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QUALITY OF LIFE AND STIGMA AMONG PEOPLE LIVING WITH LEPROSY IN SOUTHWESTERN AND NORTH-CENTRAL NIGERIA

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ABSTRACT

Background: **Globally, leprosy is one of the most stigmatized diseases and this affects the quality of life of people living with the disease, yet research on this issue in Nigeria is scarce.**

Objective: **To understand the relationship between stigma and quality of life among people living with leprosy in Nigeria.**

Methods: **A cross-sectional study conducted among 53 persons living with leprosy in Oke-Igbala and Ago-Ireti leprosy settlements in July, 2024 using a semi-structured tool to measure sociodemographic information, quality of life using the WHOQOL-BREF, and stigma using the SARI Stigma Scale. Descriptive statistics, chi-square tests and logistic regression were used to examine the data; $p<0.05$ was considered significant.**

Results: **The quality of life or general well-being was very poor for 94.3% of the respondents. The prevalence of stigma was 60.4%. Significant associations were found between source of income and quality of life (p=0.036), occupation and stigma (p=0.010). No statistical association was found between stigma and quality of life (p=0.239).**

Conclusion: **Addressing the source of income and livelihood options of people living with leprosy may improve their quality of life. Future qualitative research to gain a deeper understanding of their experiences may be beneficial to reduce stigma.**

Keywords: Leprosy, Stigma, Quality of life, Nigeria

INTRODUCTION

Leprosy ,also referred to as Hansen's disease has an estimated burden of disease of around 21,100 disability-adjusted life years (DALYs) and remains highly stigmatized, especially in parts of the world like Nigeria despite being curable.[1,2] It is one of the oldest and most neglected illnesses that is known to generate prejudice and stigma compared to other stigmatizing diseases.[3] It is a deforming disease caused by Mycobacterium leprae that primarily affects the peripheral nerves, respiratory tract mucosa, and skin.[4] Annually, over 200,000 new cases of leprosy are recorded and the World Health Organization (WHO) states that leprosy is not seen as a priority in over 120 nations especially in the African region where there are over 20,000 new cases each year.[5] This stigma not only affects individuals diagnosed with the disease but also extends to their families and communities, leading to profound implications for their quality of life.[6] Through effective treatment and public health initiatives, the World Health Organization (WHO) has made significant progress in lowering the incidence of leprosy. Nevertheless, the social consequences of stigma frequently overshadow these medical advancements, creating obstacles that prevent people from seeking care and assimilating into society.[7]

Leprosy is a public health issue in Nigeria with 4,000 new cases reported each year, with 12% of those cases resulting in disability.[5] The national prevalence rate stands at about 0.4 per 10,000 persons, showing a decline compared to previous years.[8] There are regional variations in Nigeria regarding the prevalence of leprosy such as Zaria Local Government Area (LGA) in Kaduna State which reported a high prevalence rate of 1.4 per 10,000 population[9], likely due to the presence of the National TB & Leprosy Training Centre, a referral center for many northern states[10] and a low prevalence rate of 0.1 per 10,000 in some southern states in the country.[9] A study conducted in the country revealed that some local government areas

in eight states (Zamfara, Sokoto, Yobe, Adamawa, Kaduna, Cross River, Benue and Jigawa states) are high clusters for the burden of leprosy while states such as Ekiti, Lagos, Federal Capital Territory (FCT) and Imo are low clusters for the burden of leprosy.[10]

In Nigeria, misconceptions and cultural beliefs about leprosy are widespread, and they play significant roles in the negative perceptions and attitudes that people hold toward those who are affected.[11] An environment of fear and avoidance is fostered by historical narratives that portray leprosy as a hereditary curse or a punishment for moral failings, leading to people associating the disease with dirtiness, incurability, and inferiority.[12] Communities with limited or no education often lack awareness about leprosy and its treatment options.[13] Additionally, the way the disease is represented in the media significantly influences public perceptions and attitudes towards it.[13] As a result of this, people may postpone obtaining medical treatment out of fear of prejudice or rejection, which can exacerbate their health concerns[14] All these factors have contributed to the marginalization of individuals living with leprosy.[2] A significant portion of the population avoids any association with them, forcing them to live in isolation within leprosy settlements and preventing their integration into mainstream society.[15] Studies have also shown that this stigma can cause mental anguish, and a lower feeling of self-worth among those afflicted.[16]

The relationship between stigma and quality of life is multifaceted. It manifests in various domains, including social relationships, employment opportunities, and mental health. Individuals with leprosy often face challenges in maintaining relationships due to societal rejection and discrimination.[17] This isolation can lead to feelings of shame and hopelessness, which significantly affect their mental well-being. Studies have indicated that stigma contributes to higher levels of anxiety and depression among individuals affected by leprosy which directly affects their well-being.[2] The emotional toll of living with a stigmatized condition can create a vicious cycle where the lack of social support further deteriorates their mental health.[18] The impairments and social barriers associated with the disease can lead to emotional reactions and negative behaviors among affected individuals.[19] These challenges often result in unemployment, economic and physical dependence, and difficulties with social integration.[20] Moreover, the stigma surrounding leprosy disproportionately affects women, who often encounter additional societal pressures related to marriage and family dynamics[2]. Women with leprosy may struggle more than their male counterparts to find partners or maintain familial relationships due to cultural norms that prioritize physical appearance and perceived health status.[21]

