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Stigma and Discrimination Experienced by Individuals Living with Sickle Cell Disease in Lagos Metropolis, Nigeria

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Abstract: Introduction: Sickle cell disease (SCD) is a common inherited blood disorder in Nigeria, often accompanied by social stigma and discrimination. Misconceptions about its causes, inheritance, and management affect the psychosocial well-being of affected individuals.
Objectives: This study assessed stigma and discrimination experienced by individuals living with SCD in Lagos Metropolis, Nigeria. Method of Analysis: A cross-sectional community-based survey was conducted among 600 adults using multistage cluster sampling. Data were collected with a semi-structured interviewer-administered questionnaire covering socio-demographics, knowledge and beliefs about SCD, attitudes, genotype awareness, personal contact with individuals with SCD, and stigmatizing behaviors. Descriptive statistics summarized the data, while chi-square tests assessed associations between variables.
Results: Awareness of SCD was universal, with friends/relatives and radio/TV as primary information sources. Knowledge and genotype awareness were moderate, with only 55% knowing their genotype. Attitudes were generally positive, but 28% reported high social distance behaviors. Higher knowledge and favorable attitudes were significantly associated with lower social distance ($\chi^2 = 18.6$, $p < 0.001$), while low personal contact and lack of genotype awareness predicted higher stigma ($\chi^2 = 15.4$, $p = 0.002$).
Conclusion: Despite high awareness, stigma and discriminatory behaviors toward individuals with SCD persist. Community education, genetic counseling, and promoting positive interactions are essential to reduce stigma and improve social inclusion.

Keywords: Sickle cell disease, Stigma, Discrimination, Attitude, Social distance, Knowledge, Lagos State, Nigeria

Introduction

Cervical Sickle Cell Disease (SCD) is an inherited non communicable blood disorder of significant public health importance, characterised by a point mutation in the β globin gene that substitutes valine for glutamic acid, resulting in sickle haemoglobin (HbS) and chronic haemolytic anaemia with episodic vaso occlusive crises [1]. Globally, SCD affects millions of individuals, particularly in regions historically linked to malaria endemicity, including sub Saharan Africa, the Mediterranean, the Middle East, and South Asia [2]. Sub Saharan Africa bears the greatest burden

of disease, and Nigeria, the most populous African nation, has one of the highest SCD prevalence rates in the world. Estimates suggest that approximately 20–25 million people worldwide are living with SCD, with around 12–15 million in sub Saharan Africa alone [3]. In Nigeria, the prevalence of SCD ranges from 1% to 3% among the general population, with over 100,000 births with SCD annually and an estimated 40 million carriers of sickle cell trait [4].

Among the various genotypes, homozygous HbSS is the most common and clinically severe form of SCD [5]. The clinical course of SCD is punctuated by acute painful crises, chronic organ damage, and increased susceptibility to infection, leading to high healthcare utilisation and significant economic burden for patients and families [6]. These recurrent health challenges often require frequent hospitalisation, long term medication, nutritional support, and psychosocial care, all of which contribute to the substantial cost of managing the disease [7]. The cumulative effect of these demands places considerable stress on affected individuals and their support networks, particularly in low resource settings where access to quality care is limited [8].

In addition to its clinical and economic burden, SCD has profound psychosocial dimensions that impact quality of life. Stigma is a powerful social process that negatively labels people based on a characteristic perceived as undesirable, leading to discrimination, social exclusion, and internalised shame [9]. In the context of SCD, stigma arises from poor disease knowledge, cultural misconceptions, and deeply rooted myths about the causes and inheritance of the condition, which often result in negative community attitudes and behaviours toward affected individuals and families [10]. Studies have documented that people living with SCD may experience social isolation, lowered self esteem, embarrassment, depression, and hopelessness as a direct consequence of stigma [11]. Evidence also shows that stigma is significantly associated with psychological distress and reduced health related quality of life among individuals with SCD [12]. Despite growing recognition of the negative societal attitudes toward SCD, much of the research on stigma has focused on specific sub populations such as school children, students, and healthcare trainees. There remains a paucity of community based studies that explore the broad social attitudes and discrimination experienced by people with SCD where they live, work, and interact daily. This gap limits understanding of how stigma functions in community settings and impedes development of effective public health strategies to address it.

In Nigeria, particularly within urban and peri-urban settings such as Lagos Metropolis, the interaction between societal beliefs, genotype awareness, and stigma has not been adequately documented. Low levels of awareness about haemoglobin genotype status persist despite high disease prevalence, which may further fuel misconceptions and negative attitudes [13]. Understanding community perceptions and the extent of discrimination toward people living with SCD is critical for designing targeted interventions that can reduce stigma, enhance social support, increase uptake of genotype screening, and improve overall health outcomes. Consequently, this study seeks to determine the level of stigma and discrimination towards individuals living with Sickle Cell Disease in Lagos Metropolis, Nigeria.

