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Original Article

Factors Influencing Acceptance of Newborn Screening for Sickle Cell Disease in Bauchi State, Nigeria

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ABSTRACT

Background: Sickle cell disease (SCD) is one of the most common genetic diseases worldwide, with very high prevalence rates in sub-Saharan Africa, especially Nigeria. Given the importance and benefits of newborn screening (NBS), it is essential to assess awareness and acceptance of NBS for SCD and the factors influencing its acceptance in this region.

Methods: This was a hospital-based, cross-sectional study that examined pregnant women attending the antenatal clinic for their first visit between August 1 and October 31, 2023. This antenatal clinic has an average annual attendance of 1,521 pregnant women who come for their first visit. The data obtained were analyzed using IBM SPSS Statistics (version 20), and the results were presented in prose, tables, and figures as appropriate. A level of statistical significance was set at $p < 0.05$.

Results: Three hundred and two (302) pregnant women were recruited for the study. Though there was low awareness (13.2%), there was a high acceptance rate (96.7%) of NBS for SCD amongst the women studied. However, the type of marriage (monogamous marriage, $p = 0.029$) was the only factor found to have a significant relationship with the respondents' willingness to accept NBS for SCD.

Conclusions: Community education, with an emphasis on married couples, women of reproductive age, and religious leaders, should be intensified. The monogamous marriage setting may reflect marital stability, social support, or correlated socioeconomic factors on health decision-making. However, this may have different implications in different societies.

Key words: Newborn screening, sickle cell disease, knowledge, acceptance

INTRODUCTION

Sickle cell disease (SCD) is a hereditary genetic syndrome that is caused by mutations in the β-globin gene, leading to the production of hemoglobin S (HbS). This condition comprises a heterogeneous group of hemoglobinopathies (such as HbSS, HbSC, and HbS/β-thalassemia). [1] It is characterized by chronic hemolytic anemia, recurrent

vaso-occlusion, progressive organ damage, and phenotypic heterogeneity influenced by genetic and environmental modifiers. [1] There are over 700 structural hemoglobin variants that have been identified; however, the common SCD syndromes in the African region include homozygous HbSS disease (HbSS), commonly known as sickle cell anemia (SCA), (HbSC), Hb Sβ- thalassemia (HbSβ-thal). [2]

The presence of fetal hemoglobin (HbF) has been identified as a factor that ameliorates the severity of SCD, and is found in high quantities at birth. [3] In the first 6 months of life, HbS progressively increases while HbF progressively declines to very low levels, after which an affected individual manifests with health complications from recurrent vaso-occlusion, hemolytic anemia, and chronic inflammation, which can lead to severe acute sequelae, chronic organ damage, or death. [3,4] These complications may affect quality of life and life expectancy. [4]

SCD has a high prevalence in the Middle East, Mediterranean regions, Southeast Asia, and Sub-Saharan Africa. [5] It is the most prevalent known genetic disease in Nigeria, with more than 4 million people affected. [6] In Nigeria, the birth incidence of SCD is 20 per 1,000 live births, and the World Health Organization estimates that 150,000 children are born annually with the disease in the country. [7]

Primary prevention, through a well-coordinated program involving a multidisciplinary team of caregivers, is central to reducing the incidence of SCD in the population. [8] This effective program revolves around health education, genetic counselling, prenatal diagnosis, and contraceptive counselling for unintended pregnancies in couples with sickle cell trait (AS). However, secondary preventive measures such as neonatal screening, early diagnosis, penicillin prophylaxis, and malaria prophylaxis may be more applicable in our setting due to limited access to genetic testing and counselling, as well as religious or cultural beliefs surrounding reproductive choices. Standard newborn screening (NBS) programs will lead to the early introduction of the SCD child into comprehensive care programs, thereby improving the quality of life and decreasing morbidity and mortality, as has been observed in some high-resource countries. [2,9–11] In sub-Saharan Africa, NBS tests have been initiated in many countries; however, a few of these countries have implemented universal screening programs. [12]

A study conducted by Kuznik et al. on NBS and prophylactic interventions of SCD revealed that NBS was highly cost-effective in 24 countries, including Nigeria. [13] Several studies have been carried out in Nigeria on the Knowledge and acceptability of NBS for SCD in Nigeria. These studies have found high acceptability rates amongst respondents. [14–17] Age, sex, religion, educational level, knowledge of SCD, and awareness of NBS for SCD are factors that have been found to influence acceptability in some of these studies. [4,14]

The high acceptability rates from the studies conducted suggest that the uptake of NBS for SCD will be impactful if policies are implemented and adequate facilities are provided. However, most of these studies were carried out in the Southwestern region of the country, and little is known about how acceptable NBS for SCD will be in this part of the country.

