Awareness of Sickle Cell Trait Status: A Cross-Sectional Survey of Antenatal Women in Ghana

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Abstract. This study was conducted to evaluate pregnant women's awareness of sickle cell disease and sickle cell trait and the factors that contribute to it. Two hundred and six pregnant women with at least 20 weeks gestation answered a questionnaire regarding awareness of their trait status and questions to test their knowledge of sickle cell disease. Although the majority of patients were aware of their trait status (87.4%), only 29% of knowledge questions were answered correctly; patients who self-identified as having sickle cell trait did not do better. Patients who responded that they knew a good deal about sickle cell disease scored an average of 3.5 points (number of correct responses to nine questions) more than individuals who responded that they knew nothing ($P < 0.001$). Individuals who knew they had been tested for the sickle cell trait scored approximately 2 points higher than those who did not know whether they had been tested ($P = 0.004$). Respondents with at least secondary education scored on average 1 point higher on the knowledge test than those with less education ($P = 0.004$). Knowing someone with sickle cell disease was associated with a mean score of 1.25 points higher than individuals who did not know any affected individual ($P = 0.000$). There is a deficit in the knowledge of sickle cell disease among Ghanaian pregnant women. Therefore, there is the need for public education on sickle cell disease.

INTRODUCTION

Sickle cell disease (SCD) is a hereditary blood disorder, characterized by red blood cells that assume an abnormal, rigid, sickle shape during periods of hypoxia, leading to episodes of pain, infection, and other complications. The sickle cell trait (SCT) and disease are more prevalent in sub-Saharan Africa; in Benin the prevalence is estimated to be 25%, in Nigeria it ranges from 24% to 25%, and in Uganda the trait manifests in up to 30% of the population.^{1–4}

Given that about a third of Ghanaians carry the sickle cell gene and about 2% (or 15,000) of newborns in Ghana each year have SCD, the disease presents a heavy public health burden.^{5,6} A recent study to explore the attitudes of Ghanaian women to genetic testing for the SCT showed that over half of those who had been tested were still unaware of their status and the majority of those surveyed agreed that pregnant women should undergo testing.⁷ However, the researchers did not explore why this percentage was so high. There seems to be a gap in knowledge of Ghanaian women of childbearing age between the significance of testing for the SCT before conception and how the results could impact their family planning decisions.

Although there has been considerable research and knowledge about the molecular basis and management of SCD, less attention has been paid to patient knowledge of SCT. Current knowledge of sickle cell in pregnant women is not well understood. Exploring factors that may impact individuals' knowledge of sickle cell may help improve the focus of genetic counseling. An overview of the general knowledge base of patients would provide genetic counselors or public health workers with information on which key areas

to educate the public about SCD and SCT. This also provides an opportunity to collaborate with health-care professionals to increase awareness about SCD. Health-care providers may be more likely to refer patients to genetic counselors if patients are deficient in knowledge about sickle cell and/or the clinician is not comfortable providing as much detail that may be necessary for a patient to make an informed decision. Where patients' knowledge may be lacking educational tools could be developed to educate patients and the public about sickle cell. This is particularly important for Ghana, where a strategic framework for managing and preventing SCD is in progress.⁸

This study was conducted to determine the knowledge of pregnant Ghanaian women who need the testing and to determine whether exploring factors that may impact individuals' knowledge of sickle cell could help improve the focus of genetic counseling.

MATERIALS AND METHODS

This was a descriptive cross-sectional survey of pregnant women attending the antenatal clinic of the Korle-Bu Teaching Hospital, Accra, Ghana. The pregnant women were approached sequentially in the order that they reported. After explaining the purposes of the study and obtaining a verbal informed consent, patients' medical records were checked to see the result of their sickle cell test status. After that, they were formally asked to participate by signing the informed consent form after reading or being read to if they do not decline participation. Given that about a third of females in Ghana are not literate trained, translators were available to assist, if necessary to ensure consistency and therefore validity.⁹ In this study no other education on the disease was given, beside the general talk about the need for the test and the special care given to patients found to have the disease, since the objective was to test patient's awareness of both the disease and the genetic pattern of inheritance.