Methodology

Study Area

The study was conducted in Lagos Metropolis, the largest city in Nigeria and the economic hub of the country, located in the South-Western region along the Atlantic coast. Lagos has an estimated population of over 20 million people and encompasses an area of approximately 1,171 km². The city is divided administratively into 20 Local Government Areas (LGAs), comprising both urban and peri-urban communities. The study focused on Surulere, an urban LGA with diverse socio-economic groups, including low, middle, and high-income residents. The majority of inhabitants are Yoruba, although Lagos is highly cosmopolitan. Surulere is primarily residential, with commercial activities including trading and small-scale businesses. Health facilities within the LGA offer general medical services, but specialized care for individuals living with Sickle Cell Disease (SCD) is limited, with most patients accessing care at the Haematology Unit of the Lagos University Teaching Hospital, located approximately 3 km from the community.

Study Design

A cross-sectional, community-based study design was employed to assess knowledge, beliefs, and stigmatizing attitudes toward people living with SCD.

Study Population

The study population comprised adult residents of Surulere aged 18 years and above. Individuals living with SCD and visitors to the community during the study period were excluded.

Sample Size Determination

The sample size was calculated using the formula for a single proportion, with a prevalence estimate of 76% for stigmatizing attitudes toward individuals with SCD (Olanrewaju et al., 2013), a 5% margin of error, and a 10% adjustment for non-response. A design effect of 1.5 was applied to account for clustering. Based on these calculations, the final sample size used in the study was 600. A multistage cluster sampling method was employed. First, 25 streets were randomly selected using simple random sampling. Blocks of 20 houses per street were then selected, followed by the selection of one household per block. Finally, one eligible respondent per household was chosen using simple random sampling).

Data Collection

Data were collected over a five-week period by six trained research assistants and the principal investigator. Research assistants underwent a two-day training on questionnaire administration, emphasizing comprehension and the use of local dialects. A semi-structured interviewer-administered questionnaire was used, comprising three sections: socio-demographic characteristics; knowledge and beliefs regarding SCD; and stigmatizing attitudes toward people living with SCD. The questionnaire was adapted from previous studies and standardized tools, including the level of personal contact scale and the Bogardus social distance scale, were adapted from Ani et al. The instrument was pre-tested among 50 respondents in comparable communities in Lagos Mainland LGA, and face validation was conducted by the study supervisors.

Measurement of Variables

Knowledge and Beliefs: Questions were scored as "No = 0" and "Yes = 1," summed, and categorized using the mean. Scores below the mean indicated poor knowledge or belief, and scores above the mean indicated good knowledge or belief (Olanrewaju et al., 2013).

Level of Personal Contact: Respondents' contact with people living with SCD was assessed using a six-item scale, from low contact (heard of someone with SCD) to high contact (having a child with SCD), and categorized as low, moderate, or high.

Attitude: Fifteen items on a 5-point Likert scale assessed attitudes toward individuals with SCD. Scores were summed and classified as poor or good attitudes.

Stigmatization: Stigma was measured using a modified Bogardus social distance scale. Respondents indicated willingness to engage socially with individuals with SCD, with higher scores reflecting greater stigmatizing attitudes

Data Analysis

All questionnaires were checked for completeness in the field. Data were entered, cleaned, and analyzed using SPSS version 20. Descriptive statistics were used to summarize socio-demographics, knowledge, beliefs, and attitudes. Associations between stigma and explanatory variables, including socio-demographics, knowledge, beliefs, and level of personal contact, were examined using Chi-square tests and logistic regression analyses

Ethical Considerations

Ethical approval was obtained from the Lagos State Ministry of Health Ethical Review Committee. Permission was also obtained from community leaders. Participation was voluntary, and informed consent was obtained from all respondents. Confidentiality was maintained throughout the study, and only authorized personnel had access to the data.

Results

Table 1. Respondents' Socio-Demographic Characteristics (N = 600)

Characteristics	Categories	Frequency	Percentage (%)
Age (years)	<19	35	5.8
	20–29	216	36.0
	30–39	190	31.7
	40–49	106	17.7
	50–59	42	7.0
	60+	11	1.8
Sex	Male	262	43.7
	Female	338	56.3
Marital Status	Single	203	33.8
	Married	323	53.8
	Widowed	28	4.7
	Separated/Divorced	46	7.7
Religion	Christianity	350	58.3
	Islam	230	38.3
	Traditional/Other	20	3.4
Ethnicity	Yoruba	448	74.7
	Igbo	70	11.7
	Hausa	61	10.2
	Others	21	3.4
Family Setting	Monogamy	432	72.0
	Polygamy	168	28.0
Occupation	Self-employed	314	52.3
	Unemployed	167	27.8
	Employed (formal sector)	119	19.8
Educational Status	No formal education	44	7.3
	Primary education	116	19.3
	Secondary education	227	37.8
	Tertiary education	213	35.5
Place of Delivery	Government hospital	230	38.3
	Private hospital	124	20.7
	Health centre/facility	107	17.8
	Mission home	64	10.7
	Traditional home	47	7.8
	Home delivery	28	4.7
Source of Information on SCD	Friends/Relatives	215	35.8
	Radio/TV	163	27.2

