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Sickle Cell Education: A Survey of Antenatal Healthcare Givers

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Abstract. To explore the educational practices of antenatal care providers toward pregnant women with sickle cell disease (SCD) and sickle cell trait (SCT), a survey was conducted among selected doctors and midwives who provide antenatal care at the outpatient clinic of the Obstetric Department of the Korle-Bu Teaching Hospital, Accra, Ghana. The study explored their practices of screening for and patient education about SCD and SCT. Of the 102 respondents, 100(98%) stated that they were knowledgeable in the medical and genetic aspects of the disease. Regarding screening, 82(80.4%) reported mandatory screening for SCD, 9(8.8%) did not offer screening as routine, and 11(10.8%) gave patients the choice. The majority (93.1%) always informed patients when the test was positive but health-care providers less than six years experience were less likely to communicate SCT status to patients without the trait (odds ratio [OR] = 0.41, 95% CI [0.18–0.93]). Nurses/midwives were less likely to tell patients their carrier status (OR = 0.25, 95% CI [0.10–0.59]). There was also variation in referral practices for genetic counseling, with 26.5% always referring, 28.4% never doing so, and 45.1% only referring if the patient had questions. This may affect patients' awareness of this genetic condition. Therefore, continuous medical education on SCD/SCT and standardization of counseling may help inform couples' family planning choices and reduce the burden of the disease on future generation and health care.

INTRODUCTION

Sickle cell disease (SCD) is the most common monogenetic disorder worldwide, affecting an estimated 30 million individuals and representing a major public health concern because of its associated significant morbidity and mortality.[1] Sickle cell disease is caused by a mutation in the hemoglobin (Hb) beta gene found on chromosome 11.[2] This abnormal type of Hb called Hb S causes the cells to become sticky and crescent shaped, when the Hb releases its oxygen. The stiff, sickle-shaped cells can stick to the lining of the blood vessels. This can damage the lining, creating danger signals that attract defensive cells. This response may enhance the stickiness and lead to more slowing of normal blood flow through the vessel. This reduces oxygen delivery to the tissues supplied by this partly blocked vessel.[2] Sickle cell disease is a hereditary blood disorder, characterized by red blood cells that assume an abnormal rigid, sickle shape during hypoxic state, leading to episodes of pain, increased predisposition to infection, and other complications.[3] Patients with SCD require comprehensive care, including prevention of infection by encapsulated bacteria during childhood, pain management, and blood transfusions.[4] Wide disparities exist in treatment and health outcomes for individuals with SCD living in low- and high-income countries. In developed countries, SCD pregnancies have better outcomes because of improvements in active SCD management throughout the pregnancy.[5–8] However, even though sub-Saharan countries such as Ghana and Nigeria have a high prevalence of SCD and maternal mortality rates exceeding 9%, such improvements are yet to be observed.[9] Sickle cell disease has recently been recognized as a problem of major public health significance by the WHO. Despite the fact that > 70% of sufferers live in Africa, expenditure on the related care and research in the continent is negligible, and most advances in the understanding and management of this condition have been based on research conducted in the north.[10] The higher mortality rate among women with SCD in countries such as Ghana may be caused by inadequate health-care support, particularly for pregnant women.[11]

The prevalence of the sickle cell gene in sub-Saharan Africa is 10–40%.[12] Carrier prevalence is about 25% and it affects about 2–3% of the Nigerian population, whereas in Ghana about 2% of all newborns are estimated to have SCD.[13,14] The disease runs a chronic course, characterized by recurrent ill health, progressive organ damage, and shortened life span.[13]

A recent study on the awareness of SCD and sickle cell trait (SCT) status among women attending antenatal clinic at the Korle-Bu Teaching Hospital (KBTH), the largest referral center in Ghana, showed a huge deficit in their knowledge about the condition.[15] This was an interesting finding because it is the hospital's management policy to have Hb electrophoresis in addition to other blood, urine, and stool tests for all first-visit patients with SCD background. Previous studies have also demonstrated a knowledge gap among different health-care providers (HCPs) such as primary care physicians and hospitalists.[16] Sickle cell disease is the most common genetic disorder in the United States, with higher frequency in African Americans when compared with other populations[17]; physicians whose practice comprised larger proportions of African Americans might be more attuned to issues such as SCD. Physicians who have active patients with SCD may be more familiar and more comfortable with SCD patients and the disease. Because of the significant impact on morbidity and mortality and health-care costs associated with inappropriate management of SCD,[18] a better understanding of care giver's perception of sickle cell and its management will help drive interventions to improve care for individuals with SCD. The success of SCD prevention through heterozygote detection and premarital screening is influenced by the knowledge and attitudes of HCP and community members about SCD and its treatment.[19–21] Pregnancies in the at-risk population may occur with little forethought or opportunity for well-informed reproductive health decisions and may be based on insufficient