This study aimed to investigate awareness and acceptance of NBS for SCD and to determine if any sociodemographic factors influenced willingness to accept NBS among pregnant women in Bauchi State, Nigeria. This may further strengthen the case for the national implementation of NBS policies and identify ways to address factors that may hinder acceptability if present.

MATERIALS AND METHODS

Study area

The study was conducted at the Federal University of Health Sciences Teaching Hospital, Azare. Azare is a town and traditional emirate in Bauchi State, situated at a latitude of 11.55°N and longitude 10.10°E in the Sudan savannah belt of Northeastern Nigeria. [18] The hospital is a tertiary health center serving Azare and surrounding towns in Bauchi, Jigawa, and Yobe states. The study was conducted in the Antenatal Clinic (ANC) of the facility—the Ante-Natal Clinic functions under the Obstetrics and Gynaecology Department of the hospital. The Antenatal clinic is subdivided into two: the booking clinic, where pregnant women are seen for the first time by their caregivers, and a follow-up clinic, where pregnant women who have already booked are seen at specified intervals up to their time of delivery.

Study design/population

The study was a descriptive, cross-sectional study in which pregnant women aged 18 years and above attending the antenatal clinic of the Federal University of Health Sciences Teaching Hospital, Azare, for their booking appointment (first antenatal visit) were recruited from August 1 to October 31, 2023.

Sample size determination

The Cochrane formula for descriptive studies was used for sample size calculation ($n = z^2pq/d^2$), with a standard normal deviation at 95% confidence interval (1.96), an estimated knowledge of NBS for SCD to be 42.9% and an error of precision at 5% (0.05). [19,20]

Where n = calculated sample size, z = the standard normal deviation, usually set at 1.96, which corresponds to the 95% confidence interval, p = the prevalence of the condition under study, $q = 1 - p$, equivalent to the proportion without the condition under study, and d = degree of accuracy, which will be set at 0.05 for the study. [19]

Using this formula, the calculated sample size was 376; however, the average total population of pregnant women attending the antenatal clinic annually was 1521, which is less than 10,000. The final estimate (n_f) was calculated using the formula $n_f = n/(1+n/N)$, where n = initial sample size, N = total population. [19] The final sample size calculated was 302.

Sampling technique

A systematic random sampling method was used to recruit study participants. Recruitment was conducted every week during the antenatal clinic. The sampling frame was the list of pregnant women attending the booking clinic that day, as obtained from the appointment register. The sampling interval

(k) was calculated using the following formula: $k = N/n$, where N is the number of pregnant women attending the booking clinic on that day and n is the desired sample size to be recruited on that day. [19] The calculated sampling interval (k) was 2. Simple random sampling was used to select the first respondent at each clinic; thereafter, every kth respondent (second) was subsequently recruited until the desired sample size for that recruitment session was achieved. None of the selected women declined participation.

Study procedure

At the antenatal clinic waiting area, the principal investigator provided general information regarding the survey to the women and obtained their consent.

A semi-structured questionnaire, adapted from previous studies that established the validity of the questionnaire content, was used. [21,22] This questionnaire was developed to obtain information from respondents on sociodemographic factors, SCD and NBS knowledge, attitudes, and acceptance of NBS for SCD screening. Two junior doctors, fluent in English, Hausa, and Fulfulde, were trained as research assistants over 3 days, with 2 hours of training each day, by the principal investigator. They were given the background, objectives, and methodology of the study and asked to review the questionnaire. Any questions or confusion were clarified at this stage. Agreement on how each question was to be asked in Hausa and Fulfulde was discussed to ensure uniformity. A pilot study was also conducted to locally validate the questionnaire and ensure that there was no ambiguity in its completion.

Approval was sought and obtained from the Health Research Ethics Committee of the Federal University of Health Sciences Teaching Hospital, Azare, before the commencement of the study. Informed written and verbal consent was obtained from the selected pregnant women in the booking clinic who agreed to participate in the study.

