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Determinants of marital decision despite sickle cell status awareness: a mixed method study

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Abstract

Introduction Sickle cell disease (SCD) is a significant public health concern in Nigeria. Despite widespread awareness campaigns advocating for premarital phenotype testing, many couples still make marital decisions that increase the risk of having children with SCD. This study aims to explore the factors influencing marital decisions among parents of children with SCD, focusing on the relationship between phenotype awareness and marital choices.

Method This mixed-method study was conducted among 209 parents of children with SCD receiving care at the paediatric haematology clinics of University College Hospital (UCH) and Oni Memorial Children Hospital (OMCH) in Ibadan, Nigeria. Quantitative data were collected through interviewer-administered structured questionnaires. Qualitative data were obtained through key informant interviews with stakeholders, including parents, healthcare providers, and SCD advocates. Qualitative data were thematically analysed and integrated with the quantitative findings.

Result Findings revealed low premarital awareness of sickle cell phenotypes as only 14.5% of couples had mutual knowledge, while 36.7% were completely unaware. Key factors influencing phenotype combinations that carry risk of SCD birth included a willingness to "take the risk and hope for the best" (46.7%), limited understanding of the implications of SCD (33.3%), willingness to bear consequences (26.7%) and reliance on faith (20%). Higher educational levels correlated with improved awareness.

Conclusion This study identifies significant gaps in premarital genetic awareness. Key gaps include a lack of knowledge about the implications of phenotype combinations and the tendency to prioritise cultural, emotional and religious factors over genetic risk considerations when making marital decisions. To bridge these gaps, improved public health education, accessible pre-marital genetic counselling and strategic engagement with religious and community leaders are essential to translating awareness into informed action.

Keywords Marital decision, Sickle cell disease, Phenotype incompatible, Phenotype awareness, Premarital counselling

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Introduction

Nigeria bears the highest burden of sickle cell disease (SCD) globally, which is an autosomal recessive genetic disorder characterised by an abnormal type of haemoglobin (Hb) [1, 2]. This haemoglobin polymerises under hypoxic conditions, causing red blood cells to become sickle-shaped and rigid. Notably, about 25% of Nigerians are carriers of the sickle cell gene, while the HbC trait is largely confined to the Yoruba ethnic group in Southwest Nigeria, occurring in about 6% of people [3, 4]. High risk genetic combinations from unions or marriages between two carriers, or a carrier and an individual with SCD, can lead to the conception of children with SCD.

Despite numerous awareness programmes emphasising the importance of premarital phenotype testing to prevent the birth of children with sickle cell disease (SCD), research continues to report a lack of alignment between knowledge and informed decision-making regarding marital choices. Specifically, while individuals may be aware of their phenotype, some exhibit a tendency to prioritise cultural, emotional, or societal factors over genetic risk considerations. For instance, studies have documented that a significant proportion of individuals express a willingness to proceed with marriages that carry a high risk of producing a child with SCD, with rates estimated at 14.4% in the Federal Capital Territory of Nigeria and 19.2% in Benin, Edo State, Nigeria [5, 6]. A study among unmarried adults in Lagos found that less than half of respondents (38.3%) agreed that relationships should end if phenotype combinations carry the risk of SCD birth [7]. Another study among nursing students found that, while 71.3% were aware of their phenotype, 13.3% expressed a willingness to proceed even when it carries the risk of SCD birth, and 22.4% indicated they might do so [8]. It is therefore not surprising that about 150,000 children are born annually with sickle cell anemia in Nigeria [9, 10].

When knowledge does not translate into action, notions and misconceptions rooted in tradition, cultural beliefs, and religion are often implicated. A study among undergraduates in Ibadan, Nigeria, attending pentecostal fellowships found several misconceptions: almost one third (31%) believed that people should worry less about SCD as God would take care of it; 16.9% believed that SCD cannot run in the family of Christians who believe in God; and 10.3% agreed that going for premarital genetic counselling represented a lack of faith in God [11]. These findings highlight the role that individual beliefs and opinions play in marital decisions and how they affect SCD-related marriage potentials.

SCD is a lifelong condition that requires costly continuous medical care and specialised treatment. It is also associated with high morbidity, reduced life expectancy, poor school and work attendance, and the risk of opioid dependence, which further compounds the challenges faced by affected individuals and their families [12]. These issues can lead to financial difficulties, family disharmony, separation, and divorce [13]. Hence, more attention must be paid to understanding the dissonance between the numerous premarital phenotype testing awareness programmes and the action taken by individuals.

