International Journal of Gynecology and Obstetrics 115 (2011) 264–268

Contents lists available at SciVerse ScienceDirect

International Journal of Gynecology and Obstetrics

journal homepage: www.elsevier.com/locate/ijgo

CLINICAL ARTICLE

Attitudes of Ghanaian women toward genetic testing for sickle cell trait

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ARTICLE INFO

Article history:
Received 25 March 2011
Received in revised form 1 August 2011
Accepted 15 September 2011

Keywords:
Genetic testing
Ghana
Sickle cell trait

ABSTRACT

Objective: To explore the attitudes of Ghanaian women toward genetic testing for the sickle cell trait and to investigate key factors that promote or impede the decision to pursue knowledge of the carrier status. *Methods:* A survey, administered in person to Ghanaian women, collected demographic information and information on the participants' knowledge about their carrier status, their attitudes toward genetic testing, and their perceptions of the implications of being a carrier. The results for women who had previously undergone testing and those who had not were compared. *Results:* Of 124 participants, 75 had been tested for the sickle cell trait and 49 had not. Some 53% of the women who had been tested did not know their carrier status. Most women agreed that getting a prenatal genetic test was important. However, nontested women were more likely to lack the financial resources to undergo testing, to think that testing is futile because sickle cell disease is not curable, and to believe that the outcome of their child's health is determined by God. *Conclusion:* The women tended to have favorable attitudes toward genetic testing, but numerous barriers remained that precluded knowledge of their carrier status or the pursuit of this knowledge.

1. Introduction

In most African countries, sickle cell disease has yet to be recognized as a major public health concern, mainly because its impact on mortality is relatively low compared with that of infectious diseases such as HIV/AIDS, malaria, and tuberculosis [1-3]. Recent data show an increase in morbidity and mortality related to sickle cell disease, with the highest prevalence in Ghana and Nigeria, where nearly 25% of the population are carriers for the sickle cell trait and 2% of children are born with sickle cell disease [4,5]. Furthermore, West Africans have the highest prevalence of the sickle cell trait (1 in 4) compared with other ethnic groups of African origin (e.g. East, North, and South Africans and African-Caribbeans) [4,5].

Sickle cell disease is inherited as an autosomal recessive trait. However, unlike people with the disease, those with the sickle cell trait are generally asymptomatic and can only be identified as carriers through laboratory testing, or their carrier status becomes obvious when they have a child with the disease [6]. Thus, autosomal disorders are of particular interest in reproductive planning because many couples may be unaware that they are at risk for having a child with the disorder.

In its proper context, genetic testing is an unbiased method for providing pertinent information that may be used to prepare individuals to manage a genetic disorder and/or to make informed choices based on relevant knowledge, consistent with the decision-maker's values [7]. Given the paucity of research exploring African women's attitudes toward genetic testing for sickle cell disease and given that voluntary newborn screening for sickle cell disease is due to be introduced in Ghana on a national level, it is important and beneficial to the medical community to understand better the attitudes toward the testing of individuals of childbearing age because these attitudes may strongly influence future reproductive decisions [8].

Despite the far-reaching implications of the national sickle cell newborn-screening program, a large population of trait carriers will remain unidentified—many of whom are of, or nearing, childbearing age. Furthermore, although many believe that genetic tests have the potential to minimize the incidence of disease, the ultimate benefit of predictive genetic testing is determined, in large part, by the willingness of individuals to undergo testing. Thus, the aim of the present study was to explore the attitudes of Ghanaian women toward genetic testing for sickle cell trait and the key factors that may promote or impede decisions to pursue knowledge of carrier status.