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or erroneous knowledge about genetic inheritance.[19–21] Knowing the results of sickle cell screening can impact decisions about prenatal testing and future family planning for patients. However, this relies on HCPs providing accurate patient information regarding inheritance, features and management of SCD, and possible testing options available.[20] For individuals whose children are at risk of inheriting a serious genetic condition such as SCD, the reproductive health decisions relate to the disease burden. Therefore, it is important and an individual's right to make informed decisions. However, acting on these rights requires reproductive health knowledge specific to SCD and SCT.[21]

MATERIALS AND METHODS

We performed a descriptive cross-sectional survey of antenatal HCPs at the antenatal clinic of the KBTH, the main tertiary hospital in Accra, the capital city of Ghana, West Africa. The Obstetric Department has a staff strength of 18 consultants, 60 residents (40 of them working in the department and the rest on rotation in other departments), 30 house officers, 166 midwives, 97 nurses, and 119 auxiliary staff. Thus, 490 HCPs are involved in the management of SCD/SCT. However, only 18 consultants, 40 residents working within the department, 30 house officers, 166 midwives, and 97 nurses are directly involved in clinical care of the patients, giving a total of 351. This was conducted as a parallel study at the same site as the survey on the awareness of patients on SCD/SCT.[15]

A convenience sampling method was used at a departmental meeting, where the clinical members of staff (doctors, nurses, and midwives) present were invited by the investigators to voluntarily participate in a short, self-administered questionnaire about the screening procedure used to identify SCD or as a carrier of the SCT. Questions assessing the provider's knowledge and level of comfort in discussing SCT and SCD with clients were also included. One hundred twenty questionnaires were distributed to those who were present at the meeting and showed interest to participate, following the introduction of the study. Some were also given to clinical staff who were not present but were on the lying-in, postnatal, and recovery wards as well as at the outpatient departments. The respondents were asked to fill the questionnaires and hand them in as soon as they could. Some filled the questionnaire and handed them on the same day. Others were busy and therefore took the questionnaires home, so a 2-week deadline was a limit, beyond which more questionnaires were not going to be admitted from respondents.

Questionnaires were pretested with 10 volunteers and corrections were appropriately made before carrying out the actual interviews. This HCP response was to reflect the client response regarding screening, as previously reported.[15]

Sample size determination. Using the sample size calculation formula for cross-sectional studies, sample size = $Z1 - \alpha/2\ 2P(1 - P)$; $z = 1.96$ at 95% CI; $P = 0.204$ from the study by Animasahun et al.,[22] which showed 24.3% of care givers being comfortable with management of SCD, and precision $P = 10\%$. Substituting the aforementioned into the formula gives a sample size of 71. Adjusting for a 25% error margin of inability to retrieve questionnaires and incomplete data brings the minimum sample size to approximately 90.

Descriptive statistics were used to summarize the responses. Chi square tests were used to generate the odds ratios. $P < 0.05$ at 95% CI was considered statistically significant.

Approvals from the Ethical and Protocol Review Committee of the School of Medicine and Dentistry, College of Health Sciences, University of Ghana, Accra, and from Cardiff School of Pharmacy and Pharmaceutical Sciences Research Ethics Committee, were granted before the study was initiated (MS-Et/M.4-P4.6/2014-2015, SA837658, respectively). A written informed consent was obtained and signed by participants before the questionnaires were answered.