This study shifts the focus from assessing hypothetical decisions among young unmarried individuals to examining real-life choices made by parents of patients with SCD. Unlike previous research, which often focused on probabilities and theoretical willingness to marry despite mutual sickle cell trait awareness, this research investigated actual decisions made by couples who knowingly made marital decisions despite being aware of their sickle cell status. By exploring the various factors that shaped these choices, it offers a deeper understanding of the influences behind these decisions. Our hope was that our study could inform effective awareness programmes and policies, ensuring that knowledge of sickle cell risks is effectively translated into action, ultimately reducing the incidence of SCD in Nigeria.

Materials and methods

Setting, design and study population

This mixed method study involved 209 parents of children with SCD who are receiving care at the paediatric haematology clinics of the University College Hospital (UCH) and Oni Memorial Children Hospital (OMCH) in Ibadan, Oyo State, Nigeria. The qualitative component of the study used key informant interviews (KIIs), involving 5 participants (described below), to gain in-depth insights on the research question.

Sample size

For sample size calculation, we used the formula for estimating proportions:

$$N = \frac{Z^2 P(1-P)}{d^2}$$

Where:

N = sample size.

Z = z score of 1.96 given a confidence interval of 95%

P = 0.5 (assuming a prevalence rate of 87.1 for awareness of sickle cell trait [14]).

d = margin of error of 5%

N = 173.

Assuming a non response rate of 10%, the sample size is 192. Therefore, the study requires a minimum of 192 participants.

Participant recruitment, inclusion and exclusion criteria

Parents of children with SCD attending the haematology clinics of UCH and OMCH during the study period were invited to participate. Only biological parents who provided informed consent were recruited, while non-biological parents or caregivers were excluded. For the qualitative component, key informants were selected from key populations involved in SCD, including a consultant haematologist, a public health nurse, an SCD advocate, a parent of a child with SCD, and a child living with SCD.

Participants for the qualitative study

KI 1	Consultant haematologist
KI 2	Public Health Nurse
KI 3	SCD advocate
KI 4	Mother
KI 5	Child

Data collection procedure

Participants for the quantitative and qualitative components of this study were recruited based on their relevance to the study objectives. The purpose of the study was explained to all potential participants in their preferred language—either English or Yoruba. Interested participants were provided with detailed information about the study, including its objectives, their rights as participants, and confidentiality considerations.

Parents attending the paediatric haematology clinics during the study period were invited to participate in the quantitative study. The study's objectives were explained and written informed consent was obtained before they completed a structured survey. The survey, administered by an interviewer in the respondents' preferred language, gathered sociodemographic data and explored reasons for union despite awareness of the sickle cell gene. Key informants (KIs) were purposively recruited from key populations involved in SCD. These included a consultant haematologist, a public health nurse, an SCD advocate, a parent of a child with SCD and a child living with SCD. Only the parent and child were recruited from the haematology clinics. For each participant, the study's purpose was explained, and detailed information was provided before informed consent was obtained.

Semi-structured interviews were conducted using an interview guide consisting of open-ended questions designed to explore reasons for unions despite awareness of sickle cell phenotypes. Interviews were scheduled at times and locations convenient for participants. Additional questions and prompts were included during interviews to further clarify and probe responses. Each interview, lasting approximately 30 to 40 min, was audio-recorded with the participant's consent, and transcribed verbatim for analysis. Field notes were taken as a backup in case of technical issues with audio recordings, and confidentiality was strictly maintained by de-identifying transcripts. Interviews were conducted by trained members of the research team, who explained the purpose of the study and their role while maintaining neutrality by refraining from sharing personal details. Participants were informed that they could withdraw from the study at any time without repercussions. Monetary compensation was given to participants for their participation.

Data analysis

The quantitative data from the survey were analysed using IBM SPSS Statistics version 27.0, following thorough data cleaning and visualisation. Descriptive statistics were used to generate tables that presented sociodemographic information and the reasons for union despite awareness of the sickle cell phenotype by both parents. The qualitative data, derived from semi-structured interviews, were transcribed verbatim and analysed manually using thematic analysis. This approach enabled an in-depth engagement with the data to identify patterns and recurring themes related to the reasons for unions despite awareness of sickle cell phenotypes. Thematic analysis followed Braun and Clarke's six-step framework [15]. Coding was performed by two researchers independently and discrepancies were resolved through discussion to ensure consistency and reliability.

