Acceptability of newborn screening for sickle cell disease among post-natal mothers at Homa Bay County Referral Hospital, western Kenya

John Guda Orimbo (jguda006@gmail.com)
Jaramogi Oginga Odinga University of Science and Technology
Shehu Shagari Awandu
Jaramogi Oginga Odinga University of Science and Technology
Faith Muhonja
Amref International University
Patrick Owili
African Population and Health Research Center
Dickens Omondi
Jaramogi Oginga Odinga University of Science and Technology
John Guda Orimbo
Jaramogi Oginga Odinga University of Science and Technology

Research Article

Keywords: Sickle Cell Disease Acceptability Newborn Screening Factors

Posted Date: December 7th, 2023

DOI: https://doi.org/10.21203/rs.3.rs-3676768/v1

Additional Declarations: No competing interests reported.

Abstract

Background

Sickle cell disease (SCD) is a genetically inherited blood disorder that manifests early in life with resultant significant health complications. Globally, nearly three quarters of all affected babies are in sub-Saharan Africa. Early identification of babies with SCD through newborn screening (NBS) followed by early linkage to care is recommended. However, the program has not been widely adopted in the sub-Saharan Africa. Evidence on acceptability of NBS to scale up NBS program is scarce. This study assessed factors associated with acceptability of newborn screening among mothers of newborns delivered at Homa Bay County Teaching and Referral Hospital (HCTRH), western Kenya.

Methods

This study employed a cross-sectional design among postnatal mothers at HCTRH. A semi-structured questionnaire was used for data collection. Maternal sociodemographic characteristics, knowledge, and perception were assessed. Babies were also screened for SCD using Sickle SCAN point-of-care test. The acceptability was calculated as percentage of mothers accepting to have their babies screened. Data were analyzed using logistic regression to explore factors associated with acceptability of NBS.

Results

Ninety-four percent of mothers accepted NBS. Mother's age and occupation were significantly associated with acceptability of NBS for SCD. Younger mothers (OR = 3.01;95%CI = 1.16–7.83; $p = 0.024$) and being a student (OR = 6.18; 95%CI = 1.18–32.22; $p = 0.031$) were significant at bivariate regression analysis. Only being a student (aOR = 25.02; 95% CI = 1.29-484.51; $p = 0.033$) was significant at multivariate logistic regression analysis. Male partner support was found to be a strong positive modifying factor (coef = 7.50; std error = 1.31;95%CI = 4.94–10.07; $p < 0.001$).

Conclusion

The observed high acceptability of NBS for SCD in this population is indicative of a tacit acceptance of NBS for SCD.This is especially among younger mothers, being modified by male partner influence. A high level acceptance is necessary for scaling up the NBS program.

Introduction

Sickle cell disease (SCD) is a major genetically inherited blood disorder, caused by autosomal recessive inheritance, that manifests early in life with resultant significant health complications. Globally, nearly three quarters of all SCD-affected babies are in sub-Saharan Africa (Uyoga et al., 2019). In 2011, the

World Health Organization (WHO) recommended an increased awareness, improved access to health services, and provision of technical support for prevention and management of SCD (Makani et al., 2013). Programs such as newborn screening (NBS) for SCD have shown great success towards preventing and managing the disease (Nnodu et al., 2018). However, only a few countries in Africa have piloted the screening program and none has scaled up the implementation (Inusa et al., 2015; Ohene-Frempong et al., 2008; Tshilolo et al., 2009), and yet with the successful implementation of the program, early initiation of penicillin prophylaxis, pneumococcal vaccines, and hydroxyurea treatment are likely to reduce the disease burden in low- and middle-income countries (LMICs).

Nonetheless, limited data on the prevalence of Sickle cell disease at birth in Africa still makes it difficult to quantify the magnitude of the disease burden. Additionally, approximately 90% of the children with sickle cell disease die before their fifth birthday, partly because of late diagnosis (Katamea et al., 2022), which can be solved by adequate implementation of NBS for SCD—depending on its acceptability (Sekhon et al., 2017) and socio-cultural settings (Bediako & Neblett, 2011) that vary from one community or region to another. Unacceptability of the screening program for SCD by the parents or caregivers or authorities in Africa can greatly hinder effective implementation of the program (Inusa et al., 2015), and hence a need to assess the acceptability of the program before its implementation which may not only promotes public participation but also community ownership of the intervention.

Homa Bay county is yet to implement NBS for SCD. This is despite the high prevalence of SCD among infants who were accessing MCH services in the county, which was found to be at 9.2%(Wanjiku et al., 2018).Routine NBS for SCD is recommended in regions where SCD prevalence at birth is 0.05% or more (DeBaun & Galadanci, 2022). Further, no prior study, to the best of my knowledge, had been conducted in the county to assess the acceptability of such potentially beneficial program. This then remained a major gap since acceptability is key for successful implementation of the intervention program(Sekhon et al., 2017).Either, extrapolating data from another county may not be feasible owing to the variable nature of acceptability(Marsh et al., 2011).