RESULTS

One hundred two questionnaires were returned within the 2 weeks deadline of the 120, giving a response rate of 85% (Table 1). Respondents included 54 nurses/midwives and 48

TABLE 1
Role of health-care providers and practices regarding sickle cell screening

Question		*N*	%
What is your role?	Consultant	13	12.7
	House officer	11	10.8
	Nurse-midwife	54	52.9
	Resident	24	23.5
How long have you been practicing?	≤ 1 year	17	16.7
	1–5 years	28	27.5
	6–10 years	35	34.3
	More than 10 years	22	21.6
Do you test every pregnant woman for sickle cell trait if they have an unknown carrier status?	No	9	8.8
	Yes	93	91.2
Do you give your patients the option to test (are they given a choice)?	No, it is mandatory	82	80.4
	Yes	20	19.6
If a patient is found to be a carrier for sickle cell trait, do they receive their result?	No	1	1.0
	Yes, always	95	93.1
	Yes, time permitting	6	5.9
If they are told their result, how are they told?	At next appointment	101	100
Do you tell the patient their carrier status, or does someone else?	Depends	34	33.3
	I always do	65	63.7
	Someone else	3	2.9
If a patient is not a carrier (i.e., AA), do they receive their result?	Not unless they ask	5	4.9
	Yes	91	89.2
	Yes, time permitting	6	5.9
If they are told their result, how are they told?	At next appointment	102	100
Do you tell the patient if they are not a carrier (i.e., AA)?	Depends	3	2.9
	I always do	64	62.7
	Most of the time	22	21.6
	Sometimes	13	12.7
How knowledgeable do you feel with discussing the genetic aspects of sickle cell anemia with your patients?	Knowledgeable	60	58.8
	Not very knowledgeable	4	3.9
	Very knowledgeable	38	37.3
How knowledgeable do you feel with discussing the medical aspects of sickle cell anemia with your patients?	Knowledgeable	58	56.9
	Not very knowledgeable	3	2.9
	Very knowledgeable	41	40.2
Do you refer patients for genetic counseling to discuss sickle cell disease and/or trait?	Always	27	26.5
	Never	29	28.4
	Sometimes (e.g., if a patient has questions)	46	45.1

TABLE 2
Experiences of health-care providers and practices regarding sickle cell screening

Variable	Up to 5 years of experience: Yes: *N* = 45	Up to 5 years of experience: No: *N* = 57	OR (95% CI)	*P*-value
Patients given option to do sickling test			0.47 (0.17–1.35)	0.211
Yes	6 (13.3)	14 (24.6)		
No	39 (86.7)	43 (75.4)		
Patients told their carrier status			0.89 (0.40–2.01)	0.837
Always	28 (62.2)	37 (64.9)		
Others	17 (37.8)	20 (35.1)		
Receipt of results by patients who do not have SCT			1.19 (0.19–7.47)	1.000
Yes	43 (95.6)	54 (94.7)		
No	2 (4.4)	3 (5.3)		
Communication of genotype status to patients without SCT			0.41 (0.18–0.93)	0.040
Always	23 (51.1)	41 (71.9)		
Others	22 (48.9)	16 (28.1)		

N = number; OR = odds ratio; SCT = sickle cell trait.

TABLE 3
Rank of health care providers and practices relating to sickle cell screening

	Patients given option to do sickling test: Yes: *N* = 20	Patients given option to do sickling test: No: *N* = 82	OR (95% CI)	*P*-value
Role				
Consultant	3 (15)	11 (13.4)	1.14 (0.29–4.54)	1.000
Resident/HO	8 (40.0)	27 (32.9)	1.36 (0.50–3.71)	0.604
Nurse/midwife	9 (45.0)	44 (53.7)	0.71 (0.26–1.89)	0.619
	Patients told their carrier status			
Variable	Yes: *N* = 65	No: *N* = 37		
Role				
Consultant	12 (18.5)	2 (5.4)	3.96 (0.84–18.79)	0.078
Resident/HO	27 (41.5)	8 (21.6)	2.58 (1.02–6.50)	0.052
Nurse/midwife	26 (40.0)	27 (73.0)	0.25 (0.10–0.59)	0.002
	Receipt of results by patients who do not have SCT (i.e., AA)			
	Yes: *N* = 97	No: *N* = 5		
Role				
Consultant	14 (14.4)	0 (0.0)	–	1.000
Resident/HO	33 (34.0)	2 (40.0)	0.77 (0.12–4.86)	1.000
Nurse/midwife	50 (51.5)	3 (60.0)	0.71 (0.11–4.43)	1.000
	Communication of genotype status to patients who do not have the SCT (i.e., AA)			
	Yes: *N* = 64	No: *N* = 38		
Role				
Consultant	11 (17.2)	3 (7.9)	2.42 (0.63–9.30)	0.242
Resident/HO	19 (29.7)	16 (42.1)	0.58 (0.25–1.34)	0.281
Nurse/midwife	34 (53.1)	19 (50.0)	1.13 (0.51–2.53)	0.839

