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Accuracy of Self-Reported Haemoglobin Genotype in a Rural Nigerian Community: Implications for Sickle Cell Disease Prevention

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ABSTRACT

Background: In high-burden settings for sickle cell disease (SCD), many prevention strategies implicitly assume that adults who report “knowing their haemoglobin genotype” can accurately recall it. However, in rural Nigerian communities, where testing is often sporadic and post-test counselling inconsistent, the reliability of self-reported genotype remains poorly documented.

Objective: To assess the accuracy of self-reported haemoglobin genotype among adults in Benue South Senatorial District and to describe patterns of misclassification compared with laboratory-confirmed results.

Methods: A community-based cross-sectional study was conducted among 372 adults in three Local Government Areas of Benue South, Nigeria. Participants were asked whether they knew their haemoglobin genotype and, if yes, to state it (AA, AS, or SS). All participants provided venous blood for alkaline cellulose acetate haemoglobin electrophoresis, which served as the reference standard. Accuracy was defined as concordance between self-reported and laboratory-confirmed genotype among those who claimed awareness. Agreement was assessed using cross-tabulation and Fisher’s exact test.

Results: Only 32 of 372 respondents (8.6%) reported knowing their haemoglobin genotype. Among these, 26/32 (81.3%) correctly stated their laboratory-confirmed genotype, while 6/32 (18.7%) were incorrect (Fisher’s exact $p = 0.008$). Accuracy was highest among those reporting AA (22/25; 88.0%), moderate among those reporting AS (4/6; 66.7%), and absent in the single respondent who reported SS (0/1). Misclassification occurred in both directions, with some individuals with AS misreporting as AA and vice versa.

Conclusion: Although most individuals who claimed awareness correctly identified their genotype, nearly one in five were wrong. Reliance on self-report alone is therefore unsafe for premarital or antenatal counselling and community screening decisions. SCD prevention programmes should prioritise confirmatory testing, clearer post-test counselling, and written documentation of results rather than verbal self-declaration.

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INTRODUCTION

Sickle cell disease (SCD) remains one of the most important inherited haemoglobin disorders worldwide and a leading cause of preventable morbidity and premature mortality in sub-Saharan Africa, where the majority of affected births occur [1–4]. Nigeria carries one of the highest burdens globally, reflecting persistently high carrier frequency and continued intergenerational transmission [2,5]. Beyond clinical complications, SCD imposes substantial social and economic burdens on families and health systems, including recurrent hospitalisation, lost productivity, educational disruption, and catastrophic out-of-pocket health expenditure [4,6,7].

A cornerstone of primary prevention of SCD is early identification of carriers through haemoglobin genotype testing, ideally before marriage or pregnancy, to enable informed reproductive decision-making and appropriate genetic counselling [4,8–10]. In many settings, individuals encounter genotype testing through premarital counselling, antenatal care, school health programmes, employment screening, or opportunistic testing during illness [5,7–11]. However, where testing is neither routine nor systematically integrated into primary healthcare, many adults reach reproductive age without ever being tested or receiving structured counselling [8–13].

Most community-based SCD prevention strategies implicitly assume that adults who report “knowing their genotype” can accurately recall it when needed, for example, during premarital counselling, antenatal booking, or community screening programmes [10–13]. This assumption underpins many real-world practices in Nigeria, where verbal self-declaration is frequently accepted as sufficient evidence of genotype status in schools, religious institutions, workplaces, and even some health facilities [12–16].

However, awareness does not necessarily equal accuracy. Individuals may misreport their genotype for several reasons, including misunderstanding of results, poor communication at the time of testing, use of non-standard laboratory methods, memory decay over time, or confusion between similar designations such as AA and AS [8,12]. Inaccurate self-report can have serious consequences: it may provide false reassurance to couples, delay appropriate counselling, or lead to missed opportunities for prevention of SCD births [8,10–13].

Despite this risk, most Nigerian studies have focused on awareness or uptake of genotype testing, rather than the accuracy of self-reported results [12–16]. Facility-based studies suggest that some individuals confuse AA and AS, or misinterpret earlier test results performed years before, but robust community-level evidence comparing self-report with laboratory confirmation remains scarce, particularly in rural settings where access to reliable testing and post-test counselling may be inconsistent [8,12].

Benue State, despite its large population and high SCD burden, has limited community-based data on the reliability of self-reported haemoglobin genotype among adults. Most available evidence derives from hospitals, schools, or antenatal clinics, which may over-represent individuals already engaged with the health system.

This study therefore evaluates the accuracy of self-reported haemoglobin genotype in a rural adult population in Benue South Senatorial District by comparing participants’ stated genotype with laboratory-confirmed haemoglobin electrophoresis results. Understanding the reliability of self-report is critical for improving counselling practices, designing safer community screening programmes, and informing policies that currently rely heavily on verbal self-declaration rather than confirmatory testing.

METHODS

Study design and setting

This was a community-based cross-sectional study conducted in Benue South Senatorial District, Benue State, Nigeria, across three LGAs: Ohimini, Otukpo, and Okpokwu.

Study population and sampling

Adults aged ≥18 years were recruited from randomly selected households using a multistage sampling approach. A total of 372 respondents participated.