In this study therefore, we assessed the acceptability of NBS for SCD and its associated factors in Homa Bay County. This is significant towards promoting the establishment of a systematic NBS program for SCD in Homa Bay County, and subsequently a successful implementation of the intervention (Sekhon et al., 2017). The results of this study is also important to the ministry of health at the county-level for planning of the SCD screening program in the county.

Methods

Study design, study population and study setting

This study employed a cross-sectional design at the postnatal wards in the HCTRH, Homa Bay County, Western Kenya. The study involved postnatal mothers in the postnatal wards between 14th April 2023 and 15th June 2023. The site has a SCD clinic, however, NBS for SCD has not been implemented.

Sample size and sampling technique

Cochran's formula for calculating the sample when the population is infinite was used. A maximum variability of 50% was used to estimate the maximum sample size required since the acceptability of NBS for SCD was unknown in Homa Bay County. The final sample size was 403, after adjusting for 5% non-response. Consecutive sampling technique was used to select the participants. All postnatal mothers available at the postnatal ward during the study period, who were willing to take part in our study and met the inclusion criteria were selected and enrolled in our study. The inclusion criteria were: The postnatal mother capable of giving an informed consent or assent to participate in the study and whose outcome of delivery was an alive infant. Postnatal mothers who were medically unstable to respond to the questionnaire or needed urgent critical care were excluded from participating in the study.

Data Collection Tools

Kobo collect tool was used to collect the data using a semi-structured questionnaire with five sub-sections. The first section collected demographic information: Maternal age, marital status, occupation, and religion, education level and parity. The second section contained questions on the knowledge(awareness) of the mother about SCD including ever having heard of or being aware of SCD, being aware of their haemoglobin status, there knowledge about SCD being a blood disorder, their knowledge on transmission of SCD, when it can be diagnosed and their knowledge on the existence of NBS programs. The third section contained the questions on the perceptions of the newly delivered mothers as to when screening for SCD should be done, its ethicality and about the perceived effectiveness of the NBS for SCD. The fourth section of the questionnaire explored the possible intervening variables mainly, the cultural issues around NBS and the role of the male partner in making the decision as to whether to accept NBS. The fifth section collected data on their intent/willingness to have their newborns screened and those who were willing had their newborns screened using sickle SCAN kit. The sickle SCAN test kit is capable of identifying Hemoglobin A, S and C variants in blood samples. The sex of the newborns was also captured here.

Enrollment and Data collection

A total of 399 participants were enrolled into the study, representing 99% response rate. Eligible participants provided written informed consent/assent. After consenting, a semi-structured questionnaire was administered to each participant by the research assistants. The research assistants comprised of 1 clinical officer/physician assistant,2 nurses,1 laboratory technician and 2 counsellors. The principal investigator trained the research assistants prior to the start of the study and supervised data collection. The mothers were finally questioned on their intent/willingness to have their newborns screened. Willing participants had their babies screened for SCD using the Sickle SCAN® point-of-care test following manufacturer's instructions (BioMedomics Inc., United States). The laboratory technician conducted the screening test bedside following the manufacturer's instructions. The newborns' heels were pricked using 1.2mm lancet pricker, and 2 drops of blood collected directly into the device. The results were ready in 3–5 minutes. The counsellors offered psychological counselling to all the mothers pretest and to mothers

whose babies had SCT or SCD post-test. The mothers whose newborns screened positive for SCD were referred to the Sickle Cell Disease comprehensive clinic and also received psychological counselling from the study team.

Statistical analyses

The data were entered into excel for cleaning before analysis using STATA version 16.0 (StataCorp, 2019). The level of acceptability of NBS for SCD was analyzed using descriptive statistics only. Even though acceptability is a multidimensional construct, in this study it has been defined as the willingness of the mother to accept NBS for SCD. The percentage acceptability, calculated as the percentage of mothers willing (who agreed) to have their newborns screened for SCD, was calculated and pie chart used for visual representation of the data.

The factors associated with acceptability of NBS for SCD were analyzed using both descriptive statistics and inferential statistics. Descriptively, proportions of acceptability among various factors were calculated and represented in a table. Inferentially, Chi-square and Fisher's exact test (where at least a cell has a count less than 5) were used to assess the association between the sociodemographic, maternal knowledge and maternal perception characteristics and the acceptability of NBS for SCD. The factors that had statistically significant association with acceptability were further analyzed using logistic regression analysis to establish the point estimate and the magnitude of association. After the unadjusted analysis, statistically significant variables, were fit into a multivariate logistics regressions model using forward stepwise regression approach. Both unadjusted and adjusted odds ratio (OR) and 95% confidence intervals (95% CI) were reported. The results of the newborn screening were used to calculate the prevalence of sickle cell disease and sickle cell trait among the newborns.