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0020-7292/$ – see front matter
doi:10.1016/j.ijgo.2011.08.004

2. Materials and methods

The present prospective, cross-sectional study was conducted at the Korle Bu Teaching Hospital Sickle Cell Clinic at the University of Ghana in Accra, various regional health clinics within the districts of Atwima Nwabiagya, Afigya Kwabre, and Sekyere East, and in Community-Based Health Planning and Services (CHPS) compounds in Amansie West, Ahafo Ano South, and Tolon-Kumbungu—all in Ghana. The study sites included rural and metropolitan centers because health service use among women in rural areas tends to be different from that in metropolitan areas, where income and access to education and healthcare facilities are greater [9,10]. The study cohort included Ghanaian women over the age of 18 years who were carriers or non-carriers of sickle cell trait; the women were recruited from these locations during June 2009 through February 2010.

Women over 18 years of age who were Ghanaian residents were asked if they were willing to participate in a research study about genetic testing. Research staff explained that the study involved an anonymous survey of approximately 20 minutes in length and answered any questions. Prior knowledge of their sickle cell status had no influence on a woman's eligibility for participation.

To enable the investigation of attitudes and influential factors concerning genetic testing, the survey collected information about the participants' knowledge of sickle cell disease, about their cultural views and personal beliefs, and about sociocultural factors. At the regional health clinics and CHPS compound locations, the survey was administered by 2 of the authors (L.E. and D.U.); at Korle Bu Teaching Hospital, clinic staff conducted the survey. The survey was administered in English and, if possible, in the participant's native language with the aid of a translator.

The data were analyzed using SPSS version 18.0 (SPSS, Chicago, IL, USA). Descriptive data were presented as number (percentage). The Pearson χ^2 test and the Fisher exact test were used to compare the percentages between women who had previously undergone genetic testing and those who had not. $P<0.05$ was considered statistically significant.

The study was approved by the Institutional Review Board of the University of Michigan Medical School, Ann Arbor, MI, USA; the Committee for Human Research, Publications and Ethics of the Kwame Nkrumah University of Science and Technology, Komfo Anokye Teaching Hospital, Kumasi, Ghana; and the Institutional Review Board of the Noguchi Memorial Institute for Medical Research, University of Ghana, Legon, Ghana.

3. Results

In total, 127 women (age range 16–67 years, mean age 32.7 years) were recruited into the present study. Of these, 30 (23.6%) reported being a primary caregiver of a child with sickle cell disease and 99 (76.2%) believed sickle cell disease was one of the worst diseases possible. In total, 124 women answered the question of whether they had ever been tested for the sickle cell trait. Based on their responses, the participants were divided into 2 groups, with the tested group comprising 75 (60.5%) women and the nontested group comprising 49 (39.5%) women. The characteristics of the 2 groups are described in Table 1.

A significantly greater proportion of women who had been tested disagreed with the statement "I did not have the money to get tested", compared with those who had not been tested (76.7% versus 27.1%, $P<0.001$; Table 2). Women in the tested group were also more likely to reject the notion that they did not want to get tested because the disease is incurable (87.7% versus 61.2%, $P=0.005$). No significant differences were detected between the 2 groups in terms of awareness of the availability of genetic testing, fear of testing because of a fear of needles, and the time point in relation to pregnancy at which participants desired to be tested. Also, nearly all (90.3%) participants believed pregnant women should undergo testing.

Table 1
Characteristics of the participants [a].