Data management

The data collected was checked for accuracy and completeness before the close of each clinic by the lead researcher. Data from this study were manually entered into an IBM® SPSS Statistics (version 20, Chicago, IL) software to check for errors and inconsistencies. Statistical analyses were carried out using this software to produce descriptive statistics. The outcome variable was presented in prose, frequencies, and percentages. Bivariate analysis was used to identify factors that may influence acceptance of NBS for SCD. A p-value of < 0.05 was taken to be statistically significant for those factors that influenced knowledge and acceptance of neonatal screening.

RESULTS

Three hundred and two (302) respondents were recruited for the study. The majority of respondents (53%) were between the ages of 18 and 24 years. All the respondents were married, with 70.9% of them in a monogamous marriage. All the respondents were Muslims, and the majority (60.3%) had secondary school as their highest level of education. Approximately half (51.7%) of the respondents were unemployed, and the majority (62.9%) identified as Hausa by tribe. Approximately one-third (34.4%) of the respondents were primigravida (**Table 1**).

Two hundred and ten of the women (73.4%) had a good knowledge of SCD (**Figure 1**). The majority (86.8%) of the respondents were not aware of NBS for SCD, while only 40 (13.2%) were aware (**Figure 2**). Of the three hundred and two (302) respondents, 96.7% of them were willing to have their newborn babies tested for SCD (**Figure 3**).

Of all the sociodemographic characteristics, only marriage form was found to have a statistically significant association with willingness to accept NBS for SCD (p-value 0.029). This is shown in **Table 2**. There was also no significant association between awareness of NBS for SCD and respondents' willingness to accept NBS for SCD (**Table 3**).

DISCUSSION

This study, conducted in an antenatal clinic of a public tertiary hospital, primarily consisted of women aged 18 to 24 years, with the majority also being primigravida. With the excitement and fear that come with a first pregnancy, and the hope of giving birth to a healthy baby, along with an increased awareness of the benefits of antenatal care, it is not surprising that this age group made up the majority

Table 1: Sociodemographic characteristics of respondents.

Sociodemographic characteristics	Frequency (*N*)	Percentage (%)
Age		
18–24	160	53.0
25–34	124	41.1
35–44	18	6.0
Marriage type		
Monogamous	214	70.9
Polygamous	88	29.1
Religion		
Muslim	302	100
Level of education of the respondent		
None	38	12.6
Primary	22	7.3
Secondary	182	60.3
Tertiary	60	19.9
Occupational status		
Employed	26	8.6
Unemployed	156	51.7
Self employed	120	39.7
Ethnic group		
Hausa	190	62.9
Fulani	78	25.8
Kanuri	18	6.0
Others	16	5.3
Gravidity		
Primigravida	104	34.4
Multigravida	114	37.7
Grand multigravida	84	27.8

