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Knowledge, Perception and Acceptance of Newborn Screening for Sickle Cell Disease Among Pregnant Women in Bauchi, Nigeria

Yusuf Maimuna O[1,2], Shaibu Peter A[2], Imoudu Iragbogie A[1,2]

[1]Department of Paediatrics, Faculty of Clinical Sciences, Azare, Nigeria.
[2]Department of Paediatrics, Federal University of Health Sciences Teaching Hospital, Azare, Nigeria.

Correspondence

Dr Maimuna O. Yusuf, Department of Paediatrics, Faculty of Clinical Sciences, Federal University of Health Sciences Teaching Hospital, Azare/ Federal University of Health Sciences, Azare, Bauchi State, Nigeria. E-mail: memzii@yahoo.com ; ORCID: https://orcid.org/0009-0009-7646-4227.

Abstract

Background: Newborn screening (NBS) for Sickle Cell Disease (SCD) is performed at birth or within the neonatal period to facilitate early detection of SCD. Newborn screening, though not new in Africa, is not yet a routine procedure due to its high cost and difficulty in accessing screening facilities.

Objectives: To assess the knowledge and acceptance of NBS in a part of northern Nigeria.

Methods: This study employed a descriptive cross-sectional design to examine pregnant women attending the antenatal clinic for booking over three months.

Results: Thirty-three out of 302 (10.9%) women were aware of NBS for SCD. Of this 33, the majority (84.8%) had a good level of knowledge of NBS. Most respondents (299; 99%) had a positive perception, and only 2.3% were not willing to accept NBS for SCD.

Conclusion: The Majority of respondents had a positive perception of NBS for SCD, and the study observed a high level of acceptance for NBS for SCD. Respondents were also willing to support and encourage other pregnant women to get their newborns tested for SCD, as early diagnosis will allow early initiation of interventions to reduce the morbidity and mortality associated with the disease.

Keywords: Electrophoresis, Haemoglobinopathies, Newborn screening, Sickle cell anaemia.

Introduction

SCD is a group of inherited disorders of haemoglobin synthesis, whereby an individual inherits two abnormal haemoglobin (Hb) genes, at least one of which is Haemoglobin S (HbS).[1] This disorder is characterised by the presence of sickle red cells in the blood, which leads to its characteristic pathology and symptomatology. [1] The severest and commonest form of SCD in Nigeria is Haemoglobin SS (HbSS), also known as Sickle Cell Anaemia (SCA), where an individual inherits two abnormal HbS genes.[2] Haemoglobin C (HbC) and Haemoglobin S β-Thalassemia (Hb Sβ-thal) are other less common forms in the SCD spectrum.[2] SCD does not include the sickle cell trait, also known as the carrier state (HbAS).[1]

Sickle Cell Disease (SCD) is one of the most common genetic diseases worldwide with very high prevalence rates in the Mediterranean regions, the Middle East, South East Asia and Sub-Saharan Africa, especially Nigeria.[3] Twenty to twenty-five million people are said to be affected by SCD globally, with 150,000-300,000 individuals born annually in Africa with SCD.[4,5] Nigeria is the most sickle cell endemic country in

Africa, where the prevalence rate of the sickle cell trait is about 23.7%, with about 2.69-5% of its population being affected by SCD. [6,7] Nigeria accounts for 100,000-150,000 newborns living with SCD annually, with an annual infant death of 100,000, representing 8% of infant mortality in the country.[2]

Newborn screening is done at birth or the neonatal period to enhance early detection of SCD. [2] Despite the high prevalence, newborn screening (NBS) for SCD, which allows for early prophylactic treatment, education of parents/guardians, and comprehensive management, is not widely available.

Newborn screening for SCD enables the early initiation of prophylactic treatment, comprehensive management, and parent/caregiver education, leading to a reduction in morbidity and mortality. Newborn screening, although not new in Africa, remains to be made routine due to its high cost and the difficulty in establishing screening facilities. [7] The World Health Organisation (WHO) estimates that 70% of SCD deaths in Africa are preventable with simple, cost-effective interventions such as early identification of SCD patients by newborn screening (NBS) and subsequent provision of comprehensive care. [8, 9] Adoption of these practices has led to a significant reduction in SCD mortality, with more than 90% of affected children now surviving through adulthood in some parts of the World.[10] It is, therefore, essential to educate people about the benefits of NBS for SCD to improve acceptability when it becomes readily available and accessible.