N = number; OR = odds ratio; SCT = sickle cell trait.

doctors. When asked if every pregnant woman was tested for SCT, most HCPs, 82(80.4%) stated that SCT screening was mandatory, only 9(8.8%) participants responded "no" (five nurse-midwives, two residents, one house officer, and one consultant), with the rest saying that they gave patients a choice. Forty-four percent (45/102) of the respondents had been in practice for up to 5 years (Table 1) and these were less likely to communicate negative genotype results with clients as compared with their seniors (51% versus 72%, $P = 0.04$, respectively) (Table 2). The majority, 95(93.1%), said they always informed patients who were found to be positive for the trait, and patients were informed at their next appointment by almost all participant (101/102 99.0%) HCPs.

When HCPs were asked whether patients who are found not to be carriers of SCT receive their test result, most, 91(89.2%), responded "yes," 5(4.9%) responded "not unless they ask," and 6(5.9%) HCPs responded that only if time permitted. When participants were asked how comfortable they were in discussing the genetic aspects of SCD with patients, 98(96.1%) reported feeling either very knowledgeable or knowledgeable. With regard to the discussions on the medical aspects of SCD with patients, 99(97.1%) reported feeling either very knowledgeable or knowledgeable. There were four respondents who were not very knowledgeable in discussing genetic aspect (two nurses who had worked between 1 and 5 years, a nurse who had worked up to 10 years, and a house officer who had worked for less than a year). In addition, two nurses who had worked between 1 and 5 years and a nurse who had worked for 6–10 years were not very knowledgeable in discussing the medical aspects of sickle cell anemia with patients. Doctors were more likely to communicate carrier status to clients than nurses and midwives (39 yes to 10 no as compared with 26 yes to 27 no, respectively, Table 3).

Finally, when participants were asked if they referred patients for genetic counseling to discuss SCD and/or trait, we found a wide variation in how HCPs handled referrals for genetic counseling, with 27(26.5%) always referring, 29(28.4%) never doing so, and 46(45.1%) only referring if the patient had questions.

DISCUSSION

Test results form an integral part of evidence-based management of patients, and in most cases, patients are informed about these results. However, in some settings, and to a large extent in our setting, patients leave their disease/carrier status to the discretion of the HCP and, therefore, it is reflected in the poor awareness of their situation as previously published.[15] In the present study, 93/102(91.2%) of HCPs stated they always tested their patients for SCT if they had an unknown trait status. This is lower than work carried out by Azonobi et al.[23] among obstetric-gynecologists in the United States, where 97.4% reported regularly screening people of African descent for SCD or SCT. On the other hand, the result agrees with work carried out by Knight-Madden and others in 2013 among women in their reproductive age in Jamaica.[24] It emerged that attendance at antenatal clinics, where SCT screening is routine, is not associated with increased self-report of SCT and that this was due to poor communication.

Nearly one in 10 HCPs do not test every pregnant woman for SCT if they have an unknown carrier status, which is contrary to the hospital's policy. This might reflect on the fact that not all pregnant women are financially able to pay for laboratory test so some providers may become selective on what test to request for aiding diagnosis of presenting illness. In 2005, Animasahun et al.[22] reported findings from a cross-sectional

survey of health workers at a teaching hospital in Nigeria. Although 91.3% had heard about SCD prenatal screening, only 75.3% knew that SCD could be prevented by prenatal screening. A total of 48.2% of these health workers were not aware that prenatal screening was available in Nigeria, and 42.1% would not allow preventive termination of pregnancy for positive screening results. Four-fifths (82%) of the HCPs who were interviewed knew that screening for SCT was mandatory. This concurs with the hospital's policy of screening all pregnant women. Regular updates by the unit should be encouraged by organizing educational meetings quarterly to refresh the minds of the providers about mandatory screening for SCD/SCT. At the maternity unit of the KBTH, doctors are mandated to request screening, explain results, and provide genetic counseling often, as there are very few professional genetic counselors available. Midwives can explain results to patients and they also need an understanding of the genetic basis of sickle cell because they are the main educators at the pregnancy school in the department.