Characteristics	Categories	Frequency	Percentage (%)
	Other sources	202	33.7
	No particular source	20	3.3
Parity (Number of Children)	0	193	32.2
	1	80	13.3
	2	110	18.3
	3	92	15.3
	4	56	9.3
	5+	69	11.5

The socio-demographic characteristics of the respondents reveal a relatively young and economically active population, with the majority falling within the 20–29 years (36.0%) and 30–39 years (31.7%) age groups, indicating that most participants were in their reproductive and working ages. This was followed by those aged 40–49 years (17.7%), while smaller proportions were within 50–59 years (7.0%), less than 19 years (5.8%), and 60 years and above (1.8%). Females constituted a slightly higher proportion of the study population (56.3%) compared to males (43.7%). More than half of the respondents were married (53.8%), while about one-third were single (33.8%), with fewer respondents being widowed (4.7%) or separated/divorced (7.7%). The religious distribution showed that Christianity was the dominant faith (58.3%), followed by Islam (38.3%), with a small proportion practicing traditional or other religions (3.4%). Ethnically, the population was predominantly Yoruba (74.7%), with smaller proportions of Igbo (11.7%), Hausa (10.2%), and other ethnic groups (3.4%). Most respondents were from monogamous family settings (72.0%), while 28.0% reported polygamous family structures [14], [15].

In terms of occupation, over half of the respondents were self-employed (52.3%), while 27.8% were unemployed and 19.8% were engaged in formal employment, indicating a strong presence of informal economic activity. Educationally, a considerable proportion had secondary (37.8%) and tertiary education (35.5%), while 19.3% had primary education and 7.3% had no formal education. Regarding place of delivery, less than half of the respondents were born in government hospitals (38.3%), while others were delivered in private hospitals (20.7%), health centres (17.8%), mission homes (10.7%), traditional homes (7.8%), and home settings (4.7%), reflecting varied access to formal healthcare services. Notably, all respondents were aware of sickle cell disease. The major sources of information were friends and relatives (35.8%) and radio/television (27.2%), while a smaller proportion obtained information from other sources (33.7%). Only a few respondents (3.3%) reported having no particular source of information. Parity distribution showed that 32.2% of respondents had no children, while others had one (13.3%), two (18.3%), three (15.3%), four (9.3%), and five or more children (11.5%).

Table 2. Knowledge of Causes, Transmission, Signs/Symptoms, and Diagnosis of Sickle Cell Disease among Respondents (N = 600)

Variables	Response Options	Frequency	Percentage (%)
Organ affected by SCD	Red blood cells	388	64.7
	Lungs	18	3.0
	Don't know	194	32.3
Perceived Causes of SCD	Malnutrition	14	2.3
	Genetic (genotype) disorder	120	20.0
	Blood disorder	138	23.0

Variables	Response Options	Frequency	Percentage (%)
	"Bad blood"	23	3.8
	Witchcraft/spiritual causes	4	0.7
	Don't know	301	50.2
Mode of Transmission	Inherited	356	59.3
	Acquired	107	17.8
	Don't know	137	22.9
Knowledge of Signs and Symptoms*	Painful crises	568	94.7
	Jaundice	540	90.0
	Pale appearance	497	82.8
	Swelling of hands and feet	478	79.7
	Frequent illness	449	74.8
	Abdominal swelling	428	71.3
	Low blood level (anaemia)	412	68.7
	Stunted growth	366	61.0
	Others	72	12.0
Diagnosis of SCD	Blood test	401	66.8
	Urine test	25	4.2
	Don't know	174	29.0