Data collection

Participants were asked:
“Do you know your haemoglobin genotype?” (Yes/No)
If yes: “What is your genotype?” (AA, AS, or SS)

Laboratory procedures

Venous blood (5 mL) was collected into K_2-EDTA tubes and analysed using alkaline cellulose acetate haemoglobin electrophoresis, which served as the reference standard.

Outcome measure

The primary outcome was accuracy of self-reported genotype, defined as concordance between stated and laboratory-confirmed genotype among those who claimed awareness.

Statistical analysis

Data were analysed using SPSS v22. Concordance was assessed using cross-tabulation and Fisher's exact test. Significance was set at p<0.05.

Ethical considerations

Ethical approval was obtained from the FUHSO Ethics Committee. Community entry, informed consent, and confidentiality procedures were followed.

RESULTS

Awareness of genotype status

Only 32 of 372 respondents (8.6%) reported knowing their haemoglobin genotype.

Among these 32:

- 25 reported AA
- 6 reported AS
- 1 reported SS

Accuracy of self-reported genotype

When compared with laboratory results:

- Overall accuracy: 26/32 (81.3%) correct
- Incorrect: 6/32 (18.7%)
- Fisher's exact test: p = 0.008

Accuracy by reported genotype

Perceived genotype	Correct n (%)	Incorrect n (%)	Total
AA (n=25)	22 (88.0%)	3 (12.0%)	25
AS (n=6)	4 (66.7%)	2 (33.3%)	6
SS (n=1)	0 (0.0%)	1 (100%)	1
Total (n=32)	**26 (81.3%)**	**6 (18.7%)**	**32**

*Fisher's Exact Test= 11.187, P= 0.008**

Pattern of misclassification:

- Some individuals with AS misreported as AA
- Some with AA misreported as AS
- The single person reporting SS was incorrect

DISCUSSION

This community-based study demonstrates that self-reported haemoglobin genotype is not perfectly reliable in rural Nigerian settings. Although most respondents who claimed awareness correctly stated their laboratory-confirmed genotype, nearly one in five (18.7%) were incorrect, a level of inaccuracy that has important clinical, ethical, and public health implications for SCD prevention.

The very low proportion of adults who reported knowing their genotype (8.6%) is consistent with broader evidence that routine genotype testing remains limited in many rural Nigerian communities [12–16]. However, this paper moves beyond awareness to highlight a more subtle but critical problem: even among those who believe they know their genotype, a significant minority are mistaken. Many prevention efforts assume that awareness equals accuracy; our findings challenge that assumption.

From a counselling perspective, inaccurate self-report creates real risks. In premarital or antenatal contexts, couples are often asked to state their genotype before further testing is considered. If one or both partners incorrectly report AA when they are actually AS, they may be falsely reassured and decline confirmatory testing, unknowingly risking the birth of a child with SCD [8,10–13]. Conversely, misreporting AS as AA may lead to missed opportunities for timely genetic counselling and reproductive planning.

Several factors likely contribute to misclassification. Some participants may have been tested many years earlier and forgotten or misremembered their results, particularly in the absence of written documentation [8,12]. Others may have been tested in informal laboratories using non-standard methods. Poor communication of results at the time of testing, without clear explanation of what

AA, AS, or SS means, may also leave individuals uncertain about their status. Finally, confusion between AA and AS is common in low-literacy settings, where genetic concepts are poorly understood [12–16].

The pattern of misclassification observed, where some individuals with AS reported AA and vice versa, is particularly concerning because it undermines the logic of SCD prevention. The greatest public health risk arises when AS individuals mistakenly believe they are AA, as this group is most likely to proceed into high-risk relationships without appropriate counselling [8,10–13].

Programmatically, our findings suggest that community-based SCD prevention efforts should move away from reliance on verbal self-report alone. Instead, confirmatory testing should be treated as the standard of care, particularly in premarital and antenatal settings. Point-of-care electrophoresis or reliable rapid tests integrated into outreach programmes could substantially reduce misclassification.

Equally important is the need for stronger post-test counselling and documentation. Issuing written genotype cards, digital records, or clinic slips could help individuals retain accurate information over time. Health workers should also explain results in simple language, emphasising the implications of AS versus AA for reproduction and family planning.

Strengths and limitations

A major strength of this study is its household-based sampling design, which provides population-relevant estimates rather than facility-based estimates that may overrepresent health service users. Additionally, all participants underwent laboratory-confirmed haemoglobin electrophoresis, ensuring robust measurement of misclassification.

However, the number of respondents who claimed awareness was small (n=32), limiting statistical precision. We also did not collect detailed information on when or where participants were previously tested, which could have clarified sources of error. Future studies should explore these aspects, including laboratory quality, counselling practices, and record-keeping.

Overall, this study highlights a critical but often overlooked dimension of SCD prevention: knowing one’s genotype is not the same as knowing it correctly. As Nigeria expands community screening and premarital counselling initiatives, ensuring accuracy through confirmatory testing and clear documentation will be essential to prevent avoidable SCD births and to build trust in genetic services.

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CONFLICT OF INTEREST

The authors declare no competing interests.

AUTHOR CONTRIBUTION

This work is the concept of author Michael Aanthony Onoja, who designed the study, collected, analysed and interpreted the data and wrote the final manuscript for publication. Authors Elizabeth O, Theresa AO and IAO Ujah all participated in data collection, interpretation, drafting of the article and revising it critically for important intellectual content. All authors gave final approval of this version to be published.

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