Ebereghwa et al., J Biomed & App Sci FUD (2025) 4:1
www.jobas.fud.edu.ng
ISSN: 2814-3221 (print), ISSN: 2955-0874 (online)

JOBASFUD
Journal of Biomedical and Applied Sciences

RESEACH ARTICLE

PRENATAL DIAGNOSIS OF SICKLE CELL DISEASE: ETHICAL CHALLENGES FOR COUPLE AT RISK

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Abstract

Background: Sickle cell disease (SCD) is a life-long debilitating condition, significantly impacting quality of life, healthcare resources and survival rates. Prenatal diagnosis (PD) is a vital reproductive option for at-risk couples, allowing early detection of genetic disorders. However, these advancements raise significant ethical dilemmas for parents and healthcare providers in supporting informed decision-making. **Objectives:** This study examines the ethical challenges associated with PD for SCD, focusing on its impact on couples at risk, societal implications and the role of healthcare providers in supporting informed decision making. **Methods:** Data were reviewed from PubMed, Google Scholar and African Index Medicus using relevant keywords. Ethical issues such as information provision, patient decision making process, the morality of abortion, genetic selection, cultural and religious influences and justice in healthcare access were critically analyzed. **Findings:** Invasive PD methods, such as chorionic villus sampling, pose risks of miscarriage and raise concerns about safety and reproductive choice. Ethical dilemmas stem from selective abortion, societal pressures and perceptions of genetic selection, which some equate with modern eugenics. Religious and cultural beliefs heavily influence couples' decisions, especially in contexts like Nigeria, where abortion laws are restrictive. The societal and economic burden of SCD creates tension between individual reproductive autonomy and broader public health concerns. Non-directive genetic counselling and equitable access to PD remain critical yet under-addressed aspects in low-resource settings. **Conclusion:** Ethical considerations surrounding PD for SCD extend beyond individual autonomy to include societal and cultural factors. Healthcare providers must adopt a multidisciplinary approach, ensuring equitable access, non-directive counselling and support for at-risk couples navigating these complex decisions.

Keywords: Couple at risk, ethical challenges, prenatal diagnosis, sickle cell disease

INTRODUCTION

Overview of Sickle Cell Disease

Sickle cell disease(SCD) is a life-long, debilitating disease associated with poor quality of life, increased utilisation of medical resources, high economic burden and reduced lifespan (Cortabarria et al, 2021; GBD 2021 Sickle Cell Disease Collaborators, 2023). The World Health Organization (WHO) declared SCD as a global health crisis in 2006. It projected a substantial rise in the global prevalence from 305,800 per year in 2010 to 404,200 per year by 2050, resulting to an estimated 14,242,000 persons will be living with SCD by 2050 (Beli et al, 2024). Globally, about 100 million persons have SCD and it is one of the most prevalent severe single-gene disorders notably in Africa, the Mediterranean, the Middle East and South Asia (Dimitrievska et al, 2024). Over half a million infants were born with sickle cell disease in 2021 with over three quarters in sub-Saharan Africa (GBD 2021 Sickle Cell Disease Collaborators, 2023). SCD prevalence increased in sub-Saharan Africa,

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where births in 2021 were 405,000 (GBD 2021 Sickle Cell Disease Collaborators, 2023). Nigeria was among the six countries that made up 44% of the global incidence at birth in 2021 with approximately 150,000 children per year born with SCD and has consistently exceeded an incidence at birth of 2000 per 100,000 live births since 2000 (Adegoke and Kuteyi, 2012; Adeniran *et al*., 2022; GBD 2021 Sickle Cell Disease Collaborators., 2023; Beli *et al*., 2024). In Africa most of the infant fatalities related to SCD occur in West African countries, with about 80% of these deaths recorded in Nigeria with an estimated 40 million persons having the sickle cell gene (Adegoke and Kuteyi, 2012; Beli *et al*., 2024). Notably, among the nations of the world, Nigeria is a country that is profoundly affected, with a prevalence of 2% of its population having SCD (Adeniran *et al*., 2022). Sadly, more than 100,000 newborns die as a result of SCD each year in Nigeria and it is responsible for 8% of the under-five mortality rate in the country (Beli *et al*., 2024). The persistent high prevalence of the disease in Africa and Asia can be ascribed to the survival advantage given to sickle cell trait against the severe form of malaria (Okechukwu, 2020; Dimitrievska *et al*., 2024).