Results

Summary of participant characteristics

The mean age of the mothers was 26.2 years (SD 6.07) with 25-34 years being modal age-group, comprising 44.1% of the respondents. Majority (300; 75%) of respondents were married; 59.7% had one or 2 children; 41.4% had attained secondary level education while, 70% were engaged in either informal or no employment. Only 2 mothers (0.5%) reported to have had a child with Sickle cell. Majority (371; 93%) of the respondents had ever heard about sickle cell disease; only 4% knew their sickle cell status with only 2% having ever been screened for SCD before; over 90% knew the cause of sickle cell disease; only 7% of respondents believed that SCD was as a result of God's will with less than 2% believing SCD was due to God's punishment or due to evil spirit and majority (386;96.7%) belived the best timing for SCD was during the postnatal period (Table 1)

Table 1: Participant Characteristics of Postnatal Mothers (N=399)

Variable Characteristic	Frequency	Percentage
Age group		
11-24	175	43.9
25-34	176	44.1
≥35 years	48	12.0
Education		
Tertiary	120	30.1
Secondary	165	41.4
Primary	112	28.1
No Education	2	0.5
Marital Status		
Married	300	75.2
Widowed	5	1.3
Separated	21	5.3
Never married	73	18.3
Occupation		
Student	72	18.1
Formal employment	40	10.0
Informal employment	226	56.6
No employment	61	15.3
Religion		
Roman Catholic	73	18.3
Protestant	206	51.6
Pentecostal	55	13.8
Muslim	6	1.5
Others	59	14.8
Parity		
One child	141	35.3

Two children	97	24.3
Three children	80	20.1
Four children and above	81	20.3
Child with sickle cell disease		
Yes	2	0.5
No	397	99.5
Death of child under 2 years		
Yes	29	7.3
No	370	92.7

Level of acceptability of NBS for SCD among postnatal mothers

Out of the total 399 mothers interviewed, 94.0% (n= 375) were willing to have their newborns screened for sickle cell disease (Fig. 1). This formed the level of acceptability since the acceptability in this study was based on the willingness of the mother to have the newborn screened using the test kit which was a component of the study.

Association between sociodemographic characteristics and acceptability of newborn screening for Sickle cell disease

Chi-square method was used to assess association between the sociodemographic characteristics of the respondents and their acceptability of newborn screening for sickle cell disease. We found that maternal occupation *(p=* 0.026) and maternal age (*p=* 0.023) were the only factors that had significant association with the acceptability of NBS for SCD. Respondents who were students and those younger than 25 years were more likely to accept NBS for SCD.The odds of accepting NBS for SCD among postnatal mothers who were students was higher than those in formal employment (OR=6.18; 95%CI=1.18-32.22; *p=* 0.031). Mothers who were younger than 25 had higher odds of accepting newborn screening for SCD than older mothers (OR=3.01;95%CI=1.16-7.83; *p=* 0.024). No significant association was found between acceptability of newborn screening for SCD and other sociodemographic characteristics. (Table 2).

Table 2:Relationship between acceptability of NBS and Sociodemographic characteristics

Characteristic	N=399	Percentage accepting NBS N=375 n(%)	X^2 value	df	p-value
Marital Status*				3	0.181
Married	300	279(93.00)			
Widowed	5	5(100.00)			
Separated	21	19(90.48)			
Never married	73	72(98.63)			
Education (highest completed)			2.06	1	0.357
Tertiary	120	110(91.67)			
Secondary	165	158(95.76)			
Primary	114	107(93.86)			
Religion*					
Roman Catholic	73	69(94.52)			
Protestant	206	192(93.20)		4	0.341
Pentecostal	55	51(92.73)			
Muslim	6	5(83.33)			
Others	59	58(98.31)			
Parity					
One child	141	135(95.74)			
Two children	97	92(94.85)	3.15	3	0.369
Three children	80	72(90.00)			
Four children and above	81	76(93.83)			
Age group					
11-24	175	169(96.57)			
25-34	176	159(90.34)	7.52	2	0.023
≥35	48	47(97.52)			

Child with sickle cell disease*					
Yes	2	2(100.00)	1		1.000
No	397	373(93.95)			
Occupation					
Student	72	70(97.22)			
Formal employment	40	34(85.00)	9.27	3	0.026
Informal employment	226	211(93.36)			
Unemployed	61	60(98.36)			
Death of child under 2 years					
Yes	29	28(96.55)	0.36	1	0.546
No	370	347(93.78)			

*Fisher's exact method used where cell contain value <5

Association between maternal knowledge and acceptability of newborn screening for sickle cell disease

Fisher's exact method was used to assess the association between maternal knowledge and the acceptability of NBS for SCD since the criteria for chi-square was not met. Most of the cells had values less than 5. No statistically significant association was found between maternal knowledge dimensions and acceptability of newborn screening for SCD. (Table 3)