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Pregnant women included in the study were of Ghanaian descent aged 18 years or above and were at least 20 weeks gestation at the time of the study (between January 15 and February 15, 2015). Patients who had not received their blood sample results of sickle cell status were excluded. Sample size of the study was based on the study by Treadwell and others who surveyed 282 subjects and reported that although 86.2% of respondents indicated that SCD causes serious health problems (perception), only 29.8% provided a completely correct or partially correct definition of SCD (understanding).¹⁰ Between the group of patients that responded “yes” to question of having SCT versus those who responded “no” or “not sure,” the fraction of respondents who got at least 70% correct of the knowledge/understanding questions was 70% versus 50% with a sample size of 206 at a power of 0.8. Therefore, 206 respondents were targeted for the survey. The survey had three sections. The first section collected demographic information using multiple choice and fill-in-the blank questions. The second section composed of multiple choice questions regarding participants medical care at the clinic, their sickle cell screening history, their personal familiarity with the disease, their perceptions of the disease, and what the participants had been told about SCD by their health-care providers. The third section consisted of questions, which tested the patient’s knowledge of the clinical characteristics of SCD, SCT, their incidences, and hereditary pattern.

The responses were analyzed with descriptive statistics to describe the demographics of the study population and frequencies analyzed by giving each participant a knowledge score, which consisted of the number correct out of a total of nine knowledge questions. Each correct response was allotted 1 point for each question and the mean in a group represented the mean points. *t* Test, analysis of variance, and Pearson’s χ^2 were used to analyze factors that influence awareness and knowledge of the disease and the participants’ knowledge of their trait status. Educational categories were grouped into those below senior high school and those with at least senior high school for statistical analysis. Approvals from the Research Ethics Committee of Cardiff School of Pharmacy and Pharmaceutical Sciences (SA837658) and the Ethical and Protocol Review Committee of the School of Medicine and Dentistry, College of Health Sciences, University of Ghana, Accra (MS-Et/M.4-P4.6/2014-2015), were granted before the study was initiated.

RESULTS

Approximately half (260 out of 506) of the participants who were approached were eligible (had their test results) and agreed to take part in the survey. Although the test is ordered routinely, patients without health insurance pay for it, so most patients default at first until repeat reminders are given. Some patients from the district hospitals also come in referred without the results since results are communicated at subsequent visits resulting in a total of 246 patients not having their results available (Figure 1). Fifty-four questionnaires were excluded from the study because less than half of the knowledge questions were answered as the interview was abandoned for personal reasons, since participants were given the option to continue answering when their turn was up or go for the care and return later.

FIGURE 1. Flow chart of study participants.

Most patients continued the questionnaire but some abandoned it when it was their turn for antenatal care instead of waiting until completion of the questionnaire. As one procedure followed another, some did not come back as they were in a hurry to return home. The recruitment was in this way continued until the target number of participants was met. Thus, 206 participants were included in the analysis. Patient demographics are shown in Table 1. The majority of the participants were between 20 and 40 years of age (94.5%), 57.8% had completed at least senior high school. The average gestational age was 29 weeks and 32.5% were pregnant for the second time. Twenty-one participants out of 206 were aware they had SCT, giving a self-reported prevalence of 10.2%. Thirteen percent of the participants stated that they had not been tested for SCT or that they did not know if they had been tested. Seventy-four percent (152/206) of patients were aware that they had been tested during the index pregnancy. Hundred and eighty participants were aware that they had been tested for the SCT at some point in their lifetime. Only two individuals claimed they were offered screening, but declined. Individuals who knew they had been tested scored approximately 2 points higher than those who did not know whether they had been tested ($P = 0.004$). Of the 14 participants who were told they had SCT during the index pregnancy, only five (35.7%) reported discussing any information with their health-care provider. Seventy-seven (37.4%) responded “yes,” 47 (22.8%) responded “no,” and 82 (39.8%) were “not sure” of their partners being tested for SCT. Only four of the 18 participants (22.2%) who were told they have SCT during the index pregnancy were referred for genetic counseling. Of three individuals who either had a parent or a child with SCD, only one knew she had the trait.