Sickle cell disease is an autosomal recessive disorder due to a missense mutation of the β-globin gene (Dimitrievska *et al*., 2024). It comprises at least one haemoglobin S allele (HbS) and a second pathogenic variant, which can either be another haemoglobin S allele or other haemoglobin (Hb) variants such as haemoglobin C (HbC) (Dimitrievska *et al*., 2024). The allele results when the Thymine is replaced by an adenine base in a missense mutation at the 6th position in an amino acid sequence of the β-globin gene (Dimitrievska *et al*., 2024). There are different types of SCD based on the number of HbS alleles in an individual's genetic makeup (Dimitrievska *et al*., 2024). The most severe and common type of SCD develop when an individual inherits two copies of the HbS allele (HbSS). Others include, sickle-haemoglobin C which involves the co-expression of the HbS allele with haemoglobin C (HbSC) and a rare type of sickle-β-thalassemia which involves inheriting a HbS allele and one β-thalassemia gene(HbSβ-thalassemia) (Dimitrievska *et al*., 2024). When an individual inherit one normal haemoglobin A (HbA) and an abnormal haemoglobin S (HbS) gene, this is called sickle cell trait (HbAS) (Nzekwue and Ogueh, 2022).

A couple at risk include both partners being healthy carriers of the sickle cell trait (HbAS), or one partner having the sickle cell trait (HbAS), and the other has haemoglobin C trait (HbAC) or one has sickle cell anaemia (HbSS). In contrast, the other having sickle cell trait(HbAS) (Okechukwu, 2020). The possibility of an offspring inheriting the sickle cell gene from parents includes; a 25% chance of SCD, if both parents have the sickle cell trait, if one parent has the trait and the other has SCD, a 50% chance exist and when both parents have SCD, the offspring has a 100% likelihood of SCD (Zounon *et al*., 2015).

Rationale for Prenatal Diagnosis

Prenatal diagnosis (PD) is regarded as an essential reproductive option for couples with a high risk of passing on severe genetic disorders but who desire to have a healthy child (Nzekwue and Ogueh, 2022). These diagnostic tests provide potential information regarding the foetus's health. (Kivity and Barnoy, 2023). The diagnosis of a normal foetus gives confidence to the potential parents. Still when an abnormality is detected, they are faced with a dilemma to either keep or terminate the pregnancy (Kivity and Barnoy, 2023). SCD can be diagnosed in utero following advancement in prenatal diagnosis (Cortabarria *et al*., 2021). Prenatal diagnosis identifies malformations, disruptions, chromosomal abnormalities and other genetic syndromes in the foetus (Ahmed et al., 2021). It is a reproductive option that offers parents the option to test at-risk pregnancies and make decisions regarding the pregnancies (Nzekwue and Ogueh, 2022). PD aims to provide accurate information regarding short- and long-term prognosis, recurrence risk and potential therapy and to improve counselling and outcomes (Ahmed *et al*., 2021). Concerning SCD, it remains an important option for couples at-risk of having a child with SCD (Nzekwue and Ogueh, 2022). PD helps to identify the haemoglobin genotype of the foetus, thus providing reproductive options for a couple at risk, who have the choice to opt for medical abortion if the foetus is HbSS or to prepare psychologically, socially, financially and medically for a child with a health problem or disability, if they decide to keep the pregnancy (Ahmed *et al*., 2021; Kaye, 2023).

Two main methods for PD for SCD; chorionic villus sampling (CVS) and amniocentesis (Nzekwue and Ogueh, 2022). CVS is an invasive procedure that involves the aspiration of the chorion frondosum either transabdominally or transcervical between 10- and 13-weeks gestation (Cheng, 2018). It has a pregnancy loss rate of 1 in 500 with a 2-4% risk of miscarriage (West., 2008; Cheng, 2018). CVS enables early diagnosis of foetal abnormalities, which can reassure mothers with

high risk and need for intervention (West, 2008; Cheng, 2018). It is the preferred technique for persons at risk for single gene disorder (Galbraith and Esterly, 2008; Nzekwue and Ogueh, 2022). However, it is associated with an increased risk of limb and jaw deformities, primarily if performed in infants less than 9 weeks gestation (Galbraith and Esterly, 2008). Amniocentesis is carried out between 15-20 weeks gestation through the aspiration of amniotic fluid transabdominal (Okechukwu, 2020; Nzekwue and Ogueh, 2022; Ahmed *et al*., 2021). It is associated with a 0.5-1.0% risk of miscarriage (Okechukwu, 2020).

Recent non-invasive PD techniques involves isolating foetal cells from maternal blood for deoxyribonucleic acid (DNA) analysis (Nzekwue and Ogueh, 2022). Other methods include cordocentesis for foetal blood sampling and DNA analysis at 18-19 weeks' gestation and celocentesis where the celomic fluid is aspirated at 7-9 weeks (Nzekwue and Ogueh, 2022).