Ethical approval

The study received ethical approval from the University of Ibadan/University College Hospital Ethics Committee with IRB number 23/0012. Informed consent to participate was obtained from all participants prior to their inclusion in the study. This process adhered to ethical principles outlined in the Declaration of Helsinki.

Results

A total of 209 parents of children with sickle cell disease attending haematology clinics at the study sites participated in the survey. Table 1 summarizes the sociodemographic variables of the participants. Most responses (81.3%) came from UCH, while 18.7% were from OMCH. The survey was completed by the parent accompanying the child to the clinic, or by either parent if both were present. Most participants (69.7%) fell within the 35–49 age range, with a mean age of 40.0 ± 6.8 years and a median age of 40 years, and most respondents (87.6%)

Table 1 Sociodemographic characteristics

Variable	Frequency	Percent
Site		
OMCH	39	18.7
UCH	170	81.3
Age group (years)		
Mean ± SD = 40.0 (6.8)		
20–34	44	20.9
35–49	147	69.7
≥ 50	18	8.5
Relationship with patient		
Father	26	12.4
Mother	183	87.6
Ethnicity		
Yoruba	189	90.4
Others	20	9.6
Level of Education		
Primary	12	5.7
Secondary	67	32.1
Tertiary (non-university)	42	20.1
Tertiary (university)	88	42.1
Religion		
Christianity	119	56.9
Islam	90	43.1
Employment status		
Employee	47	22.5
Housewife	1	0.5
Retired	1	0.5
Self-employed	158	75.6
Unemployed	2	1.0

Table 2 Awareness of own and spouse's' sickle cell phenotype before marriage

		Response	About self—F (%)	About partner—F (%)
Relationship	Father	No	15 (57.7)	12 (46.2)
		Yes	11 (42.3)	11 (42.3)
	Mother	No	97 (53.0)	131 (71.6)
		Yes	86 (47.0)	52 (28.4)

were mothers. Christians constituted 56.9% of the participants while 43.1% identified with Islam. In terms of educational background, 62.2% of participants had tertiary education, with others having primary or secondary education. Most participants were of Yoruba ethnicity (90.4%) and most were self-employed (75.6%).

Table 3 Awareness of self and spouses' sickle cell phenotype before marriage

	F (%)
No vs No	76 (36.7)
No vs Yes/Yes vs No	103 (49.8)
Yes vs Yes	30 (14.5)

Table 4 Reasons for marital decision among Yes vs Yes couples

Reasons for marital decision* (*N* = 30)	Frequency	% of cases
Religious reasons	6	20
Take the risk and hope for the best	14	46.7
Willing to bear the consequences	8	26.7
Not aware of the implications	10	33.3

*Multiple responses

Table 2 shows that, before marriage, 71.6% of mothers were not aware of their partner's sickle cell phenotype and 53.0% were not aware of their own phenotype. It also shows that, before marriage, 46.2% of fathers were not aware of their partner's phenotype and 57.7% were not aware of their own phenotype.

As shown in Table 3, among half of all couples (49.8%), only one partner was aware of their sickle cell phenotype, while among 36.7% of couples, neither knew. Both partners were informed in only 14.5% of couples, indicating a significant lack of awareness within couples. As one KI said, *"They (the parents) did not know (their genotype)... they just got married." (KI 7).* Also, another KI said, *"... Then there is another thing I have come to discover from interacting with people, I discovered that many people did not do genotype test when they had their marriage. From the parents, many did not, they just got married." (KI 3).*

Table 4 highlights the reasons for phenotype combinations that carry risk of SCD birth. In 20% of cases, respondents gave religious reasons. This sentiment is echoed in the narratives from the qualitative data, where KI 3 explained that some individuals believe they have faith and see their union as guided by hope rather than medical caution as supported—"*I have heard about people that said they believe that they have faith*"**.** KI 1 further emphasised this perspective, stating that many decisions are often made "based on hope and faith" in this region of the world.