Twenty-one respondents (10.2%) answered that they knew a lot about SCD, 100 (48.5%) answered they had some knowledge, and 85 (41.3%) answered they knew nothing. The participants who responded that they knew a lot about SCD scored on average 3.5 points more than those who responded that they knew nothing ($P < 0.001$). Forty-four participants (21.4%) responded that they personally knew someone with SCD/SCT (Table 2). Of those who had no prior personal experience with SCD/SCT, the

TABLE 1
Socio demographics and baseline characteristics of women included in study

Characteristics	Subgroup	Number per group	Percentage
Ethnicity (<i>N</i> = 206)	Akan	107	51.9
	Ewe	31	15.0
	Ga-Adangbe	39	18.9
	Hausa	15	7.3
	Other	14	6.8
Age (<i>N</i> = 206)	< 19 years	5	2.9
	20–40 years	195	94.5
	> 41 years	6	2.9
Highest level of education (<i>N</i> = 205*)	Nil	18	8.7
	Primary	19	9.2
	Junior high school	49	23.8
	Senior high school	57	27.7
	Tertiary	58	28.2
	Master's degree or higher	4	1.9
Gestational age (<i>N</i> = 206)	20–23 weeks	33	16.0
	24–28 weeks	48	23.3
	29–34 weeks	54	26.2
	> 34 weeks	71	34.5
Number of pregnancies (<i>N</i> = 202†)	1	37	18.0
	2	67	32.5
	3	51	24.8
	4	30	14.6
	≥ 5	17	9.2

*Failure to answer level of education, *N* = 1.

†Failure to answer number of pregnancies, *N* = 4.

majority (81.6%) had not heard of the disease. Knowing someone with SCD was associated with a mean score of 1.25 points higher than individuals who did not know an affected individual ($P = 0.000$). One hundred and eighteen (57.3%) participants considered SCD as being serious, whereas only 12 (5.8%) said it was not serious and as many as 76 (36.9%) were not sure as to the seriousness of the disease. Patients were most likely to answer correctly that SCD is a "blood disease" (130/206, 63.1%) (Table 3).

Approximately half of respondents knew that the SCT is not exclusive to people of African descent (108/206, 52.4%). Eighty-nine respondents (43.2%) knew that SCD cannot be cured and 106 participants (51.5%) knew that a pregnancy affected by SCD can be detected by genetic testing. However, only one in five respondents was aware that SCD cannot be detected in the womb with an ultrasound. Surprisingly, only a small percentage of respondents were aware that SCT did not relate to more joint pain or infections (3.4%). Roughly, a third of total participants (56/206, 27.2%) failed to answer any of the knowledge questions correctly (Table 4) and none answered more than seven questions correctly. This was mirrored in the sub-population of participants with SCT where the maximum

number of correct answers was six. A very small percentage (2.4%) was aware that if both parents have the trait, there is a 25% chance of having a child with the disease (Table 5).

There were key differences in the responses of participants who identified themselves as having the SCT compared with the total study population (Tables 3 and 5). Just over half of these SCT respondents knew that SCD is a "blood disease" (52.4%) versus 63.6% for the total population, and 38.1% knew SCT is not exclusive to people of African descent versus 52.4% for the total population. None of the participants with SCT knew that SCT was not associated with more infection or joint pain. None of those with SCT also knew that if both parents have the trait, they will have a 25% chance of having a baby with SCD. Respondents with at least secondary education scored on average 1 point higher on the knowledge test than those with less education ($P = 0.004$).

DISCUSSION

In this study, the self-reported prevalence of SCT was 10.2%. This is much lower than the reported national prevalence of 30% and the report of Edwin and others.^{5,11} Most participants (87.4%) knew their trait status. This is in contrast to the study of Treadwell et al, where only 16% knew their trait status, but very similar to the finding of Boyd and others, where 89% of African-American women aged 18–30 years were aware of their trait status.^{10,12} It is noteworthy that in the Boyd's survey respondents who admitted to not knowing about SCD (30%) were excluded, and this may explain the high awareness. The overall knowledge score of SCT/SCD was poor. Only about a third of the questions were answered correctly and patients who identified as having SCT did not do better. This suggests that many patients knew very little about SCD.

TABLE 2
Prior experience with sickle cell trait

Known relatives or acquaintance with SCD/SCT	Number	Percentage
Parent	1	0.5
Child	2	1.0
Sibling	4	1.9
Aunt or uncle	4	1.9
Cousin	9	4.4
Friend	18	8.7
Other	2	1.2
Total	44	21.4

SCD = sickle cell disease; SCT = sickle cell trait.