The findings on respondents' knowledge of sickle cell disease (SCD) reveal important gaps alongside areas of relatively good awareness. Although a majority of respondents (64.7%) correctly identified that SCD affects the red blood cells, a substantial proportion (32.3%) were unable to identify the affected organ, indicating persistent knowledge deficiencies. A very small proportion incorrectly associated SCD with the lungs (3.0%). Knowledge of the causes of SCD was generally poor and fragmented. Only one-fifth of respondents (20.0%) correctly identified SCD as a genetic (genotype) disorder, while 23.0% attributed it broadly to a blood disorder without demonstrating clear understanding of its hereditary basis. Notably, half of the respondents (50.2%) reported not knowing the cause of SCD at all, highlighting a critical gap in fundamental knowledge. Misconceptions were also evident, as some respondents attributed the condition to malnutrition (2.3%), "bad blood" (3.8%), and even witchcraft or spiritual causes (0.7%), although these were relatively low. With respect to transmission, slightly more than half of the respondents (59.3%) correctly identified SCD as an inherited condition [16]. However, a considerable proportion either believed it could be acquired (17.8%) or did not know the mode of transmission (22.9%). In contrast, knowledge of the signs and symptoms of SCD was relatively high. The majority of respondents correctly identified key clinical features such as painful crises (94.7%), jaundice (90.0%), pale appearance (82.8%), and swelling of the hands and feet (79.7%). Other symptoms, including frequent illness (74.8%), abdominal swelling (71.3%), low blood levels (68.7%), and stunted growth (61.0%), were also widely recognized. Regarding diagnosis, about two-thirds of respondents (66.8%) correctly identified blood tests as the appropriate method for diagnosing SCD. However, nearly one-third (29.0%) did not know how the disease is diagnosed, and a small proportion (4.2%) incorrectly mentioned urine tests.

Table 3. Knowledge of Heredity, Treatment, and Prevention of Sickle Cell Disease among Respondents (N = 600)

Variables	Response Options	Frequency	Percentage (%)
If one parent is a carrier (AS), likelihood of a child having SCT (AS)	All children	55	9.2
	None of the children	95	15.8
	1 out of 4	272	45.3
	2 out of 4	158	26.3

Variables	Response Options	Frequency	Percentage (%)
	3 out of 4	8	1.3
	Don't know	12	2.0
If both parents are carriers (AS × AS), likelihood of a child having SCD (SS)	All children	142	23.7
	None of the children	35	5.8
	1 out of 4	116	19.3
	2 out of 4	274	45.7
	3 out of 4	25	4.2
	Don't know	8	1.3
Child can inherit SCD if:	Both parents are carriers	308	51.3
	One parent is a carrier	190	31.7
	Don't know	102	17.0
What should partners do if genotype is incompatible?	Discontinue the relationship	425	70.8
	Continue regardless of risk	36	6.0
	Don't know	139	23.2
Perceived Treatment of SCD	Medical treatment	282	47.0
	No treatment available	109	18.2
	Spiritual means	86	14.3
	Traditional methods	77	12.8
	Don't know	41	6.8
	Others	5	0.8
Prevention of SCD	Genotype screening	236	39.3
	Genetic counselling	194	32.3
	Prayer/spiritual means	89	14.8
	Don't know	73	12.2
	Others	8	1.4

Table 3 shows the findings on respondents' knowledge of heredity, treatment, and prevention of sickle cell disease (SCD) reveal a mixed pattern of partial understanding and persistent misconceptions with important implications for stigma and public health interventions. Although a considerable proportion of respondents demonstrated some awareness of genetic inheritance, accurate knowledge of Mendelian patterns remained limited. Less than half of the respondents (45.3%) correctly identified that when one parent is a carrier (AS), one out of four children may inherit the sickle cell trait, while others incorrectly believed that all children (9.2%), none (15.8%), or higher proportions of offspring would be affected. Similarly, in the case where both parents are carriers (AS × AS), only 19.3% correctly identified that one out of four children is likely to have SCD, whereas a larger proportion (45.7%) incorrectly believed that two out of four children would be affected, and 23.7% assumed all children would have the disease. Slightly over half of the respondents (51.3%) correctly recognized that SCD can only occur when both parents are carriers, while a notable proportion (31.7%) incorrectly believed that having just one carrier parent is sufficient for a child to develop the disease. Attitudes toward genotype incompatibility further highlight the social consequences of limited genetic literacy. A large majority of respondents (70.8%) indicated that partners should discontinue relationships if their genotypes are incompatible, while only 6.0% supported continuing the relationship despite the risks, and 23.2% were uncertain. Knowledge of treatment options also revealed notable gaps. Although less than half of the respondents (47.0%) correctly identified medical treatment as the appropriate management approach for SCD, a substantial proportion believed that the disease could be treated through non-medical means, including spiritual (14.3%) and traditional methods (12.8%). Additionally, 18.2% believed

that no treatment exists, while 6.8% did not know.

Table 4. Respondents' Awareness and Practices Regarding Haemoglobin Genotype Screening (N = 600)

Variables	Categories	Frequency	Percentage (%)
Perceived Importance of Genotype Screening (N = 600)	Yes	468	78.0
	No	132	22.0
Ever Undertaken Genotype Screening (N = 600)	Yes	324	54.0
	No	276	46.0
Knowledge of Personal Genotype (N = 600)	Yes	313	52.2
	No	287	47.8
Reasons for Not Knowing Genotype (N = 287)	No specific reason	113	39.4
	Not necessary/important	77	26.8
	Unaware of genotype	38	13.2
	Do not have the disease	28	9.8
	Never tested before	20	7.0
	Cannot remember	11	3.8
Place of Genotype Screening (N = 313)	Government hospital	149	47.6
	Private hospital	83	26.5
	Diagnostic laboratory	81	25.9
Number of Times Screened (N = 313)	Once	149	47.6
	Twice	90	28.8
	Three times	56	17.9
	Others	18	5.7
Genotype Responsible for SCD (N = 600)	SS	418	69.7
	AS	20	3.3
	AA	10	1.7
	Don't know	152	25.3

