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CLINICAL ARTICLE

Attitudes of Ghanaian women toward genetic testing for sickle cell trait

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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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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%, $P=0.004$).