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Perception of the Need for Genetic Counselling and Testing for Sickle Cell Disease among Young Adults in Premarital Relationship in Jos North LGA of Plateau State

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Abstract: There has been increasing prevalence of sickle cell disease (SCD) with attendant consequences in Nigeria with low uptake of genetic counseling and testing as an effective preventive measure by young adults. This study aimed at examining the perceived need for genetic counseling and testing for SCD in Tudun Wada, Jos North Local Government Area of Plateau State towards prevention of SCD in the society. A descriptive cross sectional study design was adopted and the instrument for data collection was a researcher created Young Adults Genetic Counseling and Testing Questionnaire (YAGCAT-Q). Purposive and snowball sampling technique was used to sample 238 young adults between the ages of 18 to 45 years who were of marriageable age. The data obtained were analyzed using combination of Statistical Package for Social Sciences (SPSS) version 2.5, a descriptive statistic summarized into mean value and presented in tables. The results revealed poor attitude and poor uptake of genetic sickle cell screening by young adults as only 68 (28.57%) have ever participated in the procedure, despite 191 (80.25%) claiming they would avail themselves of the services. Attainment of higher educational level of 98 (41.2%) and prior knowledge of genotype status – 68 (28.57%) were found to be positive influencer as respondents with knowledge on genetic counselling and testing have cumulative mean of 2.896 indicating higher understanding of genetic screening and counseling. Knowledge on impact of genetic counselling and testing on young adults with cumulative mean of 2.9 while the criterion mean maintained at 2.5 were observed. The implication of this is the urgency for aggressive education of young adults for the need for voluntary genetic counselling and testing in order to reduce the prevalence of SCD in our society.

Keywords: *Sickle Cell Disease, Genetic Counselling, Genotype Testing, Attitude, Perception.*

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I. INTRODUCTION

Sickle cell disease (SCD) is a group of inherited life-long red blood cell disorders caused by a mutation in the hemoglobin subunit beta (HBB) gene, leading to abnormal, rigid, sticky and sickle-shaped red blood cells that block blood flow and cause severe health complications (Nwubuko et al, 2022, CDC, 2024; Adesola, et al, 2024 and WHO 2025). It is common among persons having family history of SCD; of African, Caribbean or South Asian descent; and persons inheriting two mutated HBB genes, one from each parent. Genetic counseling has been widely recognized and believed to be one of the most effective

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ways to prevent SCD in families, especially among young adults in pre-marital relationship (Kanma-Okafor, 2022 and CDC, 2024). However, acceptance and the uptake of voluntary genetic counseling and testing has been unacceptably low in Nigeria (Aneke and Okacha, 2016), despite the high burden of the disease in the country being put at between 2% to 3% of the population and about 150,000 newborns being affected yearly (Kingsley et al, 2019; Nwabuko et al, 2022; and Adesola, et al, 2024).

Genetic counseling and testing though a potent preventive measure against SCD, can only be effective when people understand the etiology of the disease. Kanma-Okafor, et al (2022) found out in a study in Lagos that majority of secondary school students did not know about the prevention of SCD and that better attitude towards the disease was more likely when SCD status was known. Therefore, in this context, genetic counselling and testing is determines by attitude, particularly individuals perception of the need for genotype screening as beneficial or otherwise. Positive attitudes toward genetic counselling encourage individuals to seek genotype testing and make responsible relational decisions, while negative attitudes may discourage one from participating in such preventive measures (Ajike, Bademosi & Olaoye, 2013; Nnachi, 2022).

Genetic counselling and testing have been widely recognized as important preventive strategies for reducing the incidence of SCD. It involves educating individuals and intending couples about the inheritance patterns of genetic diseases and the risks associated with transmitting such conditions to their children. Genetic testing helps individuals determine their genotype status, thereby enabling them to make informed marital and reproductive decisions (Akinyanju, 2017).

Young adults who are in premarital relationships represent a critical target for interventions aimed at preventing SCD, as they begin to make decisions regarding marriage and family. Their attitudes toward genetic counselling and testing can therefore significantly influence their decision whether to undergo genotype screening before marriage and being conscious of reproductive outcomes (Akinyanju, 2017, Adesina, et al 2022 and Oluwole, et al, 2022). Indeed, young adults play a central role in efforts aimed at preventing the transmission of SCD because they are at the stage of selecting life partners and making decisions about marriage and family formation.