METHODS

Study design and search strategy

Our search for potentially relevant articles focused on the PubMed and African Index Medicus databases. Search strategy included a combination of keywords and controlled vocabulary terms related to prenatal testing, sickle cell disease, ethical challenges and relevant factors that we were interested in, such as societal, religions and cultural influences on prenatal testing, legal concerns of prenatal testing and genetic counselling. A combination of free-text terms and specific search terms such as "prenatal diagnosis", "invasive prenatal testing", "prenatal genetic testing", "non-invasive prenatal testing", "ethical challenges", "ethical issues" were used. Studies were included if they reported on (1) prenatal testing or diagnosis for SCD, (2) ethical challenges related to prenatal testing for SCD, (3) studies related to couples at risk of having SCD children and studies had to be published in a peer reviewed journal. Studies in languages other than English were excluded for practical reasons as well as those published before 1990, which were presumed to be outdated. To explore relationships within and between all studies, themes were.

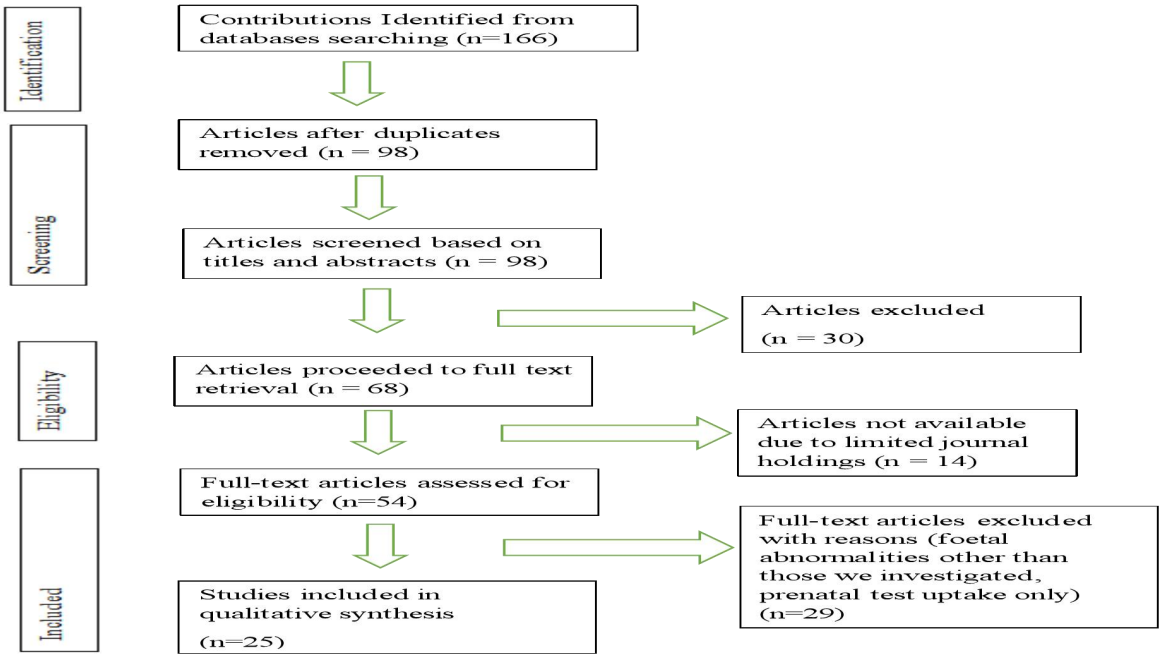

Figure 1: Study selection

RESULTS

Study characteristics

The search strategy identified 166 records, of which 98 remained after removing duplicates. After applying inclusion/exclusion criteria from review of titles and abstracts, 68 remained. Full manuscript was accessible for 54. Review of full manuscript excluded another 29. A total of 25 articles were included in the study. Studies reviewed were of qualitative and quantitative methods.

Themes

We identified a variety of themes associated with the ethical issues of prenatal diagnosis, such as information provision, genetic counselling and patient decision making process; beneficence, harm and risk assessment; impact of prenatal testing on women's autonomy and health; selective abortion and discrimination against people with disabilities; justice-based ethical challenges, societal implications of prenatal diagnosis; and impact of religion and culture on prenatal diagnosis.

Beneficence, harm, and risk assessment of prenatal diagnosis

The procedures used for PD involve risk, seldom lead to benefit for the foetus and often result in a decision of selective abortion. Invasive PD though relatively safe, yet carry a risk of miscarriage (Edwin *et al*., 2011). CVS and amniocentesis are associated with 1% and 3.2% risk of miscarriage respectively (Edwin *et al*., 2011; Fadare, 2009; Tahir *et al*., 2017). In contrast, non-invasive PD is said to have no perceived procedure related miscarriage risk (Campen *et al*., 2020). This is seen as a predictor factor that may increase the uptake of non-invasive PD, following its availability for SCD (Campen *et al*., 2020). Skirton *et al* reported an overwhelming support for non-invasive PD by carriers due to its reduced risk for miscarriage (2015). Also, the issue of uncertainty with regards to the accuracy and reliability of these tests have been raised (Kaye, 2023). How good the test has to be, to be used in different contexts, considering false positives, false negatives and the prevalence of the disorder (Kaye, 2023). In addition, with the emergence of non-invasive PD and preimplantation genetic testing, there is increasing concern of selective abortion becoming normalized (Tahir *et al*., 2017).