In 46.7% of cases, respondents cited a willingness to take risks as their reason. This aligns with the account of KI 3, who observed that people often frame these decisions as a matter of "probability." Similarly, KI 1 described

instances of couples choosing to marry despite known risks, believing they "can cope with whatever happens" as seen in statements like "*I would go for cure, I would go for stem cell transplant and that.*"

Additionally, 26.7% of respondents expressed a willingness to bear the consequences of their decision. This is supported by the narrative from KI 2, who recounted couples stating they were aware of the risk of having children with SS phenotype but proceeded with the union because "there is no other person for them to marry" and they were "getting older—"*Sometimes you see some couples when they come here with their children, you ask them, do you know the genotype before you marry, they would tell you they know. They know they're both AS and AS, if you ask them if they are aware they could have SS they tell you yes. They said since there is no other person for them to marry and they are getting older, they will go ahead and get married.*" This is further corroborated by KI 1 who recounted instances of seeing adults make decisions based on love and their willingness to cope with the possible consequences—"*I have seen adult people who say they love themselves more and can cope with whatever happens.*"

Finally, one third (33.3%) of respondents were unaware of the implications of phenotype combinations that carry risk of SCD birth. This suggests a gap in education and awareness, which public health professionals and advocates have highlighted as a critical issue. For example, KI 2 described couples who were aware of their phenotypes but might not fully grasp the long-term implications of having children with SCD.

Table 5 illustrates the relationship between educational level and awareness of sickle cell phenotypes in individuals and their partners prior to marriage. Among individuals with education below the tertiary level, a majority (73.4%) were unaware of their own sickle cell phenotype before marriage, while only 26.6% demonstrated awareness. Similarly, 81.0% of this group did not know their partner's phenotype, compared to 19.0% who were aware. In contrast, individuals with tertiary education exhibited higher levels of awareness. Most respondents in this category (58.5%) were aware of their own sickle cell phenotype prior to marriage, while 41.5% were not. Awareness of their partner's phenotype was lower, with 39.2% reporting knowledge and 60.8% remaining unaware.

Discussion

This mixed-method study shows the multifaceted determinants influencing marital decisions in the context of SCD awareness among Nigerian parents.

Most significantly, the study highlights a gap in premarital awareness of sickle cell phenotypes among participants, particularly in the context of mutual knowledge between partners. Only a few proportion of participants reported mutual premarital spousal awareness of sickle cell phenotype while a notable percentage reported mutual premarital spousal unawareness. This lack of awareness was notably more prevalent among mothers, who were often unaware of their partner's sickle cell status prior to marriage. A possible explanation for this could be the patriarchal nature of Nigerian society where women are generally less vocal and, thus, less questioning [16]. This lack of knowledge about one's partner's status among women in the study is in contrast with findings in a 2015 study conducted in the United States among adult African American women with SCD that found that nearly all women (79%) asked their partners to undergo genetic testing [17]. This stark contrast in partner phenotype awareness levels between Nigerian and African American women exists despite the fact that, in Africa, women are mostly responsible for ensuring better quality of life for their children (evidenced by 87.6% of respondents being mothers) and women usually having to bear blame for their own ill health and that of their children [18]. These results corroborate previous studies highlighting inadequate genetic health literacy in sub-Saharan Africa [14, 19–21] and underscore the critical need for enhanced sickle cell education and pre-marital screening programmes in Nigeria.

The sociodemographic profile of the study population provides crucial context for interpreting these findings. Most participants were mothers, had tertiary education and were self-employed. This profile suggests a relatively educated and economically active cohort, yet pre-marital

Table 5 Educational level and awareness of sickle cell phenotype before marriage

		Did you know about your sickle cell phenotype before marriage?		Did you know about the sickle cell phenotype of the other partner before marriage?	
		NO frequency (%)	YES frequency (%)	NO frequency (%)	YES frequency (%)
Educational Level	Below Tertiary	58 (73.4)	21 (26.6)	64 (81.0)	15 (19.0)
	Tertiary	54 (41.5)	76 (58.5)	79 (60.8)	51 (39.2)

awareness of sickle cell status remained generally low. This disconnect suggests that education does not automatically result in improved health literacy, underscoring the need for more effective dissemination of genetic health information across all educational strata [22, 23].

The study identified several key factors influencing the decision to proceed with phenotype combinations that carry risk of SCD birth. The predominant reason cited was a willingness to"take the risk and hope for the best."This finding suggests the presence of optimism bias, a cognitive phenomenon wherein individuals underestimate the probability of negative outcomes [24]. It also indicates that immediate emotional or social considerations may supersede long-term health implications in marital decision-making processes.