In many parts of Nigeria, attitudes toward genetic counselling and premarital genotype testing are influenced by several factors including cultural and religious beliefs, emotional attachment between partners, fear of stigmatization, and lack of adequate knowledge about sickle cell disease (Kanma-Okafor et al, 2022). Some individuals may ignore genotype incompatibility because of strong emotional bonds or family pressure to proceed with marriage (Adewoyin, 2015; Adesina et al., 2022). Understanding the attitudes of young adults toward genetic counselling and testing is therefore important factor in designing effective public health interventions aimed at reducing the prevalence of SCD, which is the major focus of this study.

II. MATERIALS AND METHODS

A descriptive cross-sectional study designed was adopted to find out the factors responsible for low participation in genetic counselling and testing for SCD among Young Adults of marriageable age and those in premarital relationships in Tudun Wada Community of Jos North Local Government Area of Plateau State, Nigeria.

The population of study consist of male and female young adults between the ages of 18 to 45 years, who were of marriageable and reproductive age residing in the study area.

Purposive and snowball sampling techniques were used to select 238 the young adult from the population of study who were willing and volunteered to participate in the study; Purposive sampling techniques, researcher choose respondents with similar characteristics to include in the study and Snowball sampling techniques allow other respondents with same characteristics to invite other respondents to participate in the study. The Young Adults Genetic Counseling and Testing Questionnaire (YAGCAT-Q) developed by the researchers was used for data collection and was administered on the respondents. Four Research Assistants were recruited to administer the questionnaire through face to face interaction with the respondents.

Data obtained from field were analyzed using the combination of Statistical Package for Social Sciences (SPSS) version 2.5 and descriptive statistics and presented in tables.

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III. RESULTS

Section A

Table 1: Socio-Demographic Data

Variable		Frequency n=100)		Percentage (%=100)
Gender	Male		100	42.0
	Female		138	58.0
Age Bracket	18 - 20 years		82	34.5
	21-40 years		121	50.8
	- 45 years		35	14.7
Highest Education		No formal education	15	6.3
Primary Education	Secondary education		37	15.5
	Tertiary education		77	32.4
	Others		98	41.2
Ward	Tudun Wada A		110	46.2
	Tudun Wada B		128	53.8
Year of Relationship	Less than 5 years		109	45.8
	5-10 years		95	39.9
	11 years and above		34	14.3

Source: Field Survey, 2026

Table 1 presents data on socio-demography of respondents indicating male (42%), female (58%); predominant age bracket – 21 to 40 (50%), more of those with tertiary education (41.2%) and highest number of those in relation for less than 5 years (45.8%).

Section B

Table 2: Knowledge of Sickle Cell (SDC) Genotype

Statements	***A***	***SA***	***N***	***D***	***SD***
(n=238)	n %	n %	n %	n %	n %
SCD is a genetic disease	59	142	13	9	16
I have heard of SCD	108	55	55	11	9
SCD Carriers if married can give birth to children with SCD	56.3	129.4	17.5	15	19.8
Frequent illness could be a sign of SCD	69	107	25	24	13
Genetic counselling and screening is the best technique for detecting SCD	59	140	13	14	12
I am aware of the risk of not testing for SCD	88	109	18	12	11

A, Agreed; SA, Stongly agreed; N, Neutral; D, Disagreed; SD, Stongly disagreed and SDC, Sickle cell disease

Table 2 indicates most respondents – 141 (59.5%) know what SCD is compared to the remaining participant 35 (15.8%) who do not have an ideas what SCD is. 108 and 55.2 representing (45% and 23%) respectively, have hear about SCD, 56 and 129 representing (23.7% and 54%) were aware of SCD carrier could birth children with SCD. 69 and 107 (28.9% and 44.9%) indicated frequent illness could be a sign of SCD, 59 and 104 representing (24.7% and 58.8%) were of the opinion that genetic couselling and screening is the best technique for detecting SCD. Also, 88 and 109 represeenting (36.9% and 47.9%) respondents affirmed their awareness of the risk of not testing for SCD, impling there is high level of knowledge on SCD.

Section C

Table 3: Attitudes to Genetic Counseling and Testing for Sickle Cell

Statements	**A**	**SA**	**N**	**D**	**SD**
(n=238)	n %	n %	n %	n %	n %
Genetic counselling of SCD is necessary	69	127	14	17	11
I will avail myself for genetic counselling and testing of SCD	48	143	16	14	18
Death comes from God, testing of SCD is a waste of time	13	23	13	55	134

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Genetic testing for sickle cell can lead to physical emotion pain	11	23	9	38	157
SCD testing are always reliable	62	123	16	15	23
I have participated in genetic counseling and Testing before	Yes No Not sure	68 (28.57%) 121 (50.84% 49 (20.59)			

A, Agreed; SA, Stongly agreed; N, Neutral; D, Disagreed; SD, Stongly disagreed and SDC, Sickle cell disease

The above table revealed that 69 and 127 respondents, representing (28.9% and 53.3%) know the of the need for genetic counselling; 48 and 143 (19.9% and 60%) agreed to be available for genetic counselling and testing compare to 15, 14, and 18 all representing (19.9%) whom are neutral or not ready to participate in the genetic counselling and testing.