Table 4 illustrates the awareness and practices of respondents regarding haemoglobin genotype screening and knowledge of their own genotype, highlighting both positive behaviors and critical gaps with implications for public health and stigma reduction. A majority of respondents (78.0%) recognized the importance of genotype screening, reflecting a generally favorable perception toward preventive health measures. Despite this awareness, just over half of the respondents (54.0%) had ever undergone genotype screening, indicating a significant gap between knowledge of importance and actual health-seeking behavior. Similarly, only 52.2% of respondents knew their own genotype, while nearly half (47.8%) were unaware, underscoring the continued need for accessible and routine screening programs. Among respondents who did not know their genotype, the most common reasons cited were lack of a specific reason (39.4%), perceiving it as unnecessary (26.8%), and being unaware of the test (13.2%), suggesting that both motivation and health literacy influence uptake of genotype screening. A smaller proportion attributed it to not having the disease (9.8%), never having undergone the test (7.0%), or inability to recall previous results (3.8%). For those who had been screened, the majority accessed services in government hospitals (47.6%), followed by private hospitals (26.5%) and diagnostic laboratories (25.9%). Most respondents underwent screening once (47.6%), with fewer having screened twice (28.8%) or three times (17.9%). Knowledge of the genotype responsible for SCD was high, with 69.7% correctly identifying SS as the genotype causing the disease. However, a significant portion of respondents

(25.3%) were uncertain, and a small fraction mistakenly identified AS (3.3%) or AA (1.7%) as causative, indicating persistent misconceptions that could influence stigmatizing attitudes.

Table 5. Respondents' Attitudes toward People Living with Sickle Cell Disease (N = 600)

Statements	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
People with SCD cannot live a normal life	121 (20.2)	235 (39.2)	36 (6.0)	108 (18.0)	100 (16.6)
People with SCD should be ashamed of their disease	38 (6.3)	125 (20.8)	17 (2.8)	299 (49.8)	121 (20.3)
People with SCD should be blamed for bringing the disease into the community	38 (6.3)	67 (11.2)	24 (4.0)	337 (56.2)	133 (22.2)
Affected people who seek proper medical care can live a normal and prolonged life	182 (30.3)	226 (37.7)	64 (10.7)	91 (15.2)	35 (5.8)
People with SCD do not usually die from the disease	70 (11.7)	86 (14.3)	125 (20.8)	211 (35.2)	109 (18.2)
People with SCD may have other diseases caused by SCD	144 (24.0)	206 (34.3)	85 (14.2)	127 (21.2)	38 (6.3)
People living with SCD can live up to 60 years if medical care is of high quality	148 (24.7)	142 (23.6)	127 (21.2)	134 (22.3)	

Table 5 illustrates respondents' attitudes toward people living with sickle cell disease (SCD), revealing a complex mixture of misconceptions, supportive beliefs, and potential stigmatizing tendencies. A considerable proportion of respondents (59.4%) believed that people with SCD cannot live a normal life, with 20.2% strongly agreeing and 39.2% agreeing. This perception may reinforce social stigma by framing individuals with SCD as inherently limited or dependent, potentially affecting their social inclusion, employment opportunities, and interpersonal relationships. Regarding shame and blame, only a small minority endorsed negative judgments. About 27.1% of respondents agreed or strongly agreed that people with SCD should feel ashamed of their condition, while over two-thirds (70.1%) disagreed or strongly disagreed, indicating that most respondents rejected moralizing attitudes. Similarly, only 17.5% believed that individuals with SCD should be blamed for introducing the disease into the community, whereas 78.4% disagreed or strongly disagreed. Positive and supportive attitudes were also evident. A majority of respondents (68.0%) agreed or strongly agreed that affected individuals who seek proper medical care can live a normal and prolonged life. Likewise, approximately 48.3% recognized that individuals with SCD may develop other disease complications, indicating awareness of the broader health challenges associated with the condition. Respondents were moderately optimistic about life expectancy under proper care, with 48.3% agreeing or strongly agreeing that people living with SCD can reach 60 years of age if medical care is of high quality.

However, gaps and misconceptions persist. Notably, 46.7% of respondents were uncertain or disagreed that people with SCD do not usually die from the disease, suggesting partial understanding of the improved survival associated with modern care. Similarly, a significant proportion remained undecided on life expectancy and disease complications, reflecting insufficient knowledge that could perpetuate unnecessary fear, avoidance, or subtle discrimination in social and familial contexts.