Anxiety or adverse psychological effects were identified as possible harmful consequences for parents that could result from PD and its potential outcomes (Edwin *et al*., 2011). The maternal indication for the termination of pregnancy in cases of foetal abnormalities can be viewed from the principle of beneficence and non-maleficence which shows that if pregnancy is continued, it can have adverse effect on the pregnant woman and the well-being of the extrauterine life of the child (Suryadi *et al*., 2020).

Inform consent, genetic counselling and patient decision-making process

The provision of information and depth of knowledge are important in patient decision-making process.s for PD (Tzela *et al*., 2024). Some papers reported that couples are often not appropriately informed by providers about the procedure, the potential risks and benefits, that decisions are voluntary and information on available options (Benn and Chapman, 2010; Kaye, 2023;). Inadequate medical training in genetics is a common barrier to clinicians' capacity in counselling patients (Zhong *et al*., 2021). As clinicians do not feel confident in providing information or counselling patients regarding genetic disease and may be dismissive when couples ask many follow-up questions (Zhong *et al*., 2021). Clinical genetic counselling tends to be directive, which may be due to their perceptions of the value of such information and the emphasis of their training (Jonson et al., 2017; Zhong *et al*., 2021). Some physicians approach genetic counselling as a means to reduce birth defects and deleterious genes in the population and improve the affected family's quality of life, this attitude can be seen as having eugenic tendencies (Zhong *et al*., 2021).

In countries where prenatal testing is part of routine prenatal care, couples are less likely to make a deliberate decision about having prenatal testing (Benn and Chapman, 2010; Kaye, 2023;). Routinization may result in attention be focused on screening to improve foetuses' health and disregarding the fact that a positive result could eventually lead to a decision to abort (Johnson *et al*., 2017). The accuracy of the test, certainty of the results, risks involved and availability of other options were

factors identified to influence decision to carry out non-invasive PD for SCD (Skirton *et al*., 2015). Psychological factors have considerable influence in the decision-making process regarding invasive PD, with anxiety noted as a primary determinant (Tzela *et al*., 2024). Limited access to decision support tools that incorporate patients' values and past experiences in decision making process may affect couple's ability to make informed decision (Kaye, 2023;). Informed consent and protection of patient rights are underdeveloped in many LMICs (Zhong *et al*., 2021). Limited number of well-trained and competent genetic counsellors especially in Africa (Tahir *et al.*, 2017). Myths and beliefs affect the counselling process. The use of local languages during counselling which may poorly explain genetic terminologies (Tahir *et al*., 2017).

Impact of prenatal testing on women's autonomy and health

The increasing recognition of a woman's rights to her own body, exert much of the responsibility for decision to either keep or terminate the pregnancy on the woman (Kivity and Barnoy, 2023). As the procedure is performed through her body and hence resulting in issues relating to her privacy and personal autonomy (Merrick, 2013). The complexity of possible results generated, tends to circumscribe the pregnant woman's decision making about the pregnancy, as often choices available is binary-to terminate the pregnancy or to keep the pregnancy. (Edwin *et al*., 2011; Kaye., 2023; Horn *et al*., 2024). This makes it difficult to safeguard autonomy (Horn *et al*., 2024). Based on the feminist perspective, any prenatal testing service where preferred reproductive choices are recommended by the health service provider may threaten women's reproductive rights and freedom (Stapleton, 2017).

Selective abortion and discrimination against people with disabilities

PD provide parents with the choice to either continue the pregnancy or to terminate the pregnancy. There are different views towards selective abortion based on different arguments.

Proponent views on selective abortion for foetal anomalies include; reduction of disability related expenditure for the child, the family and the society (Adrienne, 1999; Fadare, 2009; Nzekwue and Ogueh, 2022). Selectively abort foetus to prevent future child from having to endure severe physical and psychological suffering that might be associated with genetic disorder (Stapleton., 2017). Also, some argue that aborting the affected foetuses is more cost-effective as it would ultimately decrease the socioeconomic and emotional consequences of the disease (Fadare, 2009; Stapleton, 2017; Nzekwue and Ogueh, 2022).

The disposition of the foetal rights includes; life of the unborn foetus is sacred, the foetus has a moral status equal to that of any adult and so view abortion as a moral equivalent to murder (Stapleton, 2017). In addition, performing PD with a preconceived aim of aborting affected foetus on the basis that their existence represents a liability to society is seen by disability experts as sheer discrimination against persons living with disabilities and signifies that their lives are worthless (Steinbach *et al*., 2016; Tahir *et al*., 2017). Furthermore, the expressivist argues that any prenatal screening for genetic disorders disparages the lives of existing and future persons living with disability by trying to screen for and prevent the birth of babies with their characteristics (Steinbach *et al*., 2016).