Section D

Table 4: Impact of Genetic Counseling and Testing for Sickle Cell on Young Adults in Premarital Relationship Among

Statements	***A***	***SA***	***N***	***D***	***SD***
(n=238)	n %	n %	n %	n %	n %
Reduction in the rate of sickle disease carriers	77	119	9	16	15
Healthy children/ families	85	112	13	15	12
Better relationship between intending couples	81	101	9	14	33
Leads to informed decision	69	131	16	9	13
Reduces frequently visit to hospitals for check-ups	67	122	13	23	13
Less family health crisis and heath spending	148	53	12	17	12

A, Agreed; SA, Stongly agreed; N, Neutral; D, Disagreed; SD, Stongly disagreed and SDC, Sickle cell disease

From table 4, 77 and 119 representing (32.5% and 50%) believed genetic counselling and testing could reduce the rate of SCD carrier and also results to birthing of healthy children as indicated by 85 and 112 (35.8% and 47%) respondents. Also 69 and 131 representing 28.9% and 55.2%) opined that genetic counselling and testing could lead to informed relational decision.

Section E

Table 5: Factors Influencing Genetic Counseling and Testing for Sickle Cell

Statements	***A***	***SA***	***N***	***D***	***SD***
(n=238)	**n %**	**n %**	**n %**	**n %**	**n %**
Financial constraints	15	16	17	97	96
High rate of illiteracy and ignorant	48	158	13	8	11
Religious beliefs	67	142	12	11	6
Limited public awareness campaigns	89	109	9	6	17
Fear of the unknown	87	99	9	18	25
Emotional attachment to partners	69	112	14	24	11
Fear of stigmatization	56	153	5	7	9

A, Agreed; SA, Stongly agreed; N, Neutral; D, Disagreed; SD, Stongly disagreed and SDC, Sickle cell disease

Table 5 shows that 97 and 96 (40.8% and 40%) respondents were of the opinion that financial constrain was never a factor influencing genetic counselling and testing for SCD, as against the 15, 13 and 17 (18.9%) respectively. 48 and 158 (20% and 66.7%) suggested high level of illiteracy and ignorant as factor influencing genetic counselling and testing for SCD. Also 89 and 109 (37.4% and 45%) suggested limited public awareness compare to 32 (13.5%). 87 and 99 (36.6% and 41.6%) suggested fear of the unknown as a factor influencing genetic counselling and testing. 65 and 112 (28% and 48%) compared to 5, 7 and 9 representing (9%) were of the opinion emotional attachment to partners to be a factor influencing genetic counselling and testing of SCD. Also 56 and 153 (24% and 66.7%) were of the opinion fear of stigmatization could influence genetic counselling and testing compare to 21respondents, representing (9%),

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Table 6: Mean Rating of Knowledge of Genetic Counseling and Testing for Sickle Cell

SN.	Item Statement	Mean	Std. Dev.	Decision
1	Sickle cell is a genetic disease	3.832	0.456	Agree
2	I have heard of genetic testing for sickle cell disease	3.361	0.755	Agree
3	Sickle cell disease carriers if married can give birth to children with sickle cell disease	2.807	1.108	Agree
4	Frequency illness could be a sign of sickle cell Disease	2.580	1.283	Agree
5	Genetic counselling is the best technique for detecting sickle cell disease	2.546	1.146	Agree
6	I am aware of the risk of not testing for sickle cell Disease	2.699	1.140	Agree

Cumulative Mean = 2.896 Criterion Mean =2.5
Source: Field Survey, 2026

Table 6 presents rating knowledge of genetic counseling and testing for sickle cell showing mean standard deviation of 2.5, while cumulative mean was 2.9.

Table 7: Mean Rating of Attitudes to Genetic Counseling and Testing for Sickle Cell

SN.	Item Statement	Mean	Std. Dev.	Decision
1	Genetic counselling and testing for sickle cell disease is necessary	3.126	1.060	Agree
2	I will avail myself for genetic counseling and testing for sickle cell disease	3.261	1.035	Agree
3	Death comes from God; sickle cell disease testing is a waste of resource	2.950	1.197	Agree
4	Genetic testing for sickle cell can leads to physical and emotional pains	2.479	1.259	Disagree
5	Sickle cell disease testing results are always reliable	2.780	1.279	Agree

Cumulative Mean = 2.919 Criterion Mean =2.5
Source: Field Survey, 2026

Table 7 present rating attitudes to genetic counseling and testing for sickle cell indicating mean standard deviation of 2.5, while the cumulative mean was 2.9.