Table 3:Association between acceptability of NBS and Knowledge

Characteristics	Total=399	Postnatal mothers accepting NBS=375(n%)	p-value
Ever heard about SCD			1.000
Yes	371	348 (93.8)	
No	28	27(96.4)	
Knowledge of SCD status			0.612
Yes	16	16(100.0)	
No	383	359(93.7)	
Ever screened for SCD			1.000
Yes	8	8(100.0)	
No	391	367(93.9)	
SCD is blood disorder			1.000
Yes	362	340(93.9)	
No	37	35(94.6)	
SCD is contagious			1.000
Yes	6	6(100.0)	
No	393	369(93.9)	
Maternal inheritance only			1.000
Yes	2	2(100.0)	
No	397	373(94.0)	
Paternal inheritance only			1.000
Yes	1	1(100.0)	
No	398	374(94.0)	
Heard about SCD screening			0.079
Yes	133	129(97.0)	
No	266	246(92.3)	

Fisher's exact method used

Association between maternal perception and acceptability of newborn screening for sickle cell disease

Fisher's exact method was used to assess the association between maternal perception and the acceptability of NBS for SCD since the criteria for chi-square was not met. Most of the cells had values less than 5. No statistically significant association was found between maternal knowledge dimensions and acceptability of newborn screening for SCD. (Table 4)

Table 4:Association between maternal perception and acceptability of NBS

Characteristics	Total=399	Postnatal mothers accepting NBS=375(n%)	p-value
SCD occur due to God's will			1.000
TRUE	28	27(96.43)	
FALSE	371	348(93.80)	
SCD occur due to God's punishment			0.268
TRUE	5	4(80.00)	
FALSE	394	371(94.16)	
SCD occur due to evil spirit			0.268
TRUE	5	4(80.00)	
FALSE	394	371(94.16)	
Best timing for SCD Screening			0.180
Prenatally	4	4(100.00)	
0-6 weeks	386	364(94.30)	
> 6 weeks	9	7(77.78)	
NBS for SCD is morally right			0.312
TRUE	393	370(94.15)	
FALSE	6	5(83.33)	
NBS is useful for controlling SCD			1.000
TRUE	384	360(93.75)	
FALSE	15	15(100.00)	

Fisher's exact method used

Multivariate logistic regression analysis of factors with significant association with acceptability of NBS for SCD at bivariate analysis

Only being a student (aOR= 25.02; 95% CI=1.29-484.51*; p*= 0.033) was significant at multivariate logistic regression analysis, though with a wide confidence interval. Male partner support was found to be a strong modifying factor with positive effect (coef=7.50; std error=1.31;95%CI=4.94-10.07; *p<0.001)*. In the multivariate model, the coefficient of determination(r^2) was found to be 63.9%. (Table 5)

Table 5: Bivariate and Multivariate logistic regression analysis model of acceptability of NBS for SCD

	Unadjusted model			Adjusted model		
Characteristic	OR	95%CI	P-value	aOR	95%CI	P-value
Occupation						
Formal employment	REF			REF		
student	6.18	1.18-32.22	0.031	25.02	1.29-484.51	0.033
Informal employment	2.48	0.90-6.84	0.079	10.14	1.67-61.36	0.012
No employment	10.59	1.22-91.67	0.032	19.24	0.97-383.14	0.053
Age category						
24-35	REF			REF		
≤24 years	3.01	1.16-7.83	0.024	0.44	0.07-2.64	0.365
≥35 years	5.03	0.65-38.76	0.121	0.65	0.06-6.89	0.720
Cultural support						
No	REF			REF		
yes	4.32	1.13-16.49	0.032	0.24	0.01-5.89	0.380
Male partner support						
No	REF			REF		
Yes	559.50	105.46-2968.41	<0.001	1816.91	139.34-23691.24	<0.001

Table legend: model variable significant at 95% CI; p= 0.05; R^2= 63.9%

Newborn screening results

Out of the 375 newborns who were screened for sickle cell disease,182 (48.5%) were males and 193(51.5%) were females. The SCD screening result showed that 326(86.9%) had no haemoglobinopathy,42(11.2%) had SCT and 7(1.9%) had SCD.