Justice-based ethical challenges of prenatal diagnosis

High cost of the procedure and access to a facility were among factors identified to influence couple at risk decision to do PD and so form a major barrier to the control of SCD (Fadare, 2009, Okechukwu, 2020; Walters *et al*., 2024). Inadequate funding allocated to genetic testing in LMICs (Walters *et al*., 2024). As essential genetic services are usually viewed as superfluous expenditures in LMICs (Walters *et al*., 2024). This lack of state funding shifts the cost burden of genetic testing to patients and their families, with cost often exorbitant (Walters *et al*., 2024). In contrast, PD is largely available in high-income countries through antenatal and neonatal care programs. When genetic services are not widely available, people often travel long distances to access service, thus, incurring high costs (Zhong *et al*., 2021).

It is important that information about available genetic tests in pregnancy in the healthcare facilities should be communicated equitably and women who are eligible to access a test should be supported in their decision making beyond the actual pregnancy (Horn *et al*., 2024).

Societal implications of prenatal diagnosis

Some papers argued that since the PD is available, there are compelling reasons to use it, which could hinder couples' choice. Couples are faced with the dilemma of having the society put pressure on them directly or indirectly to carry out PD because of the availability of the tests (technological imperative) (Fadare, 2009). Thus, undermining couples' ability to independently choose in a bid to avoid being blamed for not utilizing the test to prevent them from having children with sickle cell disease (Fadare, 2009). Also, parents worry about the effects of social stigma associated with genetic disorder (Zhong *et al*., 2021). Couples with affected pregnancy are hesitant to disclose results to extended family and community and many experience isolation after such disclosure (Zhong *et al*., 2021).

Furthermore, the existence of legal bans of abortion in most African countries and medical abortion restricted to direct threats to maternal health (Nzekwue and Ogueh, 2022). SCD is not considered in medical indication of abortion, so termination of affected fetuses would therefore be illegal (Nzekwue and Ogueh, 2022). Some countries abortion law allows termination of pregnancy on the basis of risk to the mental health of the pregnant woman (Edwin *et al*., 2011) The statutory limits on the availability of termination of pregnancy (TOP) place undue pressure on couples at risk to take decision within a limited time frame usually within a few days or weeks (Horn *et al*., 2024).

Impact of religion and culture on prenatal diagnosis

Some religions do not permit termination of pregnancy (TOP)for foetal anomalies thus limiting options for addressing affected pregnancies (Anderson, 2009; Walters *et al*., 2024). All religions identified in a qualitative study in Ghana strongly prohibited the termination of a pregnancy affected by SCD (Dennis-Antwi *et al*., 2018). Religious affiliation was the common denominator regarding TOP decisions for affected pregnancies (Walters *et al*., 2024). Okechukwu reported that some at risk couples in Nigeria who were predominantly Christians may be unwilling to interfere with or terminate a pregnancy following a PD of SCD as they equate it with the crime of killing an individual (2020).

Karma, curses, superstitions associated with certain behaviours during pregnancy and perceived punishment from God are commonly held beliefs regarding the cause of genetic diseases (Dennis-Antwi *et al*., 2018; Zhong *et al*., 2021). Family members and spouses particularly mothers-in-law and husbands hold strong influence over decisions following PD (Zhong *et al*., 2021).