IV. DISCUSSION

➢ *Socio-Demographic Characteristics*

The findings showed that more females – 138 (58%) participated in the study; the predominant age range was of 21 to 40 years – 121 (50.8%), indicating that most participants were within the active marriageable and reproductive age bracket. This finding agrees with research conducted by Fagbamigbe et al. (2015) and that of Kanma-Okafor (2022), who also noticed similar trend in their respective studies.

In terms of educational attainment, a significant proportion of respondents attained tertiary education (41.2%), while others had secondary or primary education. The nearness to tertiary education facilities in Jos to the study location may have accounted for the high number of person's attainment of tertiary education level. This relative high educational level of respondents suggests that many participants had some level of exposure to health information, including knowledge about SCD. This is in line with findings of Adigwe, (2022), who found out that majority of those that participated in the research he conducted were told about sickle diseases at school.

➢ *Awareness of SCD and Genotype Testing*

The results revealed that most respondents had heard about sickle cell disease and were aware of premarital genotype testing. This indicates that awareness of the disease and the importance of genotype screening before marriage is relatively high among young adults in the study area. This is in agreement with the findings in a similar research conducted by (Oluwole et al (2022) and Sarpong et al (2025). However, the findings from this study and similar studies indicated that awareness does not always translate into practice, as most 121 (50.84%) respondents had not undergone genotype testing despite being aware of its importance and the devastating impact of SCD, which is in line with findings by Dilli et al (2024) and Adesola et al (2025).

➢ *Attitudes toward Genetic Counselling and Testing*

The study found out that attitudes toward genetic counselling and testing varied among respondents. Most – 196 (82.24%) indicated that genetic counseling and testing was necessary; 191 (80.25%) affirmed that they will avail themselves for the service, but 121 (50.84%) have not actually presented themselves for genetic counseling and testing, while 49 (20.59%) claimed they were not sure if they have ever participated in the procedure. Obviously, although many respondents expressed positive attitudes, agreeing that genotype testing before marriage is necessary in order to

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prevent the birth of children with SCD, nevertheless, as shown in table 3, a large proportion (50.84%) of respondents have actually not participated in genetic counselling services. Some – 188 (79%) of the respondents were hesitant to seek genetic counselling due to fear of discovering genotype incompatibility with their partners, this is in line with research conducted by Oluwole et al, (2022).

➢ *Factors Influencing Attitudes toward Genetic Counselling*

The findings from this study further revealed several factors that influence the attitudes of young adults toward genetic counselling and testing. Some were emotional attachment between partners, hence, ignored genotype incompatibility and proceed with marriage, as in a similar study conducted by (Yussif et al (2025). Other factors were financial constraints – 28 (11.76%); religious beliefs – 209 (87.82%); limited awareness – 198 (83.19%) and fear of unknown – 186 (78.15%).

Another factor was fear of stigmatization and discrimination as observed by Kanma-Okafor et al, (2022). Some participants expressed concern that being identified as carriers of the sickle cell trait could lead to social rejection or difficulties in finding marriage partners. Additionally, family pressure and cultural expectations were reported as influencing factors. In some cases, family members encourage couples to continue with marriage despite genotype incompatibility. (Bugin et al, 2018)

V. CONCLUSION

The study revealed poor attitude of young adults towards genetic counseling and testing for sickle cell, despite large proportion of respondents attaining tertiary education level and being aware of the impact of SCD on the society. Additionally, prior knowledge of genotype status was found to influence respondents' attitudes, but actual uptake was disappointingly low. Participants with higher levels of education and those who had previously tested their genotype were more likely to support genetic counselling and premarital genotype screening. We therefore recommend that in order to reduce sickle cell carriers in Nigeria, genetic counselling and screening intervention should be strategically stepped up. Therefore, efforts should be made by National Orientation Agency (NOA) and relevant departments of higher educational and religious institutions to aggressively educate young adults for the need to present themselves for voluntary genotype screening and counseling for informed decision making before marriage.

➢ *Ethical Approval*

Ethical approval was not required for this study, hence the researchers did not obtained a formal ethical approval from any Health Research Ethical Standard Committee. However, participation in the study was purely voluntary without any coercion and manipulation, and a written consent of willingness to participate was obtained from every participant before enrolment after they were each informed of the study's scope and objectives. The respondents were assured of confidentiality of their responses, and that the data collected shall be used strictly for the study, and anonymity was maintained throughout the study. No drug was administered to any of the participants and no human sample was needed or taken throughout the study.

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