Parameter	Total sample (n = 124)	Tested group (n = 75)	Nontested group (n = 49)	*P* value [b]
Age, y				
0–19	1 (0.9)	0	1 (2.3)	0.373
20–40	99 (84.6)	63 (86.3)	36 (81.8)	
≥41	17 (14.5)	10 (13.7)	7 (15.9)	
Relationship status				
Married	101 (82.1)	60 (80.0)	41 (85.4)	0.481
Living with partner	7 (5.7)	6 (8.0)	1 (2.1)	
Widowed	2 (1.6)	1 (1.3)	1 (2.1)	
Single, divorced	2 (1.6)	2 (2.7)	0 (0.0)	
Single, never married	11 (8.9)	6 (8.0)	5 (10.4)	
Education				
No school	15 (12.2)	3 (4.1)	12 (24.5)	<0.001
Completed primary or middle school	56 (45.5)	31 (41.9)	25 (51.0)	
Completed high school or college	52 (42.3)	40 (54.1)	12 (24.5)	
Occupation				
Work at home	36 (29.5)	15 (20.5)	21 (42.9)	0.024
Market place trader	26 (21.3)	16 (21.9)	10 (20.4)	
Work in an office	40 (32.8)	31 (42.5)	9 (18.4)	
Do not work	19 (15.6)	10 (13.7)	9 (18.4)	
Other occupation	1 (0.8)	1 (1.4)	0 (0.0)	
Religion				
Christianity	100 (80.6)	66 (88.0)	34 (69.4)	0.035
Islam	22 (17.7)	8 (10.7)	14 (28.6)	
No religion	2 (1.6)	1 (1.3)	1 (2.0)	
Ethnicity				
Akan	20 (16.8)	12 (16.9)	8 (16.7)	<0.001
Ashanti	43 (36.1)	20 (28.2)	23 (47.9)	
Fanti	7 (5.9)	6 (8.5)	1 (2.1)	
Ewe	12 (10.1)	11 (15.5)	1 (2.1)	
Ga-Adangbe	16 (13.4)	14 (19.7)	2 (4.2)	
Mole-Dagbani	14 (11.8)	2 (2.8)	12 (25.0)	
Guan	4 (3.4)	3 (4.2)	1 (3.4)	
Hausa	3 (3)	3 (4.2)	0 (0.0)	
Currently pregnant				
Yes	37 (29.8)	30 (40.0)	7 (14.3)	0.002 [c]
No	87 (70.2)	45 (60.0)	42 (85.7)	
Recruitment location				
Rural health clinic	62	20 (26.7)	42 (85.7)	<0.001 [c]
KBTH Sickle Cell Clinic	62	55 (73.3)	7 (14.3)	
Knowledge of sickle cell trait status				
Yes	35 (28.9)	34 (47.2)	1 (2.0)	<0.001
No	86 (71.1)	38 (52.8)	48 (98.0)	

Abbreviations: KBTH, Korle Bu Teaching Hospital.
[a] Values are given as number (percentage). Numbers may not add up to the total number of participants because some survey questions were unanswered.
[b] Pearson χ^2 test unless otherwise indicated.
[c] Fisher exact test.

Significantly more women in the nontested group (70.8% versus 28.4%, $P<0.001$) stated that they would feel less healthy if they knew that they carried the sickle cell gene (Table 3). Women who had not been tested also tended to be more concerned that they might feel singled out if they tested positive, although this difference was not statistically significant (40% versus 7%, $P=0.065$). The proportion of those agreeing with the notion that knowledge of their sickle cell status would help them to make important life decisions was significantly higher in the tested group than in the nontested group (88.6% versus 69.4%, $P=0.005$). The tested group also comprised a greater proportion of women who agreed that knowledge of the sickle cell status is valuable (90.7% versus 79.6%, $P=0.109$).

With regard to knowledge about transmission of the genetic trait (Table 3), women who had not been tested were significantly more likely to believe that it was in God's hands whether their child had sickle cell disease (69.4% versus 36.0%, $P=0.001$), and more likely to say that they would leave it to God to decide what will happen to their child (64.6% versus 33.8%, $P=0.004$).

Table 2
Attitudes toward genetic testing for the sickle cell trait [a].