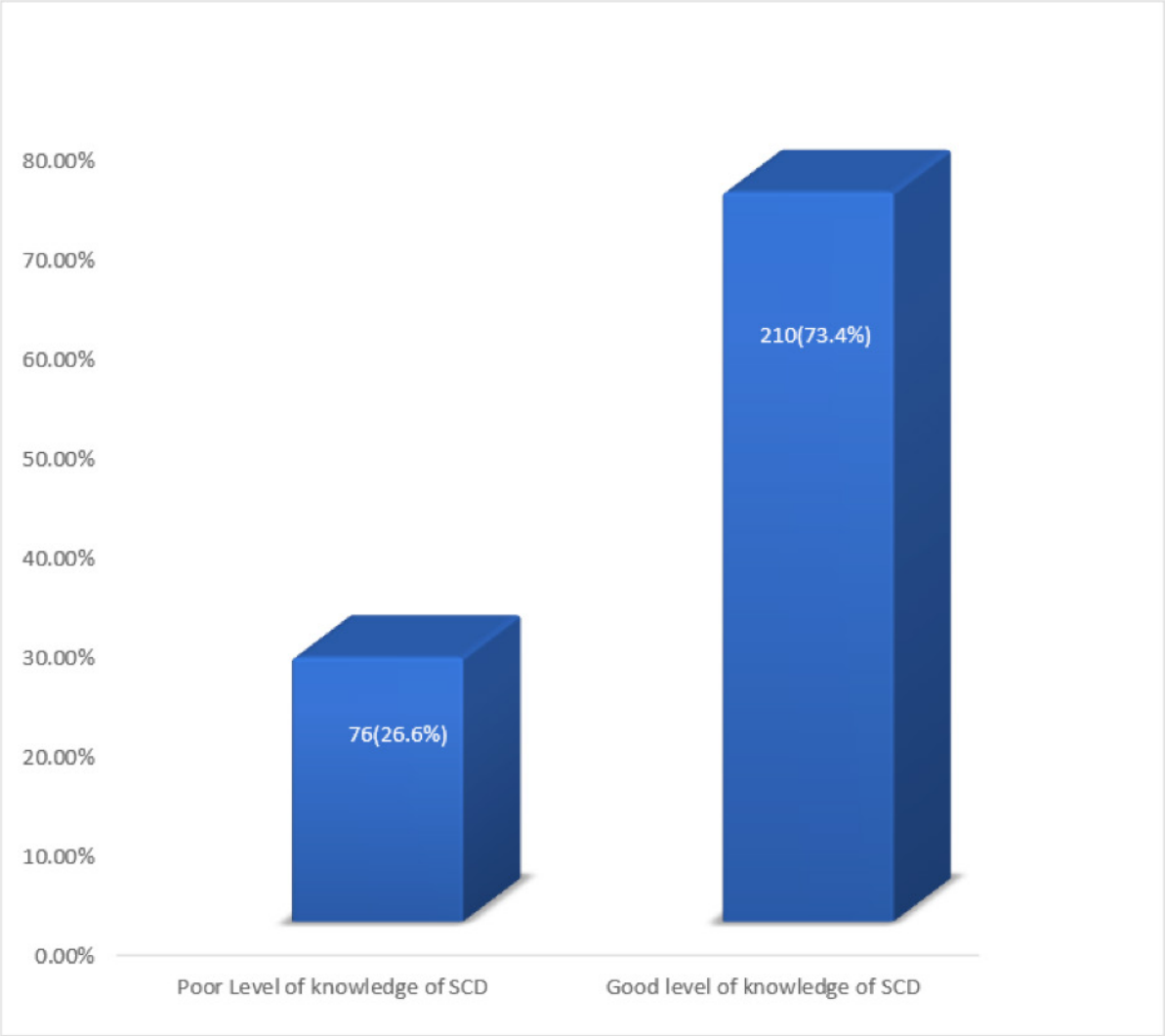

Figure 1: Level of knowledge of respondents on sickle cell disease (SCD; *N = 286*).

of the respondents. The area of study had a predominance of the Hausa and Fulani tribes; it was therefore expected, as most of the respondents belonged to these two major tribes, and all were Muslim. The majority of respondents had at least a secondary education as their highest educational qualification and were mainly unemployed.

This study revealed that 86.8% of the respondents had never heard of NBS for SCD, despite 94.7% being aware of SCD. This means that only 13.2% were aware of NBS for SCD, indicating a significant knowledge gap. Two studies, by Nnachi et al. on the acceptability of NBS for SCD among post-partum mothers in Abakaliki, and Babalola et al. in Ibadan, found low awareness, with 22% and less than 50% of respondents, respectively, being unaware of NBS for SCD. [14,16] Higher awareness rates of NBS for SCD were seen by Nnodu et al. and Katamea et al. in two different studies conducted in Nigeria and the Democratic Republic of Congo (DRC). [15,23] The lower rate found in this study may be due to the smaller population of pregnant women recruited, compared to the larger and more diverse participants in the two aforementioned studies.

This study found a high NBS for the SCD acceptance rate of 96.7% amongst the respondents. This high acceptance rate has also been found in several studies within and outside Nigeria.

Oluwole et al. in Lagos found an acceptance rate of 86%, 96% in Ekiti by Olatunya et al., Babalola et al. in Ibadan (92.8%), 92% by Nnachi et al. in Abakaliki, and greater than 80% in a multicenter study by Nnodu et al. [14–17,20] There was also a high acceptance rate in a study done outside Nigeria; 84.6% in the DRC. [23] These high rates indicate that the population aware of the test and its benefits is also willing to have this test carried out on their newborns if made available and affordable. People are now more aware of the role of preventive medicine, which should be taken seriously by the responsible government bodies. A low acceptance rate was, however, noted in a study in Eastern Gabon, which recruited respondents immediately post-partum. [4] This current study recruited women at various stages of their pregnancy who attended the antenatal clinic. We speculate that the immediate post-partum state, which is characterized by rapid hormonal changes that affect the mother physically,