TABLE 3
Responses to knowledge questions

Questionnaire	Answer	Responses	Study population <i>n</i> (%)	SC subgroup <i>n</i> (%)
Only people of Africa descent can have SCT	False	False Not sure True Total	108 (52.4) 75 (36.4) 23 (11.2) 206 (100)	8 (38.1) 21 (100)
People with SCT have more joint pain and get more infections the people that do not have SCT	False	False Not sure True Total	7 (3.4) 86 (41.7) 112 (54.4) 205 (100)*	
If an unborn baby has SCD, it can be detected by ultrasound	False	False Not sure True Total	48 (23.3) 125 (60.7) 33 (16.0) 205 (100)*	7 (33.3) 21 (100)
If a pregnancy is affected with SCD, it can be detected by genetic testing	True	False Not sure True Total	48 (23.3) 125 (60.7) 33 (16.0) 205 (100)*	10 (47.6) 21 (100)
SCD is a genetic disorder that cannot be cured	True	False Not sure True Total	27 (13.1) 90 (43.7) 89 (43.2) 206 (100)	7 (33.3) 21 (100)
SCD is	Blood disease	—	131 (63.6)	11 (52.4)

SC = sickle cell; SCD = sickle cell disease; SCT = sickle cell trait.

*Failure to answer index question, *N* = 1.

Most patients knew that SCD is a blood disorder, that the disorder is not exclusive to people of African descent, and that it has a genetic basis. Regarding participants' knowledge of risk of inheritance, none of the participants answered all SCD and Trait inheritance questions correctly. Boyd and others had similar findings where only 9% (15/162) of individuals understood the inheritance pattern of SCD.¹² This lack of knowledge is also shown in a study of African-Americans by Kessler and others, which showed their participants' knowledge of genetics was poor.¹³ More recent studies have also consistently reported poor knowledge of SCD.^{14,15} Awareness of SCT status was good in this study (87.3%) and reflected the finding of Siddiqui and others, who found that 93% of his group of African-Americans in New York City was aware of their trait status.¹⁶ These findings may reflect lack of knowledge for those individuals who have not had a child with SCD and thus may have limited information about sickle cell. A study in Nigeria among university students between the ages of 20 and 24 found that 86% knew about their hemoglobin status, which is a little lower than in the American study.^{16,17} This could reflect the social economic status of the population. In low-income countries, the cost of blood testing may be too high for most individuals.

Patients' perception of their knowledge of sickle cell was found to have a significant association with how well they scored on the knowledge questions. This association suggests that this set of knowledge questions may be a good screening tool for evaluating a patient's knowledge base regarding SCD. As expected, respondents who knew someone with SCD also knew more about the disease than individuals who did not. This finding echoes those of Siddiqui and others and Acharya and others.^{16,18} This can be explained by the fact that individuals who are close to someone with SCD are more likely to be exposed to SCD health concerns encountered in everyday life.

Educational level of participants also influenced the total number of questions answered correctly, a finding that has been demonstrated in other studies.^{14,19} Participants who were aware of their SCT status were more knowledgeable about SCT even though those who knew they had the trait did not score significantly higher than those who did not know. This is also reflected in the study among the tertiary students in Nigeria. Although 14% did not know their hemoglobin status, only 6% were not knowledgeable about the clinical manifestation of the disease.¹⁷ These students did not know that individuals with the homozygous state will be afflicted with a clinical illness known as sickle cell anemia, which is a clinical manifestation of SCD. It is possible that individuals are more likely to recall information regarding testing if they understand the implications of the test. Finally, it was hypothesized that individuals who had SCT would be more likely to know their trait status. However, it was of great concern that of the three participants in this group who were obligate carriers of SCT (having either a child or parent with SCD), only one knew her trait status. This shows that awareness of the disease is higher than awareness of the genetic implications, which was reflected in the study of Agbanusi and others.¹⁷ In that, 25% did not know that someone with hemoglobin genotype AS is said to be a sickle cell carrier or has SCT as compared with the 6% who did not know about the SCD.¹⁷

TABLE 4
Total knowledge questions answered correctly

Number of correct answers	Total participants (<i>N</i> = 206)	SC participants (<i>N</i> = 21)
	<i>n</i> (%)	<i>n</i> (%)
0	56 (27.2)	7 (33.3)
1	16 (7.8)	3 (14.3)
2	17 (8.3)	1 (4.8)
3	42 (20.4)	2 (9.5)
4	38 (18.4)	4 (19)
5	24 (11.7)	2 (9.5)
6	9 (4.4)	2 (9.5)
7	4 (1.9)	0 (0.0)