Survey item	Total sample (n = 124)	Tested group (n = 75)	Nontested group (n = 49)	*P* value [b]
I did not know I could get tested				0.218
Agree	45 (36.3)	23 (30.7)	22 (44.9)	
Neutral	9 (7.3)	5 (6.7)	4 (8.2)	
Disagree	70 (56.5)	47 (62.7)	23 (46.9)	
I did not have the money to get tested				<0.001
Agree	50 (41.3)	17 (23.3)	33 (68.8)	
Neutral	2 (1.7)	0 (0.0)	2 (4.2)	
Disagree	69 (57.0)	56 (76.7)	13 (27.1)	
I did not want to get tested because sickle cell can't be cured anyway				0.005
Agree	24 (22.6)	7 (12.3)	17 (34.7)	
Neutral	2 (1.9)	0 (0.0)	2 (4.1)	
Disagree	80 (75.5)	50 (87.7)	30 (61.2)	
I was afraid to get tested (afraid of needles)				0.385
Agree	23 (18.5)	11 (14.7)	12 (24.5)	
Neutral	3 (2.4)	2 (2.7)	1 (2.0)	
Disagree	98 (79.)	62 (82.7)	36 (73.5)	
I wanted to be tested at some point, but not while I was pregnant				0.219
Agree	73 (60.8)	46 (64.8)	27 (55.1)	
Neutral	2 (1.7)	2 (2.8)	0 (0.0)	
Disagree	45 (37.5)	23 (32.4)	22 (44.9)	
I wanted to be tested immediately when I found out I was pregnant				0.078
Agree	59 (49.6)	30 (42.3)	29 (60.4)	
Neutral	3 (2.5)	3 (4.2)	0 (0.0)	
Disagree	57 (47.9)	38 (53.5)	19 (39.6)	
I think pregnant women should get a prenatal genetic test				0.931
Agree	112 (90.3)	68 (90.7)	44 (89.8)	
Neutral	3 (2.4)	2 (2.7)	1 (2.0)	
Disagree	9 (7.3)	5 (6.7)	4 (8.2)	

[a] Values are given as number (percentage). Numbers may not add up to the total number of participants because some survey questions were unanswered.
[b] Pearson χ^2 test.

Table 3
Perceived implications of genetic testing [a].

Survey item	Total sample (n = 124)	Tested group (n = 75)	Nontested group (n = 49)	*P* value [b]
Knowing that I carry the sickle cell gene would cause me to feel less healthy than other people				
Agree	55 (45.1)	21 (28.4)	34 (70.8)	<0.001
Neutral	7 (5.7)	5 (6.8)	2 (4.2)	
Disagree	60 (49.2)	48 (64.9)	12 (25.0)	
If anyone found out that I carried the sickle cell gene it would keep me from getting married				
Agree	58 (50.4)	31 (46.3)	27 (56.3)	0.313
Neutral	5 (4.3)	2 (3.0)	3 (6.3)	
Disagree	52 (45.2)	34 (50.7)	18 (37.5)	
When I found out that I carried the sickle cell gene, it made me feel singled out				
Agree	5 (10.4)	3 (7.0)	2 (40.0)	0.065
Neutral	4 (8.3)	4 (9.3)	0 (0.0)	
Disagree	39 (60.0)	36 (83.7)	3 (60.0)	
Knowing that I carry the sickle cell gene has helped me make important life decisions				
Agree	96 (80.7)	62 (88.6)	34 (69.4)	0.016
Neutral	3 (2.5)	2 (2.9)	1 (2.0)	
Disagree	20 (16.8)	6 (8.6)	14 (28.6)	
Knowing whether I have the sickle cell gene is valuable information				
Agree	107 (86.3)	68 (90.7)	39 (79.6)	0.109 [c]
Neutral	0 (0.0)	0 (0.0)	0 (0.0)	
Disagree	17 (13.7)	7 (9.3)	10 (20.4)	
It is in God's hands if my child has sickle cell disease				
Agree	61 (49.2)	27 (36.0)	34 (69.4)	0.001
Neutral	4 (3.2)	4 (5.3)	0 (0.0)	
Disagree	59 (47.6)	44 (58.7)	15 (30.6)	
I will leave it to God to decide what will happen to my child				
Agree	56 (45.9)	25 (33.8)	31 (64.6)	0.004
Neutral	5 (4.1)	4 (5.4)	1 (2.1)	
Disagree	61 (50.0)	45 (60.8)	16 (33.3)	
It is important to my family that I have children				
Agree	116 (94.3)	69 (93.2)	47 (95.9)	0.702 [c]
Neutral	0 (0.0)	0 (0.0)	0 (0.0)	
Disagree	7 (5.7)	5 (6.8)	2 (4.1)	
I would be incomplete as a woman if I did not have a child				
Agree	88 (72.7)	53 (73.6)	35 (71.4)	0.837 [c]
Neutral	0 (0.0)	0 (0.0)	0 (0.0)	
Disagree	33 (27.3)	19 (26.4)	14 (28.6)	
Getting tested would not make a difference to me having my baby				
Agree	76 (61.8)	47 (63.5)	29 (59.2)	0.845
Neutral	8 (6.5)	5 (6.8)	3 (6.1)	
Disagree	39 (31.7)	22 (29.7)	17 (34.7)	

