Review Article

Integrating Genetic Literacy with Religious and Cultural Beliefs to Address Sickle Cell Disease Misconceptions in Africa: Findings from Selected Literatures

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ABSTRACT

Sickle cell disease (SCD) remains a pervasive public health challenge across Africa, where cultural and religious narratives often attribute the condition to spiritual misfortune or divine judgment. Terms such as “Sikila” (Hausa), “Ahotutuo” (Ashanti), “Abiku” (Yoruba), and “Ogbanje” (Igbo) illustrate how language embeds misconceptions, reinforcing stigma and deterring medical intervention. The aim of this study is to examine how integrating genetic literacy with religious and cultural belief systems can effectively address misconceptions, reduce stigma, and improve understanding of sickle cell disease among communities in Africa. This study adopts a qualitative synthesis approach to examine the intersections of language, religion, and health in shaping understandings of sickle cell disease (SCD) in Nigeria and Ghana. Peer-reviewed journal articles published between 2015 and 2025 were retrieved from PubMed and Google Scholar, supplemented with community-based reports and grey literature, including health ministry publications and NGO reports from Nigeria and Ghana. Cultural and religious interpretations shape perceptions of sickle cell disease (SCD) across West Africa, with terms like Sikila, Abiku, Ogbanje, and Ahotutuo reinforcing stigma and spiritual explanations. Christian and Islamic teachings often foster fatalistic attitudes but can also support compassion and healing. Recent studies show newborn screening is culturally acceptable, while genetic literacy improves counseling. Faith-anchored education, linguistic reframing, and community outreach offer promising strategies for reducing stigma and improving SCD management. Misconceptions about SCD in Africa rooted in cultural terms such as “Abiku”, “Ogbanje”, “Sikila”, and “Ahotutuo”, and in religious interpretations of illness perpetuate stigma and obstruct prevention. However, integrating genetic literacy into religious and cultural frameworks would creates a powerful pathway for change

Keywords: Cultural, Genetic literacy, Sickle cell disease

INTRODUCTION

SCD is caused by a mutation in the HBB gene, producing abnormally shaped hemoglobin (HbS) that leads to vaso-occlusion, chronic pain, anemia, and organ damage.[1] In sub-Saharan Africa particularly Nigeria and Ghana between 1–2% of newborns are affected, representing the highest burden globally.[2]

Africa carries the greatest global burden of sickle cell disease (SCD), with countries such as Cameroon, Ghana, Nigeria, Tanzania, and the Democratic Republic of Congo (DRC) reporting prevalence rates of 1–3% for SCD and 20–30% for sickle cell trait (SCT)[2]. Each year, an estimated

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405,000 infants are born with SCD in sub-Saharan Africa, accounting for nearly 79% of global annual SCD births[3]. The region also experiences the highest levels of mortality, particularly under-five deaths related to SCD[3]. Given this heavy disease burden and its associated economic, social, and psychological impacts, genetic testing and screening initiatives for SCD and SCT represent potentially effective strategies for disease management[3]. Three key approaches are recommended: new-born screening (NBS), premarital or preconception screening for SCT, and prenatal screening. NBS enables early detection, which can significantly improve infant care and outcomes. Prenatal screening provides at-risk couples with information about the likelihood of having a child with SCD, supporting decisions on pregnancy management, including preparation for care or medical termination. Premarital screening, on the other hand, identifies SCT carriers, thereby guiding reproductive planning and informed decision-making.

Cultural and linguistic framings are central to these misperceptions. Among the Hausa, “Sikila” is commonly linked to ancestral curses.[3] Yoruba cosmology labels children with SCD as “Abiku”, reinforcing cycles of stigma.[4] Among the Igbo, “Ogbanje” perpetuates the belief in spirit-possession,[5] while in Ghana, the Ashanti expression “Ahotutuo” (body pinching) describes painful crises as supernatural assaults.[6]

It is impossible to overestimate the significance of culturally sensitive education in preventing sickle cell disease (SCD) in adolescents. By acknowledging and respecting the varied cultural, socioeconomic, and linguistic backgrounds of those impacted by sickle cell disease, culturally tailored education acts as a link between healthcare professionals and the communities they serve. This method recognizes that, especially for marginalized groups, cultural variables have a major impact on health attitudes, practices, and results. Culturally tailored education tackles the special requirements and difficulties faced by adolescents with sickle cell disease (SCD) and their families by modifying educational activities to conform to culture norms, beliefs, and practices. Raising awareness of SCD in communities where stigma and misunderstandings may be prevalent is one of the main advantages of culturally adapted education.

Religious thought further shapes these beliefs. In Christianity, illness is sometimes framed as a consequence of humanity's fall, leading some to interpret SCD as divine punishment.[7] In Islamic contexts, illness may be attributed to jinn or viewed as a test from Allah, though the Qur'an encourages the pursuit of remedies.[8] These interpretations perpetuate stigma and fatalism, obstructing genetic screening and premarital counseling programs. This study was therefore set up to examine how integrating genetic literacy with religious and cultural belief systems can effectively address misconceptions, reduce stigma, and improve understanding of sickle cell disease among communities in Africa.

MATERIALS AND METHODS

This study adopts a qualitative synthesis approach to examine the intersections of language, religion, and health in shaping understandings of sickle cell disease (SCD) in Nigeria and Ghana. The methodology combined systematic literature search, screening, and thematic coding to generate an interpretive analysis.