TABLE 5
Responses to inheritance questions

Questionnaire	Answer (%)	Responses	Study population	SC subgroup
If a couple already has a child with SCD, what is the chance they will have another child with SCD?	25	0	4 (1.9)	0 (0.0)
		25	18 (8.7)	2 (9.5)
		50	39 (18.9)	4 (19.0)
		100	64 (31.1)	5 (23.8)
		NS	81 (39.3)	10 (47.6)
		Total	206 (100)	21 (100)
If both mum and dad have SCT, what is the chance they will have a baby with SCD?	25	0	5 (2.4)	0 (0.0)
		25	5 (2.4)	0 (0.0)
		50	27 (13.1)	4 (19.0)
		100	89 (43.2)	5 (23.8)
		NS	80 (38.8)	8 (38.1)
		Total	206 (100)	21 (100)
To have a child with SCD, one of the parents must have the disease.	False	False	48 (23.3)	3 (14.3)
		NS	125 (60.7)	18 (85.7)*
		True	33 (16.0)	
		Total	206 (100)	21 (100)

NS = not sure; SC = sickle cell; SCD = sickle cell disease; SCT = sickle cell trait.

*Collectively answered NS or true.

Although genetic counseling focuses on educating patients to allow them to make informed decisions about genetic testing, this may not occur in other settings, such as obstetrics. In this study, the majority of participants were aware of being screened. An important aspect of genetic counseling is making sure that patients have a sufficient level of knowledge so that they can make informed reproductive decisions. Thus, it is important that genetic counselors including obstetricians, midwives, and anyone a pregnant woman may approach for advice are able to gauge patients' understanding of the genetic disorder being discussed. If the individual at risk of having the SCT is unaware of the inheritance pattern, as was found in this study population, it is a cause for concern. Genetic counselors could be instrumental in helping to increase educational efforts in a country where nearly one in three people have the SCT, as well as to collaborate with health care professionals who regularly interact with patients to assist them in increasing patient awareness. Being aware of factors that may influence an individual's knowledge of SCD or the extent of the knowledge can also be beneficial. Screening is only a small part of what genetic counselors cover during a session and more time may need to be spent on discussing specific aspects of SCD for some patients. On the basis of the findings of this study, simply because an individual knows they have SCT does not necessarily mean that they understand the significance or the far-reaching consequences of this diagnosis.

The knowledge from this study shows that information for education on sickle cell should be tailored toward the education level of each individual. This could be achieved by distribution of leaflets with counseling sections and explanation in local language by health-care professionals or social workers.

One limitation of the study may be that patients were not clear on the difference between SCT and SCD and therefore responded "no" when asked if they had SCT thinking that the disease was being referred to. Further supporting this theory is the fact that none of the patients was able to answer correctly whether people with SCT have more joint pain and more infections than people who do not have

SCT. Only 10% of patients self-identified as having SCT, which supports the view that there may have been under-reporting of SCT status in the study. Furthermore, it is not clear if all individuals with SCT truly knew their test results because this study was based on self-report and patients' test results were not used for comparison. It is possible that more patients were given a positive SCT result, but did not remember. It was also unclear whether patients with SCT were informed that their partners needed to be tested as well. Studies have shown that in developing countries, the indirect cost of attending antenatal clinics can be a barrier, particularly for those based in rural areas.²⁰ Our sample may therefore not be truly reflective of the population and only included those patients who had the financial means to attend. The study may have also overestimated the knowledge level of patients.

Carrying out a similar study in other regions, particularly including nonurbanized/remote areas of the country might prove useful and provide a more complete picture of the educational needs. It would also be interesting to perform this type of study in people of African descent in the Diaspora, in the United Kingdom to determine whether their knowledge/awareness is similar. Thus, further studies are recommended to examine patients' knowledge including awareness of the differences between the disease and trait and its genetic basis on a much larger and wider scale. Such data might provide the basis for the development of assessment tools that HCPs could then use. This is particularly so as the nine knowledge questions in this study have not been used in any previous studies.

The knowledge from this study shows that information for education on sickle cell should be tailored toward the education level of each individual. This could be achieved by distribution of leaflets with counseling sections and explanation in local language by health-care professionals or social workers. Moreover, such a tool may be very useful to busy health-care professionals when assessing their knowledge base (a target of further studies) and how much information needs to be presented to the patient.

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