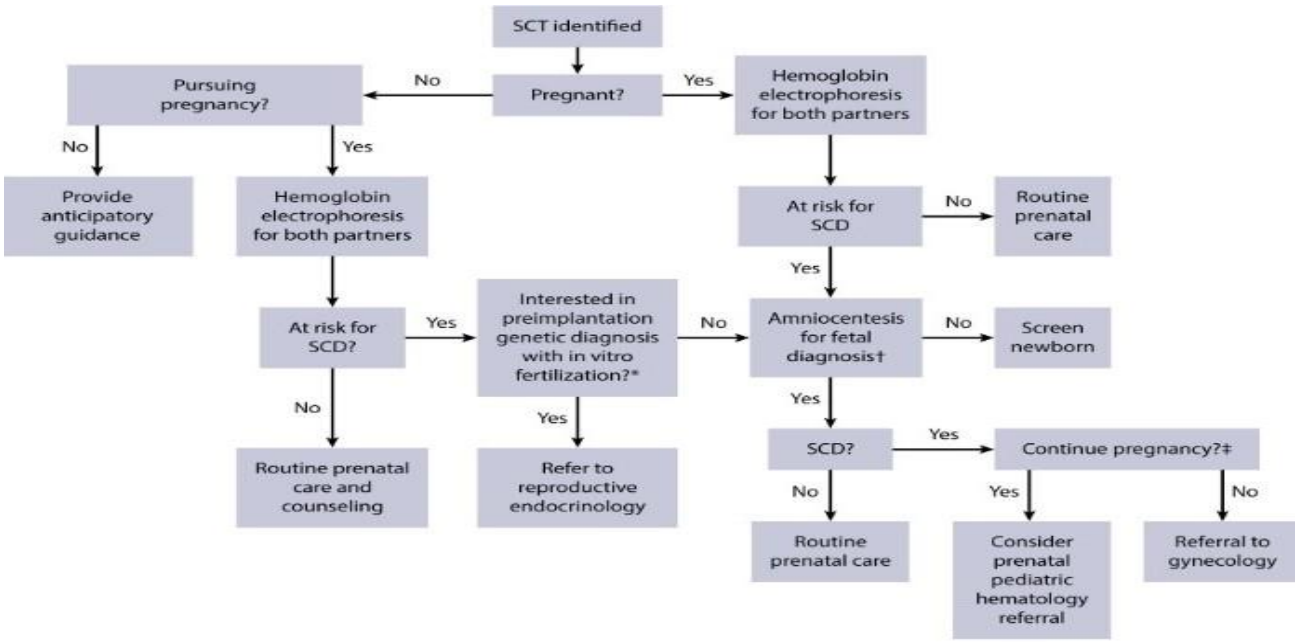

Figure 2: PD decision-making process for couples at risk of SCD.

DISCUSSION

Prenatal diagnosis, have some benefits such as the provision of information about the unborn child to expectant parents and physicians, the reduction of anxiety in at-risk pregnancies and the avoidance of unnecessary terminations (Edwin *et al*., 2011). Nevertheless, it may have some implications for the foetus, the parents, the family and the society. This may lead to several ethical concerns.

The procedures commonly used for prenatal diagnosis; amniocentesis or chorionic villus sampling are invasive, though relatively safe, however, are associated with a 1-3% risk of miscarriage (Fadare, 2009; Edwin *et al*., 2011). This may lead to significant loss of a genetically normal foetus following these invasive procedures, which creates an ethical conundrum (Edwin *et al*., 2011; Tahir *et al*., 2017). A woman has a one in thirty chance of miscarrying what might be a normal foetus following CVS for prenatal diagnosis (Edwin *et al*., 2011). With the emergence of non-invasive PD, there is increasing concern of selective abortion becoming normalised. The progressive expansion of PD tends to offset the balance between believing the real aim of the procedure which is to allay anxiety or prepare couples to care for the affected child and believing that the procedure is subtly aimed at selective abortion (Tahir *et al*., 2017). Also, the issue of uncertainty with the tests result; the variable expressivity of the disorder and the incomplete penetrance of most genetic variants have long posed interpretive challenges (Johnson *et al*., 2017). How much risk is the couple willing to take that the test is wrong and that they will conceive a child that might carry the genetic traits? (Kaye, 2023). This uncertainty is particularly important where one intends to perform an invasive test such as CVS and amniocentesis which carry significant risks to the foetus (Kaye, 2023).

While prenatal testing historically expanded as a response to couples' demands to enhance their autonomy, improve their reproductive choices, promote their informed choices and manage their pregnancies (Zhong *et al*., 2021). It is however not clear from identified findings that reproductive choice is actually enhanced (Gates, 1993). As identified by our results, societal and technological advancement of this technology resulted in depriving patients of their autonomy, either by creating societal pressure towards undergoing PD or circumscribing their choices to a limited number of options (Fadare, 2009; Kivity and Barnoy, 2023; Horn *et al*., 2024). So, does PD offer women a window of control or an anxiety provoking responsibility? Notwithstanding, some features of PD do increase control but allocate it to someone other than a pregnant woman herself (Gates, 1993). Various concerns have been raised regarding the influence of PD on a woman's sense that the decisions made about her pregnancy are really her own (Gates, 1993). In cases where the couples are faced with the dilemma of having the society put pressure on them directly or indirectly to carry out PD because of the availability of the tests as this portrays a sign of responsible parenting (Gates, 1993; Fadare, 2009). Is a couple acting irresponsibly in the eyes of the society if they refuse the test? Will the couple face less sympathy and support if test is forgone and a child is born with the disorder or if pregnancy is continued despite adverse result? If these above perceptions are felt among couples at-risk, then the availability of PD may in fact limit autonomy rather than enhance reproductive choice (Gates, 1993).

The existence of legal frameworks that restrict or prohibit termination of pregnancy introduces a level of complexity, that undoubtedly affect not only the availability of abortion but also the social perception of the procedure (Tzela *et al*., 2024). The specific legal restrictions and their impact on reproductive rights, provides an essential context for understanding the broader dynamics surrounding termination of pregnancy (Tzela *et al*., 2024).

