younger individuals do not get the opportunity to be tested. It has also been reported that medical examinations in the senior high schools and universities in the country do not include SCD (Boadu and Adoah, 2018). This finding is quite intriguing and worrying because these are young adults, are reproductively active, and are probable to make decisions on their marriage partners. It would therefore be imperative to include SCD screening as part of the routine medical examinations in both our second cycle and tertiary educational institutions. Also, most participants regarded SCD patients as a burden on society and hence would not hesitate to decline a marriage proposal from such individuals. This might come from the fear of stigmatization meted to families with SCD patients coupled with beliefs and myths about SCD. For instance, a participant in a previous study by Marsh *et al.* (2011) said, "my parents always cautioned us from marrying from a certain family because they always heard somebody hospitalized."

Ignorance and misconceptions of SCD have been cited as barriers to the effective management of SCD (Batina *et al.*, 2017). Most of the participants chose the orthodox form of management as their choice of management in SCD. They cited reasons as efficacy, safety, and the fact that orthodox professionals had the requisite knowledge and equipment in the management of SCD. This indicates that most of the individuals had the right information about the orthodox healthcare system and hence trust in the orthodox system of management. However, their choice of management had no correlation with their educational background. Interestingly, a substantial number (28.5%) of the respondents also chose herbal medicine as their treatment option for the management of SCD. This might be due to the erroneous notion that herbal medicine has the ability to cure the disease, and it also might come at a cheaper cost compared to the orthodox form of management. This is consistent with a study carried out among sickle cell patients visiting a tertiary hospital in Nigeria, where it was revealed that these patients use a form of complementary and alternative medicine in one way or the other in the management of their SCD (Busari and Mufutau, 2017). More so, herbal medicines are used to manage sickle cell crises associated with morbidities among individuals living in low- and middle-income countries (Amujoyegbe *et al.*, 2016).

Most respondents declined to marry sickle cell patients. This is consistent with findings reported by Ameade *et al.* (2015), where public servants even agreed to divorce their partners if they become aware of genetic incompatibility because they are aware that they might end up giving birth to SCD children. And these children are mostly perceived to drain the resources of their families due to their frequent visits to the hospital. Interestingly, most respondents chose rather to keep a sickle cell pregnancy in case it happened rather than aborting it, citing morality as their reason. This may be due to the notion that these are innocent

children who by no fault of theirs have this disease and hence should be given the opportunity to live. However, a substantial proportion of respondents (30.6%) would rather abort than give birth to an SCD child. This decision can be due to their fear of public ridicule, stigmatization of the family, and the financial burden associated with its management and hence would rather abort than give birth to an SCD child. This finding brings back the idea of selective abortion as a means of controlling and managing SCD as proposed by some healthcare professionals in Ghana (Kyerewaa *et al.*, 2011).

Irrespective of how grave the disease is, coupled with its psychosocial burden on families, most of the respondents had no idea that there are sickle cell units in the various hospitals where they could walk in for management and also get the right information with regard to the disease; also, they were of the view that public sensitization of the SCD is poor. The poor public sensitization can be a result of the fact that previous governments and the ministry of health had not made SCD a priority and hence see no reason to embark on sensitization of the disease. This finding is quite alarming especially when genetic counseling is being propagated as a way of curbing SCD. This can only be effective if public sensitization on the condition is heightened and intensified so as to aid individuals in making informed decisions when they are about to marry. This will go a long way in helping the nation as a whole curb the incidence of SCD. They may even affect the acceptability and practice of premarital screening for the disease (Olakunle *et al.*, 2013).

CONCLUSION

Findings suggest the need for more effort to promote sickle cell awareness in Ghana, with emphasis on the inclusion of sickle cells in public health education campaigns.

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AUTHOR CONTRIBUTIONS

All authors made substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data; took part in drafting the article or revising it critically for important intellectual content; agreed to submit to the current journal; gave final approval of the version to be published; and agree to be accountable for all aspects of the work. All the authors are eligible to be an author as per the international committee of medical journal editors (ICMJE) requirements/guidelines.

ETHICAL APPROVALS

Ethical approval (CHRPE/AP/196/19) for the study was given by the Committee on Human Research, Publication, and Ethics of the School of Medical Sciences and Komfo Anokye Teaching Hospital.

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CONFLICT OF INTEREST

The authors declare no conflict of interest whatsoever.

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