Discussion

The acceptability of NBS for SCD observed in the current study sample was relatively high (94%). Comparatively, Kuta et al., (2019) previously observed NBS acceptability of 99.4% in Kisumu County, Kenya. However, acceptability and uptake of NBS remains variable across the African region (Katamea et al., 2022). Studies from Nigeria by Oluwole et al. (2020) and Nnodu et al. (2018) both observed 86% acceptability of NBS, compared to 99.7% by Odunvbun et al., (Odunvbun et al., 2008). On the contrary, studies conducted in Koula-Moutou (Gabon) (Mombo et al., 2021) and DRC Congo (Katamea et al., 2022) showed low acceptability rates of about 30% despite satisfactory knowledge among the respondents, demonstrating wide variabilities (Marsh et al., 2011). There were obvious variations across socio-economic and demographic stages, with younger single mothers being more receptive. Awareness and knowledge levels as well as availability and access to services in high burden areas have been observe to influence acceptability (Nnodu et al., 2018). Despite the high willingness of the service recipient, other factors not explored in this study such as cost barriers and service availability remain important factors in the overall evaluation of the intervention acceptability. It is important that a policy to make the intervention universally available and accessible in the county is made (Gates et al., 2021). Awareness about the intervention or awareness of the existence of the intervention helps improve acceptability since those with low knowledge or awareness are less likely to accept the interventions (Newman et al., 2013; Zhao et al., 2021). It is critical that prior to implementation of the NBS program in the county, adequate awareness creation is made and cost barriers eliminated(Izizag et al., 2018).

Primary interventions such as newborn screening program are highly recommended to avert disease complications and early deaths. Acceptance of health technologies is necessary for progressive adoption and continued use by consumers as well as for its implementation at scale (Kuta et al., 2019). Despite the relatively high acceptability rate, which might imply higher willingness for NBS by the recipients, recent studies in Africa show that acceptance for NBS is diverse and variable over time across different population groups as well as the implementation contexts (Sekhon et al., 2017; Katamea et al., 2022). This might be accounted for by health technology acceptance as a dynamic concept, that evolves sequentially through a continuum of stages including, pre-use acceptability; initial use acceptability and sustained use acceptability. However, few studies exist on the pre-use health technology acceptance in Africa (Sekhon et al., 2017). The current study examined pre-use acceptability. Whether high acceptability across these stages necessarily translates to scalability remains a multidimensional challenge.

This study found out that occupation was strongly associated with acceptability of NBS for SCD and those in formal employment were less likely to accept NBS for SCD when compared to the students and those in other occupations. This is comparable to the findings of Nnodu et all in a multicenter survey in Nigeria (Nnodu et al., 2018). Reasons for this were not explored in this study but it is likely that the students were much younger and younger age has been associated with increased acceptability.

Maternal age was found to be a strong predictor of acceptability of newborn screening for SCD. Mothers who were younger than 25 years were found to be 3 times more likely to accept newborn screening than

those older. This finding is comparable to the findings of a study done in Gabon where mothers younger than 29 years were more likely to accept newborn screening than those older (Mombo et al., 2021). Similarly, a study done in Nigeria found that mothers younger than 21 years were more likely to accept newborn screening for SCD than those older (Nnodu et al., 2018).Younger women are considered less culturally bound and therefore more likely to accept newborn screening for SCD(Misati Akuma, 2015; Mombo et al., 2021).

Male partner support was found in this study to improve the odds of acceptability of newborn screening for SCD across the various occupational categories. Male partner support may reflect not only mutual consensus on decisions regarding the health interventions but also, potential influence (Dsouza et al., 2022). It is therefore important to involve males in planning of implementation of health interventions such as this (Mboane & Bhatta, 2015).The multivariate model in this study had the significant factors explaining up to 63% of the variable relationships. The unexplained 37% is likely due to unexplored factors. Previous similar studies (Katamea et al., 2022; Mombo et al., 2021) indicate diverse factors may be involved but there is no consensus on how different factors interact to influence or potentially affect maternal acceptability of the newborn screening for SCD.

The study also found that the confidence intervals for most of the odds ratios of the associated factors were very wide. This typically could have been due to reasonably high variability in the factor characteristics within the community of study (Marsh et al., 2011). However, this may also, result from study limitations in that, in as much as acceptability is a multidimensional aspect, only willingness was assessed in this study.

Conclusion

The acceptability of Newborn screening for Sickle cell disease among the postnatal mothers in Homa Bay County was high, mainly among mothers who were still students. Male partner support was found to be a strong motivating factor NBS acceptability with positive effect. The high acceptability is indicative of a willingness for screening for sickle cell and is necessary for scaled up programming. Implementation of routine newborn screening program for sickle cell disease is highly recommended in view of the good user acceptability and high prevalence of sickle cell disease at birth in the county. Additionally, there is need to explore other determinants of acceptability and how they impact on acceptability and actual uptake. The current study model only accounted for about 63% of explanatory factors.