There is currently no national neonatal screening policy for the diagnosis and management of SCD in Nigeria, as most people with SCD are identified when they become symptomatic. The diagnosis is confirmed by qualitative electrophoresis which is usually very expensive. [11] Given the importance and benefits of the NBS, this study aimed to evaluate the knowledge it is imperative to assess the knowledge and acceptance of NBS by mothers in the northern part of Nigeria. This study will help create awareness about NBS and may also assist policymakers in making scientifically informed decisions regarding NBS for SCD in Nigeria.

Methods

Study setting

The study was conducted at a public tertiary hospital in the Northeastern region of Nigeria, which serves as a tertiary health facility for both adults and children. The study was conducted in the antenatal clinic (ANC) of the facility, which is part of the hospital's Obstetrics and Gynaecology Department. The antenatal clinic is divided into two parts: the booking clinic, where pregnant women are first seen by their caregivers, and a follow-up clinic, where pregnant women who have already booked are seen at specified intervals up to the time of their delivery.

Ethical consideration

Ethical approval was obtained from the hospital's Health Research Ethics Committee before the commencement of the study. Informed written consent was obtained from the pregnant women at the booking clinic as part of the enrolment process. For participants who did not understand English, consent was obtained, and the interview was conducted in a language they understood best.

Study design

The study was a descriptive, cross-sectional study of pregnant women attending the antenatal clinic for booking. The study was conducted over three months, from 1st August to 31st October 2023.

Sampling technique

A systematic random sampling method was used to recruit study participants. Recruitment was conducted on a weekly basis during the booking

clinic. The sampling frame consisted of the list of pregnant women attending the booking clinic that day, as obtained from the booking attendance register.

Data collection

A semi-structured questionnaire, adapted from previous studies that established the validity of the questionnaire content, was used. [12] This questionnaire was developed to obtain information from respondents on sociodemographic factors, NBS knowledge, attitudes and acceptance of SCD screening, and attitudes towards voluntary termination of affected pregnancy, if the participant is expected to give birth to a child affected by SCD.

The questionnaire consisted of thirty-one open-ended and closed-ended questions subdivided into five sections: (1) sociodemographic characteristics; (2) awareness of SCD; (3) knowledge of Newborn Screening; (4) attitudes and perception of Newborn screening for SCA; (5) acceptance of NBS and factors influencing acceptance of NBS for SCA. Knowledge was assessed based on answers chosen from the given options. Respondents who scored 50% or above were considered to have good knowledge, while those who scored below 50% were deemed to have poor knowledge. A Likert scale scoring method was used to assess perceptions.

Statistical analyses

Data from this study were manually entered into an IBM Statistical Package for the Social Sciences (SPSS version 21, Chicago, IL) software to clean the data. Statistical analyses were carried out using descriptive statistics. The outcome variables were presented in frequencies and percentages.

Results

Three hundred and two pregnant women met the inclusion criteria and were recruited into the study. The majority of respondents (47.4%) were under the age of 24. All the respondents were married, with 74.5% of them in a monogamous marriage. Two hundred ninety-six (98%) of the respondents were Muslims, and the majority (54.6%) had received their education up to the secondary level. More than half (64.2%) of the respondents were unemployed, while the majority (62.9%) belonged to the Hausa ethnic group. Approximately one-third (30.8%) of the respondents were primigravida (Table I).

The majority (269; 89.1%) of the respondents were unaware of Newborn screening for Sickle cell disease, while only 33 (10.9%) were aware. Of the 33 women who were aware of NBS for SCD, the majority (84.8%) had a good level of knowledge of NBS, while 15.2% had a poor understanding of NBS for SCD. Most respondents (99%) had a positive perception of NBS for SCD, while only 3 (1%) had a negative perception.