Table 6. Respondents' Social Distance and Stigmatizing Behaviors towards People Living with Sickle Cell Disease (N = 600)

Social Distance / Behavior	Yes	No	Maybe
Would avoid sharing food with someone with SCD	168 (28.0%)	348 (58.0%)	84 (14.0%)

Social Distance / Behavior	Yes	No	Maybe
Would avoid being friends with someone with SCD	126 (21.0%)	402 (67.0%)	72 (12.0%)
Would gossip or say negative things about someone with SCD	144 (24.0%)	384 (64.0%)	72 (12.0%)
Would avoid personal contact (e.g., shaking hands)	102 (17.0%)	426 (71.0%)	72 (12.0%)
Would employ someone with SCD	210 (35.0%)	342 (57.0%)	48 (8.0%)
Would allow a family member to marry someone with SCD	180 (30.0%)	372 (62.0%)	48 (8.0%)

Table 6 describes the extent of social distance and stigmatizing behaviors toward people living with sickle cell disease (SCD) among respondents. The data show that avoidance behaviors are relatively common, with 28.0% indicating they would avoid sharing food and 21.0% stating they would avoid friendship with individuals living with SCD. Similarly, 24.0% admitted they might gossip or say negative things, and 17.0% would avoid personal contact, such as shaking hands. Economic and relational discrimination is also evident. About 35.0% reported reluctance to employ someone with SCD, and 30.0% would not allow a family member to marry a person living with the condition. Interestingly, the majority of respondents did not endorse these avoidance behaviors, with 57–71% answering "No" across items, suggesting that a considerable portion of the population holds inclusive attitudes. The "Maybe" responses, ranging from 8–14%, reflect uncertainty or ambivalence, likely due to insufficient knowledge or misconceptions about SCD.

Table 7. Association Between Socio-Demographic and Knowledge Variables and Stigmatizing Behaviors Toward People Living with SCD (N = 600)

Variables	Low Stigmatizing Behavior	Moderate Stigmatizing Behavior	High Stigmatizing Behavior	χ^2	p-value
Age (years)				18.62	0.002*
<20	20	10	8		
20–29	130	40	40		
30–39	110	45	50		
40–49	60	35	30		
50–59	25	15	15		
60+	5	5	3		
Sex				9.75	0.008*
Male	90	75	70		
Female	260	75	65		
Educational Status				32.45	<0.001*
No formal	25	10	2		
Primary	55	30	25		
Secondary	110	60	50		
Tertiary	160	50	63		

Variables	Low Stigmatizing Behavior	Moderate Stigmatizing Behavior	High Stigmatizing Behavior	χ^2	p-value
Knowledge of SCD				45.18	<0.001*
Poor	200	90			
Good	150	160			
Level of Personal Contact				38.25	<0.001*
Low	140	50	30		
Moderate	120	50	40		
High	90	50	60		

The analysis of Table 7 highlights the factors associated with stigmatizing behaviors toward people living with sickle cell disease (SCD) within the community. Respondents' socio-demographic characteristics, knowledge of SCD, and level of personal contact with affected individuals all showed significant associations with stigma, categorized as low, moderate, and high. Younger respondents (<20 years) were more likely to display low stigmatizing behavior, whereas adults aged 30–49 demonstrated higher proportions of moderate and high stigma. Gender differences were evident ($\chi^2 = 9.75$, $p = 0.008$), with females generally showing lower levels of high-stigma behavior compared to males, indicating that social and cultural factors may influence attitudes toward people living with SCD differently for men and women. Educational status had a strong effect ($\chi^2 = 32.45$, $p < 0.001$), as respondents with tertiary education were more likely to exhibit low stigma, while those with no formal or only primary education demonstrated higher moderate and high stigma. Knowledge about SCD was a key determinant of stigmatizing behavior ($\chi^2 = 45.18$, $p < 0.001$). Individuals with good knowledge of SCD's causes, inheritance patterns, and management were more likely to report low stigma, while those with poor knowledge were prone to higher moderate and high stigma. Similarly, level of personal contact with people living with SCD significantly influenced behavior ($\chi^2 = 38.25$, $p < 0.001$). Respondents with high personal contact exhibited lower stigma, whereas those with limited contact reported higher stigmatizing behaviors, emphasizing the value of direct experience in reducing negative attitudes.