Data Sources and Search Strategy: Peer-reviewed journal articles published between 2015 and 2025 were retrieved from PubMed and Google Scholar, supplemented with community-based reports and grey literature, including health ministry publications and NGO reports from Nigeria and Ghana. Keywords included “sickle cell disease”, “cultural narratives”, “religion and health”, “community interventions”, and “Nigeria/Ghana”. Reference lists of key papers were also screened to identify additional sources.

Inclusion and Exclusion Criteria: Studies were included if they addressed linguistic representations of SCD, religious and cultural interpretations, or described public health and faith-based interventions in West Africa. Excluded were studies focused solely on biomedical treatment outcomes without socio-cultural analysis.

Data Extraction and Coding: Relevant texts were imported into NVivo 14 for systematic analysis.

Thematic coding was applied using a hybrid approach: deductive codes were pre-defined based on the study aims (e.g., "linguistic constructions," "religious narratives," "faith-based interventions"), while inductive codes emerged during reading (e.g., "stigma in local proverbs," "healing ministries," "intermarriage prevention").

Analytical Framework: The synthesis emphasised three thematic domains:

- Linguistic constructions of SCD (e.g., terms such as Sikila, Abiku, Ogbanje, Ahotutuo) that reflect indigenous understandings of illness.
- Religious narratives and interpretations, including Pentecostal, Islamic, and traditional beliefs framing SCD as spiritual affliction or divine test.
- Public health and faith-based interventions, covering newborn screening campaigns, premarital testing, and partnerships with churches and mosques.

RESULTS AND DISCUSSION

Of 1,500 records identified, 700 were screened after removing duplicates. Full texts of 50 studies were assessed, and 8 were included for the study

1. Linguistic Influences

Terminology significantly shapes perceptions of SCD. Hausa-speaking communities often link "Sikila" to curses.[3] Yoruba cosmology labels children with SCD as "Abiku", reinforcing cycles of stigma.[4] The Igbo concept of "Ogbanje" sustains the idea of spirit-possession,[5] while the Ashanti term "Ahotutuo" attributes painful crises to supernatural pinching.[6] These misconceptions encourage spiritual rather than medical interventions, delaying treatment.

2. Religion and Stigma

Christian doctrines of the Fall foster interpretations of disease as divine retribution.[7] Among Islamic communities, illness may be understood as a divine trial or the influence of jinn.[8] Both contexts can produce fatalistic attitudes, discouraging premarital screening or acceptance of medical care. Yet scripture also offers opportunities: the Bible emphasizes compassion, while the Qur'an highlights knowledge and healing, aligning with a genetic-literacy approach.

3. Recent Evidence and Implications

Recent studies highlight evolving dynamics:

A multi-country study in Cameroon, Ghana, and Tanzania found that newborn screening is more culturally acceptable than premarital or prenatal testing due to concerns over stigma and family conflicts.[10]

Research among Ghanaian nurses showed that stronger genetic literacy and cultural competence significantly improved counseling effectiveness, suggesting a critical role for faith-informed education.[11]

Among young adults in Ghana, persistent beliefs linking SCD to spiritual or cultural explanations hinder prevention strategies, showing the urgency of linguistic and cultural reframing.[12]

4. Framework for Integration

Based on these insights, we propose:

1. Faith-Anchored Genetic Counseling: Train church leaders and imams to deliver simple explanations of autosomal-recessive inheritance, linking it to stewardship of life.[7],[8],[11]

2. Linguistic Reframing: Redefine traditional terms through health campaigns (e.g., "Abiku is not a spirit—it is a genetic condition we can manage").[3],[4],[5],[6],[12]

3. Community Outreach: Expand faith-based initiatives, modeled on programs by the Sickle Cell Foundation of Ghana.[9]

4. Evaluation: Monitor whether faith-informed interventions increase screening uptake and reduce stigma.[10],[11],[12]

CONCLUSION

Misconceptions about sickle cell disease (SCD) in Africa are deeply embedded in cultural and religious frameworks. Terms such as the Yoruba "Abiku" ("born to die"), the Igbo "Ogbanje" ("spirit child"), the Hausa "Sikila", and the Ashanti "Ahotutuo" (painful pinching) reflect cosmologies that frame SCD as a spiritual or supernatural phenomenon rather than a genetic condition. Similarly, religious interpretations often view illness as divine punishment, trials of faith, or the influence of spirits, reinforcing fatalism and stigma.[7–8] These narratives delay medical care, discourage premarital or prenatal screening, and perpetuate secrecy around the condition.

However, integrating genetic literacy within cultural and religious frameworks offers a transformative pathway. By training church leaders, imams, and traditional authorities to communicate scientific explanations of inheritance in culturally resonant language, communities can reframe SCD as a manageable health condition rather than a curse. Reinterpreting local terms, for instance redefining Abiku as "a child with a genetic condition who can live with care," bridges science and tradition while reducing stigma.

Recent evidence demonstrates that faith-informed, community-based interventions enhance the acceptability of newborn screening and improve counseling effectiveness among healthcare providers. Aligning biomedical strategies with cultural narratives and religious teachings fosters informed decision-making, reduces stigma, and builds sustainable, community-owned models for SCD prevention across Africa..

Recommendations

Training faith leaders and traditional authorities to communicate accurate genetic information in culturally meaningful ways can help reframe SCD from a supernatural condition to a manageable genetic disorder, reducing stigma and fatalism. Reinterpreting indigenous terms such as Abiku or Ogbanje in non-stigmatizing language allows communities to retain cultural identity while promoting biomedical understanding. Culturally competent healthcare services, combined with faith-informed community education and screening initiatives, can improve acceptance of newborn and premarital screening, encourage early care-seeking, and support informed decision-making.

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