Abbreviations

APHRC: African Population and Health Research Centre

aOR: Adjusted Odds Ratio

CI: Confidence Interval

EC: Ethics Committee

EDCTP: European and Developing Countries Clinical Trials Partnership

HPLC: High Performance Liquid Chromatography

JOOUST: Jaramogi Oginga Odinga Teaching University of Science and Technology

NACOSTI: National Commission Of Science, Technology and Innovation

NBS: Newborn Screening

OR: Odds Ratio

SCD: Sickle Cell Disease

SCT: Sickle Cell trait

SSA: Sub-Saharan Africa

Declarations

Ethical approval and consent to participate

The proposal was approved by the board of postgraduate studies of Jaramogi Oginga Odinga University of Science and Technology. Ethical approval for the study was obtained by JOOUST Ethics Committee (ERC 36/02/23-33) and the NACOSTI permit obtained the National Commission of Science, Technology and Innovation (Research License 101836). Using the approvals from the Ethic Committee (EC) and NACOSTI, the County authorization was obtained from the County Health Management Team and the County Director of Medical Services and notice issued to the Hospital management and the relevant department. The research assistants signed a confidentiality agreement form before starting the data collection and were adequately trained to minimize any potential harm to the participants. Informed consent was obtained from the study participants prior to any study procedure. The data collected was kept confidential and in a password-protected computer. Data was entered directly into the password-protected computer with limited access. The access of the research assistants was terminated immediately data cleaning was complete. No paper data was intended for the study. Key personal identifying information such as name of the participant were not captured in order to deidentify the participant and minimize chances of harm from breach of confidentiality. Mothers of newborns who were willing to have their newborns screened were offered psychological counselling pre and post the test and those whose newborns screened positive and need advanced psychological counseling were referred to the counselling department of the Homa Bay County Teaching and Referral hospital. The newborns who screened positive for SCD were linked with the SCD clinic of the Homa Bay County Teaching and Referral Hospital for early initiation of comprehensive care, usually initiated at the age of 2 months. The mothers of the newborns who were found to have SCT were offered genetic counselling. The risk to the newborns

screened for SCD included minimal pain, swelling and bruise at the sample collection site due to the prick but this was minimized by having the blood sample collected by adequately trained and professional research assistants with experience in neonatal blood sampling from the heels. The heel prick was done while maintaining the infection prevention control measures like adequate sterilization of the prick site to minimize chances of prick site infection.

Consent for publication

Not applicable

Competing interests

The authors declare they have no competing interests

Acknowledgment

We acknowledge the postnatal mothers who consented to take part in the study which may improve the policy on newborn screening and the care of patients with sickle cell disease.

Funding

This data collection for Msc program was funded by The European and Developing Countries Clinical Trials Partnership (EDCTP) through the African Population and Health Research Centre(APHRC), Lund University, Jaramogi Oginga Odinga University of Science and Technology and Amref International University.

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Authors Contributions

JO conceptualized the idea, drafted the protocol, collected data, did data analysis and wrote the manuscript.

SA did critical review of the protocol and guided its writing, reviewed data collection tools, did data analysis and reviewed the manuscript.

FM did critical review of the protocol and guided its writing, reviewed data collection tools, did data analysis and reviewed the manuscript.

PO did critical review of the protocol and guided its writing, reviewed data collection tools, did data analysis and reviewed the manuscript.

DO did critical review of the protocol and guided its writing, reviewed data collection tools, did data analysis and reviewed the manuscript.

References

1. Bediako, S. M., & Neblett, E. W. (2011). Optimism and Perceived Stress in Sickle-Cell Disease: The Role of an Afrocultural Social Ethos. *Journal of Black Psychology*, *37*(2), 234–253. https://doi.org/10.1177/0095798410385681
2. DeBaun, M. R., & Galadanci, N. A. (2022). *Sickle cell disease in sub-Saharan Africa*. 39.
3. Dsouza, J. P., Van Den Broucke, S., Pattanshetty, S., & Dhoore, W. (2022). Factors explaining men's intentions to support their partner's participation in cervical cancer screening. *BMC Women's Health*, *22*(1), 443. https://doi.org/10.1186/s12905-022-02019-y
4. Gates, A., Gates, M., Rahman, S., Guitard, S., MacGregor, T., Pillay, J., Ismail, S. J., Tunis, M. C., Young, K., Hardy, K., Featherstone, R., & Hartling, L. (2021). A systematic review of factors that influence the acceptability of vaccines among Canadians. *Vaccine*, *39*(2), 222–236. https://doi.org/10.1016/j.vaccine.2020.10.038
5. Inusa, B. P., Juliana Olufunke, Y. D., & John Dada, L. (2015). Sickle Cell Disease Screening in Northern Nigeria: The Co-Existence of Î'-Thalassemia Inheritance. *Pediatrics & Therapeutics*, *05*(03). https://doi.org/10.4172/2161-0665.1000262
6. Izizag, B. B., Situakibanza, H., Mbutiwi, T., Ingwe, R., Kiazayawoko, F., Nkodila, A., Mandina, M., Longokolo, M., Amaela, E., & Mbula, M. (2018). Factors associated with acceptability of HIV self-testing (HIVST) among university students in a Peri-Urban area of the Democratic Republic of Congo (DRC). *Pan African Medical Journal*, *31*. https://doi.org/10.11604/pamj.2018.31.248.13855
7. Katamea, T., Mukuku, O., Mpoy, C. W., Mutombo, A. K., Luboya, O. N., & Wembonyama, S. O. (2022). Factors Associated with Acceptability of Newborn Screening for Sickle Cell Disease in Lubumbashi City, Democratic Republic of the Congo. *Global Journal of Medical, Pharmaceutical, and Biomedical Update*, *17*, 5. https://doi.org/10.25259/GJMPBU_7_2022
8. Kuta, E. S. M., Tenge, C. N., Ganda, B. K. O., & Njuguna, F. M. (2019). Newborn screening for sickle cell disease at Kisumu county hospital, Kisumu -Kenya. *East African Medical Journal*, *96*(2), 2419–2429. CABDirect. https://www.ajol.info/index.php/eamj/article/view/198133
9. Makani, J., Ofori-Acquah, S. F., Nnodu, O., Wonkam, A., & Ohene-Frempong, K. (2013). Sickle Cell Disease: New Opportunities and Challenges in Africa. *The Scientific World Journal*, *2013*, 1–16. https://doi.org/10.1155/2013/193252
10. Marsh, V. M., Kamuya, D. M., & Molyneux, S. S. (2011). 'All her children are born that way': Gendered experiences of stigma in families affected by sickle cell disorder in rural Kenya. *Ethnicity & Health*, *16*(4–5), 343–359. https://doi.org/10.1080/13557858.2010.541903
11. Mboane, R., & Bhatta, M. P. (2015). Influence of a husband's healthcare decision making role on a woman's intention to use contraceptives among Mozambican women. *Reproductive Health*, *12*(1),