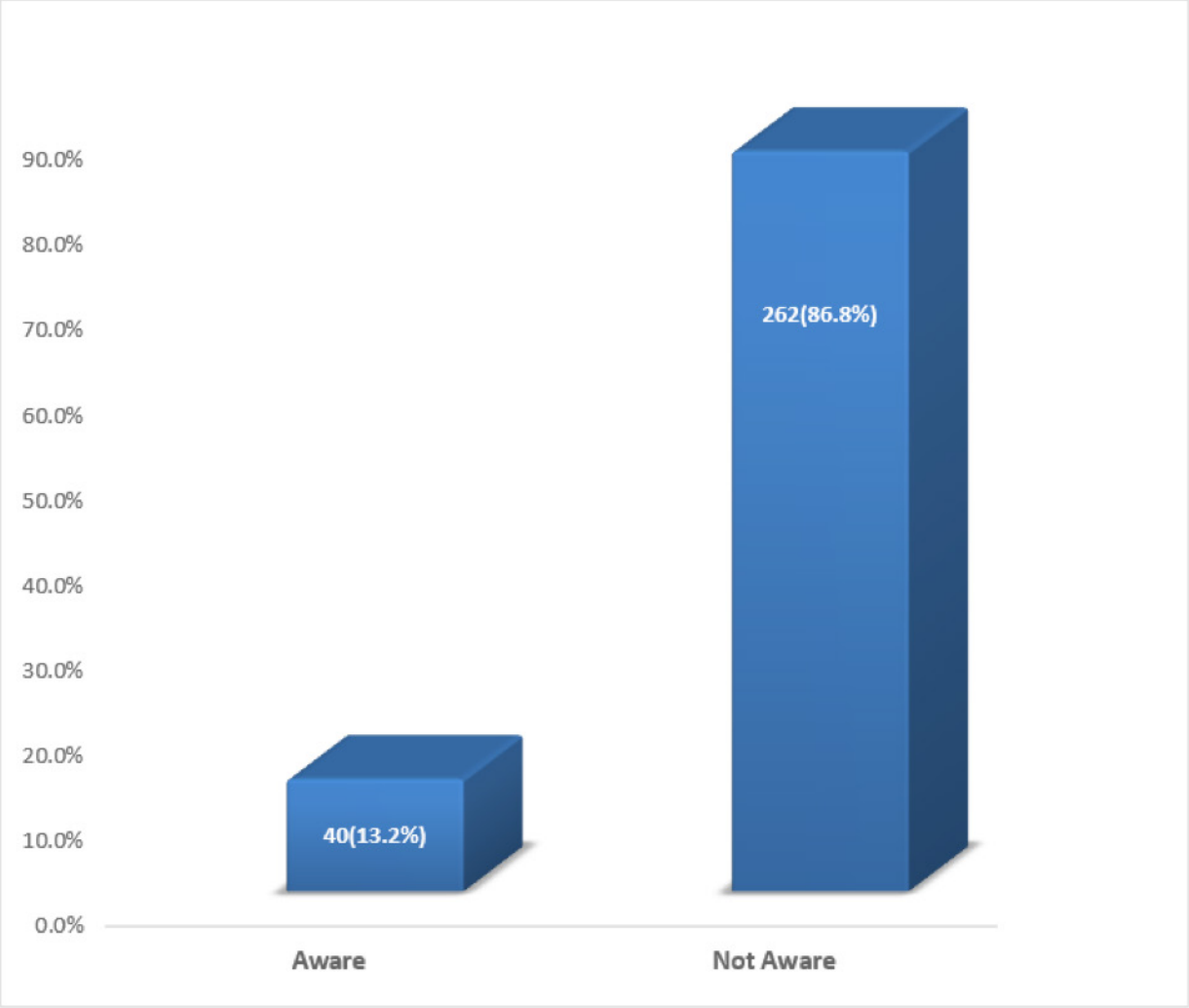

Figure 2: Awareness of newborn screening for sickle cell disease (SCD; *N* = 302).

emotionally, and mentally, especially following the stress of labor, may negatively affect her decision to accept any test on her baby. This factor may be responsible for the higher acceptance rate in this study when compared to the Eastern Gabon study.

This study revealed that only the type of marriage influenced the acceptance of NBS for SCD. Most of the women studied were in a monogamous marriage. It is possible that marriage type affected decision making by the couple especially with the woman's opinions being significant where the children are involved unlike in a polygamous setting where most decisions concerning children were left for the man alone, also the man was more available for decisions to be taken as he spent more time with the one family, unlike the divided attention he would have with polygamous marriage setting.