Health-care providers' overall comfort level with the genetic and medical aspects of SCT was much higher than anticipated. However, there was a wide variation in how they handled referrals for genetic counseling, with 26.5% always referring, 28.4% never doing so, and 45.1% only referring if the patient had questions. This may be because of scarcity of specialists in genetic counseling service. Therefore, it may be better that existing clinical staff be trained on SCD in addition to supplying information pamphlets to HCPs for their patients regarding SCD/SCT and the repercussions of being a carrier. This is a form of task shifting to compensate for the scarcity of genetic counselors.

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, it is a cause for concern. In a country where one in three people have the trait, genetic counselors could be instrumental in helping to increase educational efforts as well as collaborate with HCPs who regularly interact with patients to assist them in increasing patient awareness. Being aware of factors that may influence what an individual knows about 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. For example, based on the findings of our previous study, simply because individuals know they have SCT does not necessarily mean that they understand the significance or the far-reaching consequences of their condition.[15] Despite the fact that the majority of HCPs (greater than 95%) reported that they felt very knowledgeable or knowledgeable in discussing the genetic and medical aspects of the disease with their clients, our previous study with patients visiting the same department did not reflect the impact. It may be that the HCPs of these women lacked the guideline for discussing SCD in depth with patients.

Four and three respondents reported not being very knowledgeable in discussing the genetic and medical aspects of the disease, respectively, with their clients. It is recommended, therefore, that continuous medical education include the genetic and medical aspects of sickle cell anemia to enable healthcare personnel to give optimum care to patients with SCD/SCT. It is not clear why 29 participants do not refer patients for genetic counseling, and authors can only speculate that it may be as a result of the scarcity of genetic counselors.

Health-care providers were experienced, with at least half having practiced for at least 5 years. Twenty-two (21.6%) had more than 10 years' experience. Doctors and nurses/midwives who had up to 5 years practice were 53% less likely to give patients the option of deciding whether they wanted to do sickling test or not. This finding, although not statistically significant, has some clinical implications. Given the relatively high prevalence of sickling genotype in the Ghanaian population and the fact that sickling test is one of the required tests to be performed by all pregnant women in Ghana, there is the need for education on the fact that the test is mandatory, especially among nurses and doctors who have practiced for up to 5 years. Health-care providers who had up to 5 years of practice were also less likely to tell patients if they had negative results or they only had the SCT on receipt of the patients' laboratory results, but were more likely to respond in the affirmative that patients always receive their results even if they do not have the SCT as compared with HCPs with more than 5 years of experience. Therefore, there is a need for periodic auditing of the health professionals' practices to ensure they are behaving according to the policies, which includes encouraging and supporting patients' acceptance of SCD testing.

There was no statistically significant difference when the role of care givers as consultant obstetricians, residents in obstetrics and gynecology, or house officers as well as nurses was compared in terms of giving patients the option to check for their sickle cell genotype, communication of patients' sickle cell genotype laboratory results when they are normal, as well as patients receiving their results when they do not have SCT. However, the nurses were 75% less likely to tell patients if they have a carrier status compared with doctors. This was significant and may be attributed to the fact that the carrier status may not have a direct bearing on the course of the pregnancy so the nurses/midwives expect the doctors to communicate these findings to the patients for future management. There is, however, the need for this practice to be reversed, as the carrier status has a direct bearing on the genotype of the fetus and that of subsequent unborn children.

The strength of our study is the involvement of a wide distribution to HCPs who were present at the meeting and the few found immediately after. This prevented a possible bias finding that could have happened if the investigators had selected just one group of HCPs. Participation was voluntarily, so analysis was carried out on responses submitted by those who took the time to read and sign the consent agreement. The limitation, on the other hand, is giving the questionnaire away for 2 weeks. This may have facilitated discussion with other colleagues and might not have been individuals' opinion. The 2 weeks also caused a 15% lost to follow-up. However, these limitations were not significant to affect our study conclusion.

In conclusion, antenatal HCPs were not adequately prepared in communicating medical and genetic aspects of SCD/SCT to their clients despite reporting that they are knowledgeable in this field. This may have a negative impact

on education of antenatal attendants on SCD/SCT and may be due to the lack of standard guidelines. Continuous medical education on SCD/SCT and proper communication methods to patients is needed in reversing this observation. It would therefore be helpful to examine patients' knowledge of SCD/trait, including awareness of the differences between the disease and trait and its genetic basis on a much larger scale in future studies. Such data might provide the basis for the development of assessment tools and patient education information sheet that HCPs could use for standardization of counseling.

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