Out of the 302 respondents, 295 (97.7%) were willing to have their newborn babies tested for SCD. A majority (255; 86.4%) required permission from their husbands, with 8.6% also needing permission from other family members. Out of the 7 (2.3%) respondents who were not willing to have their newborns screened for SCD, 14.3% said they were unlikely to receive spousal permission, another 14.3% thought that the baby was too fragile for the test, as one mother had a fear that the baby could be injured during the procedure. Other reasons, such as parents' phenotypes, were already known; therefore, there was no need for NBS for SCD, which was indicated in the remaining 28.6% (Figure 1).

Discussion

This study, which was carried out in an antenatal clinic, had a majority of the women aged 24 and below, with a majority of them being primigravida. The reason for the predominance is

not immediately apparent. Still, one can speculate that, with the excitement and anxiety that come with any pregnancy, the wish to give birth to a healthy baby, and an increase in awareness of the benefits of antenatal care, it is not surprising that this age group made up the majority of the respondents.

Table I: Sociodemographic characteristics of respondents

Sociodemographic Characteristics	Frequency (N)	Percentage (%)
Age (years)		
≤ 24	160	53.0
25-34	124	41.0
35-44	18	6.0
Marriage type		
Monogamous	214	70.9
Polygamous	88	21.1
Religion		
Muslim	302	100.0
Level of education		
None	38	12.6
Primary	22	7.3
Secondary	182	60.2
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
Grandmultigravida	84	27.9

This study revealed that 84.8% of the respondents had never heard of NBS for SCD, despite 97% of them being aware of SCD and most having a good understanding of the disease. This means that only 10.9% were aware of NBS for SCD, indicating a significant knowledge gap. Two studies, one by Nnachi *et al* on the acceptability of newborn screening for sickle cell disease among post-partum mothers in Abakaliki, also found a low awareness rate of NBS (22%) for SCD. Another study by Babalola *et al* in Ibadan also found that less than 50% of its respondents

were aware of NBS for SCD. [13, 14] These two studies also had a population of only pregnant women or young mothers, as in the present study with a smaller population size, which may also explain the low rate of awareness of NBS. The awareness rate of NBS for SCD in this study is significantly lower than the 51.3% and 73.4% awareness rates of NBS found by Katamea *et al*. in the Democratic Republic of Congo among 2032 adults and Nnodu *et al*. in a multicentre survey of 1,301 Nigerian adults in their respective studies on the subject matter. [15, 16]

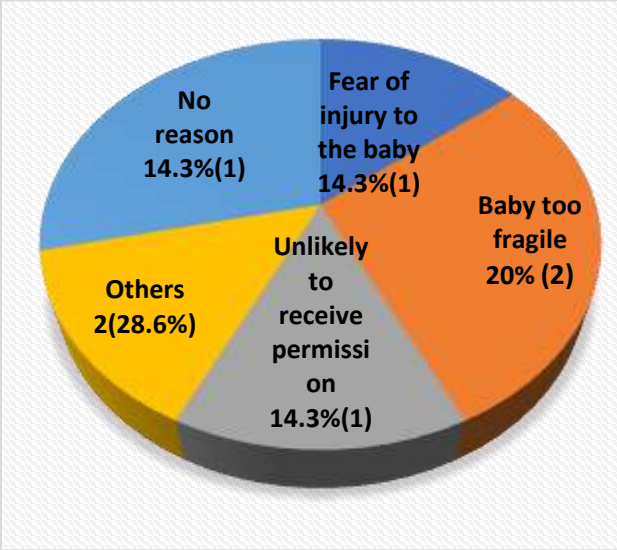

Figure 1: Reasons for lack of willingness to accept newborn screening for SCD
***Others: Mother's phenotype is known; therefore, no need for NBS for SCD**

The lower rate found in this study may be because of the population studied, as only pregnant women attending the ANC were questioned, unlike Nnodu's multicentre study, where the respondents included both genders, health professionals, parents of children with SCD, individuals with SCD and undergraduate students, with representation from the six geopolitical regions of Nigeria.[16] The study in DRC was also a multi-municipality research in an urban area involving both genders. Both studies also had a large study population. The findings of this study, which reveal a low awareness rate of NBS for SCD, indicate that significantly more effort is needed to raise awareness of NBS for SCD in this region, particularly through collaboration with the news media. With more awareness, there may be more requests for the test. High requests and demands for a particular investigation are a driving force for hospital authorities and health policy makers to provide the required testing facilities within their locality.