This finding could also reflect marital stability, social support, or correlated socioeconomic factors on health decision-making. Sociodemographic factors, including age, educational level, ethnicity, and occupation, did not significantly influence the acceptance of NBS for SCD.

Awareness of NBS for SCD did not influence acceptance of NBS in the current study. A study in Eastern Gabon among parturient women in a regional hospital also did not find any significant association between acceptance of NBS amongst the women studied. [4] The findings from this study, however, are not in line with those observed among mothers of young children and those with children with SCD in the Ibadan study by Babalola et al., where the level of education, awareness, and perspectives towards SCD and neonatal screening were identified as influential factors. [14] This study did not assess whether the respondents had any children with SCD, which may have influenced their acceptance, as in the Babalola et al. study. Katamea et al. in the DRC found that age, sex, and religion were factors influencing the acceptability of NBS for SCD. [23] In the current study, though religion was found not to have a significant association with the acceptance of NBS for SCD, a majority of the women studied, who were all Muslims, were willing to have their babies tested. In recent times, Measures have been put in place by the Bauchi state government to increase awareness campaigns about SCD, and it is also mandatory for intending couples to present their

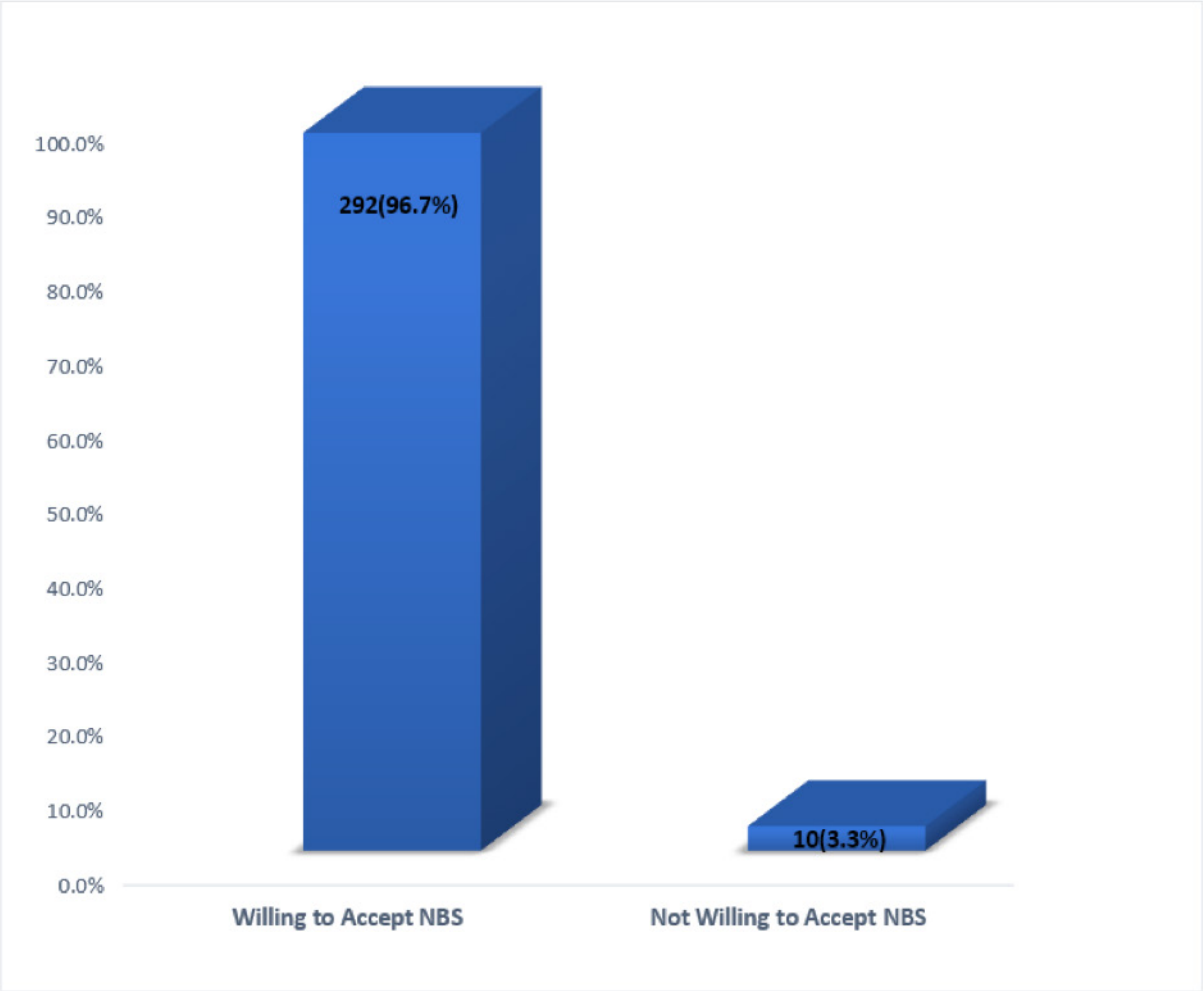

Figure 3: Willingness of respondents to accept newborn screening for sickle cell disease (SCD; *N* = 302). NBS: newborn screening.

Hb electrophoresis results to the Imams before being joined in marriage. This will go a long way in reducing the incidence of the disease if it is strictly adhered to.

This study, which was conducted to evaluate the factors influencing the acceptance of NBS for SCD, is the first of its kind in this region, to the best of the authors' knowledge, and will serve as a starting point for an essential discussion on NBS for SCD.

Further studies on the understanding of NBS and SCD, as well as the prevalence of SCD using NBS techniques and the acceptance of the test outcomes in this region, could be conducted. Assessing the acceptability of NBS for SCD may serve to either encourage or deter health services decision-makers in their need to provide these testing facilities.