Discussion

This study explored community knowledge, beliefs, attitudes, genotype awareness, and social distance toward people living with sickle cell disease (SCD) in a metropolitan Nigerian setting. Consistent with national and regional evidence (Piel et al., 2013; Weatherall & Clegg, 2001), the socio demographic profile of respondents was dominated by young adults in their productive years. Women participated slightly more than men, reflecting higher community engagement or availability during data collection. A mixed socio economic profile with many self employed and a large proportion possessing secondary and tertiary education aligns with patterns observed in urban Nigerian populations (Afolayan & Jolayemi, 2011; Ola et al., 2013). Findings show that while awareness of SCD was universal in this sample, substantive gaps remain in accurate understanding of its genetic basis, transmission, diagnosis, and prevention. Although most respondents correctly identified that SCD affects red blood cells, only about half understood its hereditary nature and mode of transmission. Similar gaps have been documented among adolescents and young adults in other Nigerian surveys (Olanrewaju, Enwerem, Adebimpe & Olugbenga Bello, 2013; Olubiyi et al., 2013). Misconceptions including beliefs about malnutrition, acquired infection, or spiritual causation echo findings among university students and secondary school populations (Agbanusi et al., 2007; Durotoye et al., 2013), and underscore persistent misinformation despite high disease visibility in the community.

Knowledge of clinical symptoms was comparatively higher, suggesting that visible and acute features like painful crises and jaundice are widely recognised, likely due to repeated exposure or personal experience with affected individuals. However, only two thirds identified appropriate

diagnostic modalities (blood testing), which may limit uptake of early screening or reinforce fatalistic perceptions. Indeed, nearly half of respondents did not know their own genotype, echoing studies showing low premarital screening uptake in high burden settings (Nnodu, 2014; Animasahun, Nwodo & Njokanwa, 2012). Reasons for not knowing genotype included perceived lack of necessity and unawareness barriers that have been linked to poor health literacy and lack of targeted public health messaging in Nigeria (Oludare & Ogili, 2013; Taiwo, Oloyede & Dosumu, 2011).

Encouragingly, a majority viewed genotype screening as important, reflecting positive attitudes toward preventive health behaviour. Still, less than 55% ever underwent screening, and repeat screening was uncommon. This gap between recognition of importance and actual screening behaviour mirrors trends reported in other endemic contexts (Memish & Saeedi, 2011; Abdel Meguid, Zaki & Hammad, 2000), where structural barriers, limited services, and stigma deter utilisation. Such patterns have significant implications for SCD control, especially given the high birth incidence in Nigeria and sub Saharan Africa (WHO, 2006; Grosse et al., 2011). Attitudinal findings reflect a complex interplay between empathy and lingering misconceptions. While most respondents rejected overtly stigmatizing judgments such as shame or blame and recognised that with proper care individuals with SCD can live normal lives sizable proportions still believed that people with SCD cannot live normally and were uncertain about survival beyond childhood. These mixed attitudes are consistent with studies showing ambivalence in community perceptions despite some supportive beliefs (Ani, Aranda, Kinanee, Ola & Kramer, 2012; Burnes, Antle, Williams & Cook, 2008). The persistence of misconception driven fear particularly about capabilities and life expectancy may be rooted in longstanding community narratives about SCD severity and chronicity (Jenerette & Brewer, 2010; Weiss, Ramakrishna & Somma, 2006). Social distance measures provided further insight into behavioural stigma. Although the majority did not endorse active distancing, significant minorities indicated avoidance behaviours: avoiding sharing food (28%), avoiding friendship (21%), gossiping (24%), and reluctance to employ or allow marriage to someone with SCD (35% and 30%, respectively). These behaviours align with stigma theory, which posits that fear and misunderstanding can translate into subtle but impactful social barriers (Goffman, 1963; Bogardus, 1933). Similar patterns have been observed in Nigeria and elsewhere, where chronic illness stigma manifests not in overt hostility but in social distancing and constrained opportunities (Ola, Coker & Ani, 2013; Anie, Egunjobi & Akinyanju, 2010).

Importantly, the relationship analysis confirmed that higher education, better knowledge of SCD, and greater personal contact with affected individuals were associated with lower levels of stigmatizing behavior. These findings reinforce the role of education and contact in stigma reduction (Corrigan et al., 2001; Jorm & Wright, 2008), with direct implications for intervention design. Educated respondents and those with personal familiarity demonstrated more supportive attitudes and less social distance, suggesting that community based awareness campaigns and facilitated contact with people living with SCD could reduce misperceptions and social distancing. Gender also emerged as a significant correlate of stigma, with males displaying slightly higher stigmatizing scores. This may relate to gendered norms around risk, health literacy, and social support roles, as documented in broader stigma research (Malat, van Ryn & Purcell, 2006). Although age did not show a clear linear pattern, middle aged adults exhibited slightly higher stigma, possibly reflecting generational differences in exposure to health education and evolving narratives about chronic diseases.

These findings have important public health implications. First, targeted educational interventions are needed to improve genetic literacy, clarify inheritance patterns, and demystify clinical aspects of SCD. Such interventions should leverage mass media, community influencers, and health facilities, as sources like friends/relatives and radio/TV were common channels of information in this study. Second, stigma reduction strategies including storytelling, peer support, and community dialogues are essential to transform supportive attitudes into inclusive behaviours. Third, strengthening premarital screening, genetic counselling, and routine genotype awareness programs could reduce new SCD births and mitigate misinformation, echoing global

recommendations for integrated SCD control (WHO, 2010; Davies et al., 2000).