An increasing number of countries now recognize a woman's right to abortion choice when faced with health, social or mental risk (Nzie, 2021). They argue that forcing a woman by threat of abortion being criminal, to carry a foetus to term unless she meets certain criterion unrelated to her own priorities and expiration is a profound interference with a woman's body and thus a violation of security of the person (Nzie, 2021). It gradually became a legal position that psychological concerns of the pregnant woman make an abortion lawful in some developed countries (Izunwa and Ifemeje, 2011). Unlike, the English Abortion Act which states that abortion can be performed to prevent grave permanent injury to the physical or mental health of the pregnant woman (Izunwa and

Ifemeje, 2011). The Nigeria abortion law does not state this clearly, it only permits medical abortion for the preservation of the woman's life (Izunwa and Ifemeje, 2011). Parental distress related to foetus pathology such as SCD is not specifically considered in the Nigeria abortion law. Since the existing Nigeria law does not permit abortion for foetal deformity, the question then is what then is the real aim of PD? (Tahir *et al*., 2017). Thus, in a case of an affected foetus, the potential parents are left with the option to prepare to raise a child with genetic disorder (Tahir *et al*., 2017). Also, this may lead to illegal abortion by unqualified personnels and its subsequent complications (Tahir *et al*., 2017).

Also, some view disability as a burden to the affected child as it decreases their possibility of life worth living (Steinbach *et al*., 2016). This may describe the synecdoche argument which points out that stigmatization of persons with disability causes potential parents to mistakenly allow one trait to stand in for the whole child in evaluating prenatal testing and termination decisions (Steinbach *et al*., 2016). Therefore, it is not possible to avoid the implicit assumption about the undesirability of the existence of people with such disorder and of giving birth to and bringing up such people (Edwin *et al*., 2011). Hence, some school of thought argue that PD could lead to systematic elimination of the genetic mutation from the population (Fadare, 2009). Could this be called a form of eugenics?

One of the interests considered in the justifications for selective abortion following the detection of foetal abnormalities are the prospective parents and family (Hall *et al*., 2017**).** Assuming the responsibility for affected child is likely to significantly impact on the social and economic circumstances of parents and immediate family (Hall *et al*., 2017**).** Selective abortion in this context may be an expression of parental rights to promote their own wellbeing (Hall *et al*., 2017**).**

The argument that favour selective abortion for society benefit is similar to the justification in favour of the interest of the family (Hall *et al*., 2017**).** Both consider the interests of morally significant beings other than the foetus in determining the morality of selective abortion (Hall *et al*., 2017**).** In this case, the question that may arise is, does the resources demanded by disability impact a significant burden upon the society which might justify making an exception to the rule against killing morally significant beings, that is selective abortion (Hall *et al*., 2017)**.** Furthermore, determining the value of human life based on cost to the society may imply that if persons with disabilities increase the cost of healthcare and are unable to participate fully in the labour force, then their existence makes life less worth living for those who judge the quality of life by economic measures (Hall *et al*., 2017; Edwin *et al*., 2011**).** Conversely, the concepts of disability as a burden have the theoretical capacity to result in discrimination against individuals with disabilities on the grounds that their existence represents liability to society that could be prevented with the aid of prenatal screening technologies (Steinbach *et al*., 2016). Those echoing this view, argue that individuals with disabilities should not be born because they exert a burden on others (Steinbach *et al*., 2016). This argument stems from the idea that individuals are responsible for their reproductive choices and should not burden the larger society with their decision to continue an affected pregnancy (Steinbach *et al*., 2016). From the perspective of the disability rights, this view of genetic disability as a reproductive choice may result in decrease societal commitment and support to people with genetic disorders, leading to stigmatization and social exclusion of those with disabilities (Benn and Chapman, 2010; Steinbach *et al*., 2016).

If SCD was not compatible with life or there was no satisfactory treatment available, the ethical challenge would have been less. At present, SCD has a reasonable life expectancy and acceptable quality of life despite the challenges in caring for persons with the disorder (Edwin *et al*., 2011). It has been suggested that the most significant source of suffering for many affected families is the lack of support for the care of affected children from the society (Muoghalu, 2016**).** Thus, when society chooses selective abortion of foetuses with SCD, it has chosen the convenient option, not necessarily the best one (Edwin *et al*., 2011).