This study was a hospital-based cross-sectional study conducted in a semi-urban area with a small sample of women. This, therefore, makes it difficult to generalize its findings.

CONCLUSIONS

Overall, the study observed that there was poor awareness of NBS for SCD. However, following education on its usefulness, a high acceptance rate of NBS for SCD was observed. It will therefore be imperative for the general populace to be educated, especially married couples and women of reproductive age, about this test. Marriage type, which influenced the acceptance of NBS for SCD, may reflect marital stability and social support, but may not be universally applicable, as monogamous marriages have different implications in various societies.

AUTHORS' CONTRIBUTION

Each author has made a substantial contribution to the present work in one or more areas, including conception, study design, conduct, data collection, analysis, and interpretation. All authors have given final approval of the version to be published, agreed on the journal to which the article has been submitted, and agreed to be accountable for all aspects of the work.

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None.

CONFLICT OF INTEREST

None.

Table 2: Association between sociodemographic characteristics and willingness to accept newborn screening (NBS) for sickle cell disease (SCD) amongst respondents.

Sociodemographic characteristics	Willingness to accept NBS for SCD		χ^2	*p*-value
	Willing *n* (%)	Unwilling *n* (%)		
Age			4.634	0.099
18–24	154(51.0)	6(2.0)		
25–34	122(40.4)	2(0.7)		
35–44	16(5.3)	2(0.7)		
Marriage form			4.770	**0.029**
Monogamous	210(69.5)	4(1.3)		
Polygamous	82(27.2)	6(2.0)		
Level of education			4.020	0.259
None	36911.9)	2(0.7)		
Primary	22(7.3)	0(0.0)		
Secondary	178(58.9)	4(1.3)		
Tertiary	56(18.5)	4(1.3)		
Occupational status			3.513	0.173
Employed	26(8.6)	0(0.0)		
Unemployed	148(49.0)	8(2.6)		
Self employed	118(39.1)	2(0.7)		
Ethnic group			1.780	0.619
Hausa	182(60.3)	8(2.6)		
Fulani	76(25.2)	2(0.7)		
Kanuri	18(6.0)	0(0.0)		
Others	16(5.3)	0(0.0)		
Gravidity			6.419	0.400
Primigravida	98(32.5)	6(2.0)		
Multigravida	114(37.7)	0(0.0)		
Grand multigravida	80(26.5)	4(1.3)		

χ^2= Pearson's chi square.

Table 3: Association between awareness of newborn screening (NBS) for sickle cell disease (SCD) and willingness to accept NBS among respondents.

Awareness of NBS for SCD	Willingness to accept NBS for SCD			χ^2	*p*-value
	Yes *n* (%)	No *n* (%)	Total *n* (%)		
Yes	40 (13.2)	0 (0)	40 (13.2)	1.579	0.236
No	252 (83.4)	10 (3.3)	262 (86.8)		

χ^2= Pearson's chi square.

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