[a] Values are given as number (percentage). Numbers may not add up to the total number of participants because some survey questions were unanswered.
[b] Pearson χ^2 test unless otherwise indicated.
[c] Fisher exact test.

Finally, the majority (94.3%) of women overall confirmed that it was important to their families that they have children (Table 3), and more than half (61.8%) said that getting tested would not make any difference as to whether they would have their child.

Table 4 illustrates that, although participants did not have an accurate understanding of the disease etiology (only 18.3% answered the first question correctly and 6.5% answered the second question correctly), more participants understood the etiology when only 1 parent is a carrier than when both parents are carriers of sickle cell trait. However, participants did have a moderate understanding of how being a carrier affects a person.

4. Discussion

The present study highlights the complexities of deciding whether to undergo genetic testing and acknowledges that these decisions can be influenced both by personal factors (values and belief systems) and by factors originating from larger social-structural forces (social hierarchies of wealth and power). The findings of the present study indicate that women in Ghana may recognize the benefits of genetic testing, but that structural barriers may preclude them from acting in accordance with their beliefs. As with previous studies, various sociodemographic characteristics were associated with the decision to undergo testing for the sickle cell trait [11,12]. More specifically, the present study identified low financial resources and a low level of education as potential barriers to genetic testing.

Geller and Holtzman [13] suggested that "those at the lower end of the socioeconomic spectrum, for whom genetic testing may be a low priority, are thought to be those least able to afford the consequences of not knowing about genetic diseases in their families". A lower level of education generally indicates a lack of awareness that testing is available, but in the present study, those with a lower level of education were not only less likely to undergo testing; they were also less likely to have an accurate knowledge of the implications of being a carrier of the sickle cell trait.

One of the key findings of the present study is that women recruited from the sickle cell clinic were more likely to have undergone testing than people recruited from a rural health clinic. This finding may reflect the expertise of providers who specialize in this area and who, by training and exposure, are more knowledgeable about the clinical sequelae of sickle cell disease and the availability and locations for testing, and who are generally more confident in providing quality genetic counseling. Additionally, the present results indicate that although a large portion of participants reported having been tested, only 47% of those women knew whether they actually carried the sickle cell trait. This strongly suggests a lack of understanding of the test results—an area that is apparently in much need of improvement. Gordon and colleagues [14] suggest that the way in which genetic risk is communicated by healthcare providers and interpreted by those at risk too often results in a less than ideal understanding of the information provided, and that decreased retention of the information over time limits the ability to make an informed decision. With illnesses such as sickle cell disease, the ability of healthcare

Table 4
Knowledge about the reproductive and clinical implications of being a carrier of the sickle cell trait [a].