Culture-related factors like religion, government policy and customs influence the decision to terminate a pregnancy following the diagnosis of a genetic disorder (Kivity and Barnoy, 2023). Many religions suggest that children are a gift from God and shouldn't be a matter of choice (Okechukwu, 2020). Parents should accept the health condition of children just the way they are and depend on God for the sustenance of life (Okechukwu, 2020). Christianity, particularly the Catholic church opposes abortion under any circumstance (Okechukwu,

2020). Conversely, Islam permits abortion in cases where there is threat of harm to the mother and the presence of foetal abnormalities that are incompatible with life (Al-Matary and Ali, 2014; Kivity and Barnoy, 2023). The decision to perform an abortion is associated with religiosity, where stronger religious beliefs is associated with less inclination to perform selective abortion (Kivity and Barnoy, 2023). Regarding religious beliefs and PD, Okechukwu reported that some at risk couples in Nigeria who were predominantly Christians may be unwilling to interfere with or terminate a pregnancy following a PD of SCD as they equate it with the crime of killing an individual (2020). Muslim Saudi couples' attitude towards termination of pregnancy was mainly influenced by religious values, and education about religious ruling significantly affected parents' attitude towards accepting abortion and PD (Alkuraya and Kilani, 2001; Dennis-Antwi *et al*., 2018; Abdulazeez *et al*., 2019; Shoaib, 2024). Religion and faith were considered an important factor in decision making but the perceived severity of the condition was said to play a more important role among South-Asian and African-Caribbean communities towards termination of pregnancy for SCD (Ahmed, 2006). Cultural beliefs can deeply affect attitudes towards affected individuals when there is a lack of biological understanding of genetic. Western model of individual autonomy may not be appropriate for collectivist cultures, where the individual's choice incorporates opinions of others (Zhong *et al*., 2021).

Ethical challenges arise from the scope of genetic counselling given by healthcare providers (Fadare, 2009). The recognition of patients' individual right decrease (Zhong *et al*., 2021). Family members and spouses particularly mothers-in-law and husbands hold strong influence over decisions following PD (Zhong *et al*., 2021). Thus, the to decide if they wish to receive testing or not and then to make reproductive choices based on test results is the starting point of present-day provision of PD (Benn and Chapman, 2010). Thus, genetic counselling must be geared towards the respect and support of the reproductive autonomy of couples and the provision of non-directive, client-centered counselling and sufficient information to enable couples make informed and voluntary decisions about their pregnancies (Fadare, 2009; Horn *et al*., 2024). The minimum requirement of informed consent is that patients be provided with sufficient relevant information needed to take decisions which should be voluntary and uninfluenced by external pressures (Benn and Chapman, 2010). However, is it possible for counselling to be completely non-directional? Is it possible for an individual to push aside his or her own clairvoyance and sense of morality when faced with a quagmire? The counselling for SCD is more difficult due to the variability in the severity of the disease manifested among affected persons (Fadare, 2009). The way and manner healthcare providers communicate the importance of prenatal testing to pregnant women and expectant couples and the implications of its outcome for the parents to be, family and the larger society play vital role in what parents do after PD (Edwin *et al*., 2011). There is need to ensure that healthcare professionals are equipped with not only accurate and up to date information but also the skills to communicate these effectively and empathetically (Tzela *et al*., 2024).

In addition, based on the principle of justice, it is imperative that access to prenatal diagnosis should be fair and equitable (Fadare, 2009). Unfortunately, this is not so due to the intra-country and inter-country discrepancy in the availability and affordability of PD. This is the case in many LMICs like Nigeria and so form a major barrier to the control of SCD (Fadare, 2009). To improve access to these services, some LMICs government provide insurance and subsidies but high cost of genetic services still remains a barrier particularly in low-income and rural patients (Zhong *et al.*, 2021).

CONCLUSION AND ETHICAL RECOMMENDATIONS

This review article has discussed some of the ethical challenges that can arise in prenatal diagnosis for sickle cell disease. It is important that attention should be paid not only on the impact of prenatal diagnosis on the foetus but also, on the pregnant woman and family members. There is need for healthcare providers to be aware of these challenges particularly when offering these services to clients.

The crucial role of healthcare providers goes beyond the mere provision of information, as their ability to navigate and address the ethical and psychological aspects of decision making largely influences patient choices (Tzela *et alThus,*., 2024). This brings out the need to integrate psychological training into the education and professional development of healthcare professionals involved in in prenatal care. Also, the establishment of interdisciplinary

collaboration, including midwives can contribute significantly to improving the holistic support provided to couples during this critical decision-making process, thus promoting a more patient-centered care.

The subsidization of the cost of genetic testing by the government such as through inclusion of the coverage of genetic testing into the national health insurance scheme could help address the financial barrier associated with accessing genetic service. Furthermore, raising awareness among the populace through public health advocacy and awareness program could increase the general public 's knowledge of genetic diseases and genetic screening and also reduce stigmatization towards affected persons.

Acknowledgement: None

Source of funding: There was no financial support for study.

Conflict of Interest:

The authors declare no conflicts of interest.

Authors' Contribution:

Study conceptualization and design: ABE and EEM; data collection, data analysis and interpretation: EEM, ABE; drafting and revision of the manuscript critically for important intellectual content; EEM, ABE KN, EOE. All the authors read and approved the final version of this manuscript.

Article History:

Received: 21st December 2024.

Accepted: 24th February 2025.

Published online: 1st October 2025.

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