36. https://doi.org/10.1186/s12978-015-0010-2

12. Misati Akuma, J. (2015). Socio–cultural and family change in Africa: Implications for adolescent socialization in Kisii County, South Western, Kenya. *Les Cahiers d'Afrique de LEst*, *50*, 80–98. https://doi.org/10.4000/eastafrica.296
13. Mombo, L. E., Makosso, L. K., Bisseye, C., Mbacky, K., & Edou, A. (2021). *Acceptability of neonatal sickle cell disease screening among parturient women at the Paul Moukambi Regional Hospital in rural Eastern Gabon, Central Africa*. 6.
14. Nnodu, O. E., Adegoke, S. A., Ezenwosu, O. U., Emodi, I. I., Ugwu, N. I., Ohiaeri, C. N., Brown, B. J., Olaniyi, J. A., Isa, H., Okeke, C. C., Bene, B. A., Balongun, M. T., Okocha, E. O., Aneke, J. C., Lawson, J. O. J., Usman, A. M., Diaku-Akinmumi, I. N., Okolo, A. A., Israel-Aina, Y. T., … Adekile, A. D. (2018). A Multi-centre Survey of Acceptability of Newborn Screening for Sickle Cell Disease in Nigeria. *Cureus*. https://doi.org/10.7759/cureus.2354
15. Odunvbun, M. E., Okolo, A. A., & Rahimy, C. M. (2008). Newborn screening for sickle cell disease in a Nigerian hospital. *Public Health*, *122*(10), 1111–1116. https://doi.org/10.1016/j.puhe.2008.01.008
16. Ohene-Frempong, K., Oduro, J., Tetteh, H., & Nkrumah, F. (2008). SCREENING NEWBORNS FOR SICKLE CELL DISEASE IN GHANA. *Pediatrics*, *121*(Supplement_2), S120–S121. https://doi.org/10.1542/peds.2007-2022UUU
17. Oluwole, E. O., Adeyemo, T. A., Osanyin, G. E., Odukoya, O. O., Kanki, P. J., & Afolabi, B. B. (2020). Feasibility and acceptability of early infant screening for sickle cell disease in Lagos, Nigeria—A pilot study. *PLOS ONE*, *15*(12), e0242861. https://doi.org/10.1371/journal.pone.0242861
18. Sekhon, M., Cartwright, M., & Francis, J. J. (2017). Acceptability of healthcare interventions: An overview of reviews and development of a theoretical framework. *BMC Health Services Research*, *17*(1), 88. https://doi.org/10.1186/s12913-017-2031-8
19. Tshilolo, L., Aissi, L. M., Lukusa, D., Kinsiama, C., Wembonyama, S., Gulbis, B., & Vertongen, F. (2009). Neonatal screening for sickle cell anaemia in the Democratic Republic of the Congo: Experience from a pioneer project on 31 204 newborns. *Journal of Clinical Pathology*, *62*(1), 35–38. https://doi.org/10.1136/jcp.2008.058958
20. Uyoga, S., Macharia, A. W., Mochamah, G., Ndila, C. M., Nyutu, G., Makale, J., Tendwa, M., Nyatichi, E., Ojal, J., Otiende, M., Shebe, M., Awuondo, K. O., Mturi, N., Peshu, N., Tsofa, B., Maitland, K., Scott, J. A. G., & Williams, T. N. (2019). The epidemiology of sickle cell disease in children recruited in infancy in Kilifi, Kenya: A prospective cohort study. *The Lancet Global Health*, *7*(10), e1458–e1466. https://doi.org/10.1016/S2214-109X(19)30328-6
21. Wanjiku, C. M., Njuguna, F., Asirwa, F. C., Njuguna, C., Roberson, C., & Greist, A. (2018). Validation and Feasibility of a Point of Care Screening Test for Sickle Cell Disease in a Resource Constrained Setting —A New Frontier. *Blood*, *132*(Supplement 1), 2229–2229. https://doi.org/10.1182/blood-2018-99-118876