Survey item	Total sample (n = 124)	Tested group (n = 75)	Nontested group (n = 49)
If only 1 parent is a carrier of the sickle cell trait and the other is not, what are the chances that the child will have sickle cell disease			
All children will have sickle cell disease	8 (6.7)	5 (6.9)	3 (6.3)
None of the children will have sickle cell disease	22 (18.3)	15 (20.8)	7 (14.6)
One in 2 (50%) children will have sickle cell disease	26 (21.7)	15 (20.8)	11 (22.9)
One in 4 (25%) children will have sickle cell disease	24 (20.0)	17 (23.6)	7 (14.6)
One in 10 (10%) children will have sickle cell disease	6 (5.0)	4 (5.6)	2 (4.2)
Don't know	34 (28.3)	16 (22.2)	18 (37.5)
If both parents are carriers of the sickle cell trait, what are the chances that the child will have sickle cell disease			
All children will have sickle cell disease	38 (38.9)	20 (27.0)	18 (36.7)
None of the children will have sickle cell disease	1 (0.8)	1 (1.4)	0
One in 2 (50%) children will have sickle cell disease	41 (33.3)	33 (44.6)	8 (16.3)
One in 4 (25%) children will have sickle cell disease	8 (6.5)	6 (8.1)	2 (4.1)
One in 10 (10%) children will have sickle cell disease	4 (3.3)	1 (1.4)	3 (6.1)
Don't know	31 (25.2)	13 (17.6)	18 (36.7)
How does the sickle cell trait usually affect a person?			
They usually go on to develop sickle cell disease	11 (9.3)	8 (11.4)	3 (6.3)
They sometimes have no symptoms and many do not know that they are carriers	34 (28.8)	26 (37.1)	8 (16.7)
They have the same symptoms as people with sickle cell disease but do not get ill as often	47 (39.8)	26 (37.1)	21 (43.8)
They start off with sickle cell disease but get better as they get older	2 (1.7)	0 (0.0)	2 (2.9)
Don't know	23 (19.5)	8 (11.4)	15 (31.3)

[a] Values are given as number (percentage). Numbers may not add up to the total number of participants because some survey questions were unanswered.

professionals to engage in effective communication may have a profound influence on whether the encounter with a patient supports or discourages decisions and subsequent actions [15]. Unfortunately, most Ghanaian initiatives to educate patients about sickle cell disease are limited to sickle cell centers in Accra and Kumasi [3].

Finally, existing cultural mores—developed through religious membership, tribe affiliation, and regional influences—greatly influence women's attitudes toward motherhood and family size [16,17]. In Ghana, women have historically occupied a lower social status than men and they often view children and grandchildren as a source of pride and a means of improving their status [18,19]. The findings of the present study indicate that women in Ghana place a high value on fulfilling cultural and familial expectations about childbearing. It would therefore be prudent for community health programs to take the significance of motherhood into consideration when developing educational programs of any kind.

Furthermore, the group who were not tested included a higher proportion of women who believed that God determines the outcome of their child's health, who did not undergo testing because sickle cell is incurable, and who stated that they would proceed with childbirth regardless of a diagnosis of sickle cell disease. These findings indicate that sufficient attention should be given to effective disease management rather than prevention. Efforts should be made to ensure that parents are able to recognize the symptoms of sickle cell disease and to prepare them to manage this disease in a variety of social settings (e.g. rural, urban). Also, more women in the nontested group than in the tested group reported that knowledge that they were carriers would make them feel less healthy and singled out. Therefore, an effort should be made to decrease the stigma associated with being a carrier, which also may discourage women from pursuing a test for the sickle cell trait. For potential genetic testing programs in Ghana to be successful, the use of culturally acceptable approaches must be taken into consideration [3].

Several limitations of the present study should be noted. Given that the survey was administered in English, participants could have misunderstood the questions even if an interpreter was present. Also, given the limited number of study sites, the participants may not be a representative sample of Ghanaian women.

Genetic testing can potentially be an effective strategy for identifying sickle cell trait carriers and serve as a tool for informed reproductive decision-making [3,20]. However, for this method to be effective, it is important to understand the ways in which structural forces, social norms, and traditional beliefs influence a woman's ability to make such decisions and act upon them [16]. Additionally, while women may decide to undergo testing, they may continue to lack a clear understanding of the underlying concepts and consequences associated with carrying the sickle cell trait. Proximity to regional medical centers may play a role in community exposure to information about sickle cell disease and carrier testing. Further research is needed to explore the acceptability of genetic testing in relation to family planning and the effectiveness of existing educational materials used outside the 2 sickle cell centers (Accra and Kumasi) in order to improve informed reproductive decision-making in Ghana.

Conflict of interest

The authors have no conflicts of interest.

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