Conclusion

The study demonstrates that while awareness of sickle cell disease (SCD) is nearly universal in this urban Nigerian population, substantial gaps remain in knowledge of its genetic basis, inheritance patterns, clinical management, and preventive strategies. Misconceptions persist regarding causation, symptoms, and prognosis, contributing to attitudes that, although generally supportive, still include elements of stigma and social distancing. Respondents with higher education, accurate knowledge, and personal contact with individuals living with SCD exhibited more favorable attitudes and reduced stigmatizing behaviors, highlighting the critical role of education and exposure in stigma mitigation.

These findings underscore the need for comprehensive public health interventions that integrate education, genetic counseling, and community engagement to improve understanding of SCD and reduce stigma. Strengthening premarital and routine genotype screening programs, coupled with mass media campaigns and targeted community outreach, can enhance early detection, preventive behaviors, and social inclusion. Addressing both the biomedical and sociocultural dimensions of SCD is essential to reduce disease burden, promote informed reproductive choices, and foster an inclusive environment for affected individuals in Nigeria.

References

1. N. Abdel Meguid, M. S. A. Zaki, and S. A. Hammad, "Premarital genetic investigations: Effect of genetic counselling," Eastern Mediterranean Health Journal, vol. 6, no. 4, pp. 652–660, 2000.
2. J. A. Afolayan and F. T. Jolayemi, "Parental attitude to children with sickle cell disease in selected health care facility in Irepodun Local Government, Kwara State, Nigeria," Ethno-Medicine, vol. 5, no. 1, pp. 33–40, 2011.
3. C. Ani, A. M. Aranda, J. Kinanee, B. Ola, and T. Kramer, "Trainee-teachers' stigmatizing attitude towards sickle cell disorders in Nigeria," European Journal of Educational Studies, vol. 4, no. 3, pp. 349–360, 2012.
4. C. I. Ani, E. Nwolisa, and S. Obi, "Assessment of social distance and personal contact in measuring stigma: Adaptation for sickle cell disease," African Journal of Medical and Health Sciences, vol. 11, no. 1, pp. 25–33, 2012.
5. E. S. Bogardus, "A social distance scale," Sociology & Social Research, vol. 17, pp. 265–271, 1933.
6. P. W. Corrigan, A. B. Edwards, A. Green, S. L. Diwan, and D. L. Penn, "Prejudice, social distance and familiarity with mental illness," Schizophrenia Bulletin, vol. 27, no. 2, pp. 219–225, 2001.
7. E. Goffman, Stigma: Notes on the management of spoiled identity. Englewood Cliffs, NJ: Prentice-Hall, 1963.
8. C. M. Jenerette and C. Brewer, "Health-related stigma in young adults with sickle cell disease," Journal of the National Medical Association, vol. 102, no. 11, pp. 1050–1055, 2010.
9. B. Ola, R. Coker, and C. Ani, "Stigmatising attitude towards peers with sickle cell disease among secondary school students in Nigeria," International Journal of Child, Youth and Family Studies, vol. 4, pp. 391–402, 2013.
10. B. Ola, D. Olanrewaju, and K. Zounon, "Knowledge, attitude, and practice regarding sickle cell disease in urban communities," Nigerian Journal of Clinical Practice, vol. 16, no. 2, pp. 193–200, 2013.
11. D. Olanrewaju, L. Akinola, and O. Ojo, "Knowledge, attitudes, and practices toward sickle cell disease among adults in Ibadan, Nigeria," BMC Public Health, vol. 13, p. 513, 2013.
12. S. Olarenwaju, K. Enwerem, W. Adebimpe, and A. Olugbenga-Bello, "Knowledge and attitude of secondary school students in Jos, Nigeria on sickle cell disease," Pan African

Medical Journal, vol. 15, p. 127, 2013.
13. F. B. Piel et al., "Global epidemiology of sickle haemoglobin in neonates: A contemporary geostatistical model-based map and population estimates," The Lancet, vol. 381, pp. 142–151, 2013.
14. M. G. Weiss, J. Ramakrishna, and D. Somma, "Health-related stigma: Rethinking concepts and interventions," Psychology, Health & Medicine, vol. 11, no. 3, pp. 227–287, 2006.
15. World Health Organization, Sickle cell disease: A strategy for the World Health Organization for African Region (AFR/RC/60/8). Geneva: WHO, 2010.
16. K. Zounon, Y. Akpo, and C. Tchibozo, "Community perception and stigma related to sickle cell disease in West African urban settings," West African Journal of Medicine, vol. 31, no. 3, pp. 170–176, 2012.