Figures

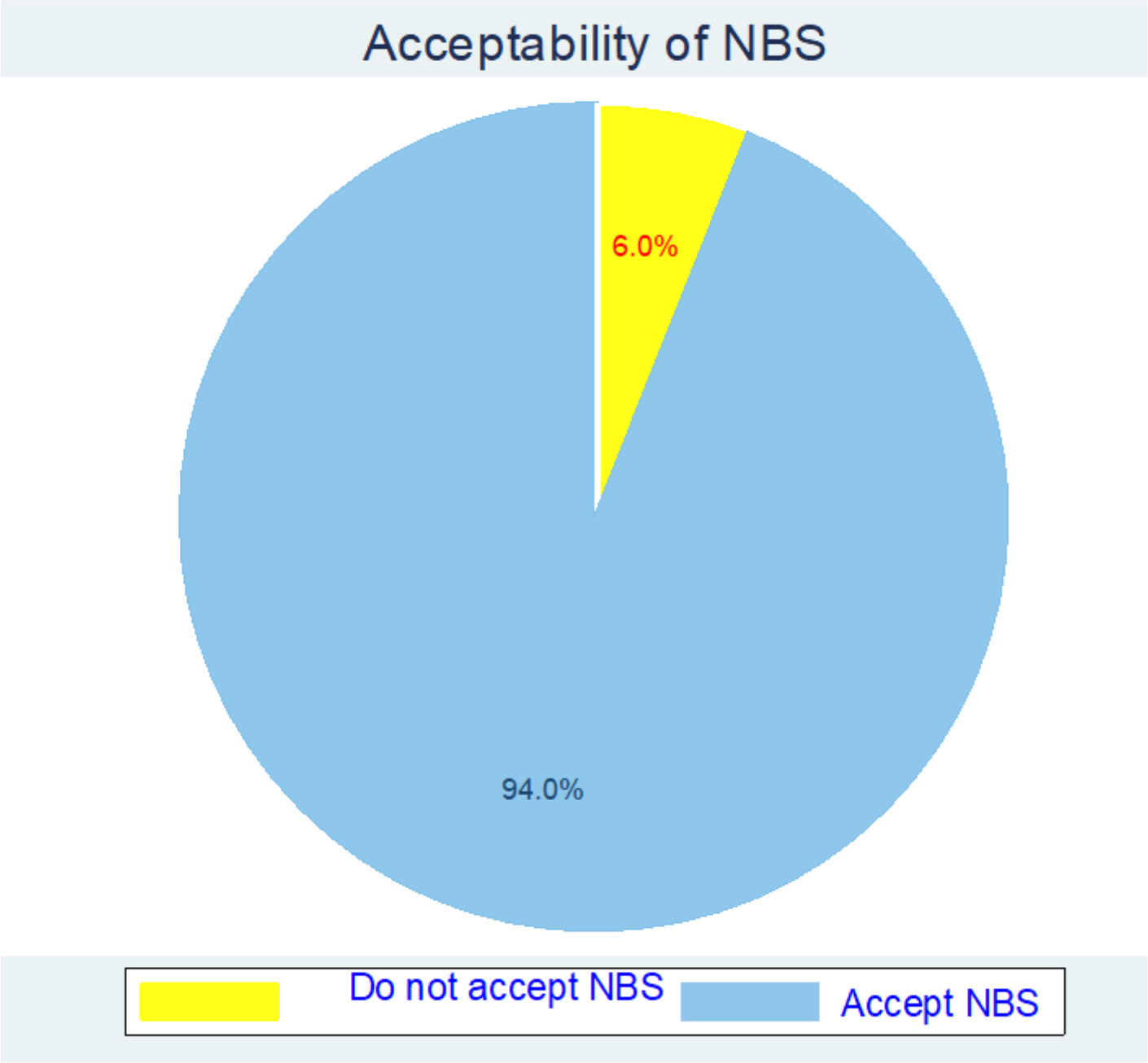

Figure 1

Pie chart of acceptability of NBS for SCD among postnatal mothers