Our study points to a concerning trend of individuals making decisions that carries the potential risk of SCD birth on the basis of willingness to bear the consequences of the outcome. This decision may be influenced by various factors, including social pressure and fear of stigma [25], limited partner options, or a lack of appreciation for the long-term challenges of raising a child with SCD. Our study findings are consistent with the findings of a Saudi cross-sectional study that identified poor knowledge of short and long term complications among respondents [26]. The comment from a public health nurse about couples proceeding with marriage despite awareness of their AS status due to age concerns or lack of alternative partners in the present study underscores the complex interplay of social and personal factors in these decisions.

Notably, the study reported significant levels of unawareness of the implications of phenotype mismatch, especially as it concerns heterosexual marital decisions. This not only raises critical questions about the efficacy of existing health education programmes and the accessibility of genetic counselling services in Nigeria, but also emphasises the urgent need to critically review the content of SCD education and ensure widespread dissemination of verified information.

Additionally, respondents cited religion as a ground for proceeding with phenotype combinations that carry risk of SCD birth. Our qualitative data also suggests that faith plays a role in decision-making. Comments from healthcare providers indicate that some couples rely on faith or divine intervention to mitigate the risk of having a child with SCD. This finding highlights the importance of engaging religious leaders in SCD awareness campaigns and incorporating cultural sensitivity into genetic counselling approaches.

The study's findings have significant implications for public health policy and practice in Nigeria. Firstly, they underscore the need for more comprehensive and accessible pre-marital genetic screening programmes, coupled with robust genetic counselling services. These interventions should aim to ensure that couples fully comprehend the implications of their genetic compatibility. Secondly, the results call for intensified and tailored public health education campaigns that address the specific reasons individuals cite for proceeding with marital decisions despite awareness of sickle cell status. These campaigns should focus on dispelling misconceptions, providing accurate information about the long-term impact of SCD, and offering support for informed decision-making. Thirdly, the influence of religious and cultural factors on marital decisions necessitates a multidisciplinary approach to SCD prevention. Engaging religious leaders, cultural figures, and community influencers in awareness campaigns could help bridge the gap between scientific knowledge and cultural practices.

While this study provides valuable insights, it has several limitations. This study precludes causal inferences, and the sample's ethnic concentration may limit generalisability to other regions of Nigeria or Africa. Future research should consider longitudinal designs to examine the long-term outcomes of couples who knowingly enter phenotype-incompatible marriages. Understanding their experiences and coping mechanisms could provide valuable insights for developing support systems and interventions for families affected by SCD. Additionally, further investigation into the relationship between educational level, religious beliefs, and genetic health decisions is warranted. Such research could inform the development of more effective, culturally sensitive interventions to prevent phenotype combinations that carry risk of SCD birth marriages.

Conclusion

This study found significant challenges in preventing phenotype combinations that carry risk of SCD birth, despite awareness of SCD. The complex interplay of knowledge, beliefs, and social factors in marital decisions underscores the need for a multifaceted approach to SCD prevention. Our findings contribute to the growing body of literature on genetic health literacy in developing countries and provide a foundation for evidence-based policy interventions in Nigeria and similar contexts.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12889-025-23066-8.

Supplementary Material 1

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Clinical trial number
Not applicable.

Authors' contributions
AAA, JSL, DMA, AOO, OEA and AAB conceived the study and designed the experimental protocol. AAA, JSL, DMA, AOO, OEA and AAB carried out the experiment. AAA analysed the data. AAA, JSL, DMA, AOO, OEA and AAB and BJB wrote the manuscript. All authors read and approved the manuscript.

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Data availability
This will be made available on request from the corresponding author.

Declarations

Ethics approval and consent to participate
The study received ethical approval from the University of Ibadan/University College Hospital Ethics Committee with IRB number 23/0012. Informed consent to participate was obtained from all participants prior to their inclusion in the study. This process adhered to ethical principles outlined in the Declaration of Helsinki.

Consent for publication
All participants in this study provided informed consent for the use and publication of their data. This manuscript contains no identifying information of the participants, ensuring confidentiality in accordance with ethical standards.

Competing interests
The authors declare no competing interests.

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