This study aimed to determine the level of knowledge among individuals aware of NBS for SCD on the subject. This study found that more than 80 per cent of the respondents who were aware of NBS for SCD had good knowledge of NBS for SCD. The respondents' good knowledge of the test may be attributed to their source of information. Most of them accessed information about NBS for SCD from the media, health workers or relatives who have children with SCD. There was generally a positive perception of the screening test among the respondents, as a majority showed support for NBS and would also encourage other women to have their newborns screened for SCD.

Their perception is that the earlier a child is diagnosed with SCD, the earlier they will be started on appropriate management, which will reduce the complications and, by extension, the burden of the illness. This may also reduce the burden of care and financial implications on caregivers, especially mothers, thereby explaining their support for early diagnosis. Nnodu *et al* in their multicentre study also found a high support rate for NBS for SCD, 79% of support across all age groups interviewed. [16] Another study by Olatunya *et al* in Ekiti State showed that 75% of the physicians interviewed were willing to recommend NBS to patients. [17] Though not medical workers, 95% of the pregnant women in the present study were willing to encourage other women to have their newborns

tested for SCD. This higher rate of support in pregnant women may be explained by the "power to cure or help" that physicians possess and "the power to care" that mothers possess, as postulated by Wonkam and Hurst.[10] This is because women have that bond of feeling each other's pain when it comes to motherhood, and also goes to show that health-related outcomes for children will be better if such decisions to choose what is right are left to mothers.

This study found a high NBS for the SCD acceptance rate of 97.7% 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 reported 92.8%, Nnachi *et al* in Abakaliki reported 92% and greater than 80% in a multicentre study by Nnodu *et al*. [13, 14, 16 – 18] There was also a high acceptance rate in a study done outside Nigeria; 84.6% in the DRC. [15] These high rates show that the populace who are aware of the test and its benefits are also willing to have this test carried out on their newborns if made available and possibly 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 sought to screen babies of mothers in the immediate post-partum period. [19] The present study recruited women at various stages of their pregnancy who attended the antenatal clinic. The immediate post-partum state, which is characterised by rapid hormonal changes which affect the mother physically, emotionally and mentally, especially following the stress of labour, 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.

The major reason for refusal of NBS in this study was the mother's knowledge of her and her spouse's Hb phenotype and the possibility of never having a child with SCD. This reason, though valid, may not be entirely accurate, as laboratory errors could occur in the premarital determination of parental Hb electrophoresis, hence the need to screen all babies for SCD where possible. The other reason given was that newborn babies were too small and fragile to have blood samples taken from them.

To reduce the burden of SCD mortality and morbidity through comprehensive newborn screening and subsequent comprehensive healthcare management of the disease, caregivers need to know about SCD and the value of newborn screening. Some limitations of this study include the fact that it was conducted in a semi-urban area, which may not be representative of the entire female population. Additionally, considering the educational levels, the findings may not be generalisable. Additionally, the study was hospital-based, which means it was not likely to be representative of the entire community.

Conclusion

This study revealed a lack of awareness of NBS for SCD in the population. However, those who were aware of NBS for SCD had a good level of knowledge on the procedure. The study found that after creating awareness about NBS for SCD, the majority of respondents had a positive perception towards newborn screening for sickle cell disease. Overall, the study observed a high acceptance rate for NBS for SCD, as most of the respondents were willing to have their newborns tested for SCD. The respondents were also willing to support and encourage pregnant women to get their newborns tested for SCD, as early diagnosis will allow early initiation of interventions to reduce the morbidity and mortality of the disease.

Authors' Contributions: YMO and IAI conceived and designed the study. YMO conducted the literature review and analysed the data using SPA. YMO did data interpretation and drafted the manuscript. SPA and IAI revised the draft for sound intellectual content. All the authors approved the final version of the manuscript.
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