Quality of life (QoL) is a multifaceted concept encompassing physical health, psychological health, level of independence, social relationships, personal beliefs, and the environment.[22] QoL is influenced by factors such as the ones explained earlier among people living with leprosy.[23] Previous studies have suggested an association between leprosy-related stigma and diminished QoL, with physical disabilities and discrimination leading to adverse psychosocial and economic outcomes[24] However, the strength and consistency of this relationship require further scrutiny. This study aimed to understand the relationship between stigma and well-being (QoL) among individuals affected by leprosy in Nigeria. While existing literature suggests a significant link, this study seeks to determine whether stigma independently influences QoL when examined through a rigorous statistical lens. By exploring individual experiences and broader societal contexts, this research highlights the need for targeted interventions addressing both the medical and psychosocial dimensions of leprosy. The significance of this study lies not only in its contribution to academic discourse but also in its practical implications for public health policy and community engagement. Understanding the outcomes of this relationship may help shape future research and intervention strategies aimed at improving the well-being of individuals affected by leprosy.

MATERIALS AND METHODS

Study design

A community-based cross-sectional study conducted in June and July, 2024 to understand the relationship between stigma and the quality of life of people living with leprosy in two settlements in Akure, Ondo State and Omu-Aran, Kwara State, Nigeria.

Sampling

A simple random sampling technique was used to select 2 leprosy settlements and total sampling was used to select a total of 53 eligible participants aged 18 years and above in the two settlements between June and July, 2024.

Study location

The study was carried out in two settlements in Nigeria namely Oke Igbala Leprosarium, Kwara state and Ago Ireti Leprosy settlement in Akure, Ondo state. The Oke Igbala Leprosarium, also known as the Omu-Aran Leprosy Settlement, is situated in a dense forest area between Omu-Aran and Oke Onigbin villages in Kwara State, Nigeria. It was established by the Evangelical Church Winning All (ECWA). Ago-Ireti,

meaning "Settlement of Hope," is a leprosy colony located in Akure, the capital of Ondo State, Nigeria. It was founded in 1943 and it has served as a safe haven for individuals affected by leprosy for over 80 years.

Study population

The study was conducted among 53 eligible participants aged 18 years and above in the two settlements.

Data collection

We used a semi-structured questionnaire consisting of the socio-demographic characteristics of the participants, SARI (Stigma Awareness Resources Infrastructure) Stigma scale and the World Health Organization Quality of Life Brief (WHOQOL-BREF) that are used to assess stigma and quality of life (Well-being) respectively. Trained research assistants were employed in the data collection process.

Outcome measures

World Health Organization Quality of Life Brief (WHOQOL-BREF)

The WHOQOL-BREF is a validated 26-item questionnaire used to assess the quality of life across four domains namely physical health, psychological health, social relationship and environment. It is a tool that can also be used to measure overall well-being of people. It is made of a 5 Likert scale indicating zero as no and four as very good or very satisfactory. The domain scores were calculated by averaging the item scores within each domain. The total score is the average of the four domain scores. The tool is graded as a score of 0 to 2.99 as very poor, score of 3 to 3.99 as poor, score of 4 to 4.99 as fair and a score of 5 as excellent quality of life.[25] The total WHOQOL-BREF score was further categorized as ≤13 and ≥14 indicating poor quality of life and good quality of life respectively.[26]

SARI-stigma scale

The SARI-stigma scale is a validated questionnaire that is used to assess leprosy-related stigma. It is made of a 4 Likert scale with zero as no and three as very sure. The total obtainable score is 33. The tool is graded as a score of 0 to 8 as low stigma, score of 9 to 16 as moderate stigma, score of 17-24 as high stigma and a score of 25-33 as very high stigma.[27] The total SARI score was further categorized as ≤10 and ≥11 indicating no stigma and stigma respectively.[28]

Data analysis

Data entry and analysis were done using IBM Statistical Product for Service Solution (SPSS) statistical software version 26. For the univariate analysis, continuous variables were coded, categorized and presented using frequencies and proportions. Bivariate analysis using Chi-square test was used to determine the association between socio-demographic characteristics, stigma and also with quality of life. It was also used to determine the association between stigma and quality of life. Multivariate analysis using logistic regression was used to determine the predictors. The level of statistical significance was set at p value of <0.05.

Ethical approval

Ethical approval was obtained from the National Health Research Ethics Committee through the Oyo State Ministry of Health, with code number NHREC/OYOSHRIEC/10/11/22. In addition, appropriate clearance was sought and obtained from the respective Ethics Committee of both Ondo and Kwara State Ministry of Health. Confidentiality of the study participants and data collected from them was ensured. All participants gave a written informed consent before participating in the study.

RESULTS

A total number of 53 participants were recruited for the study, 31 and 22 participants in Ago Ireti and Oke Igbala settlements respectively. The mean age of participants was 67.25±13.6 years, with more than half falling within the 51–70 age group, followed by those above 70 years (34%) and those aged 31–50 years (13.2%). Male respondents constituted a higher proportion (62.3%) compared to their female counterparts (37.7%). Most of the respondents were married (64.2%), and identified as Christians (86.8%). More than half of the respondents (56.6%) had received formal education, while 43.4% had no formal education. In terms of occupation, 50.9% were farmers, and 26.4% worked as artisans. Regarding the duration of leprosy, 83% had lived with the disease for over 20 years, and 69.8% had resided in leprosy settlements for the same period. Additionally, 52.8% had received support from the state government or

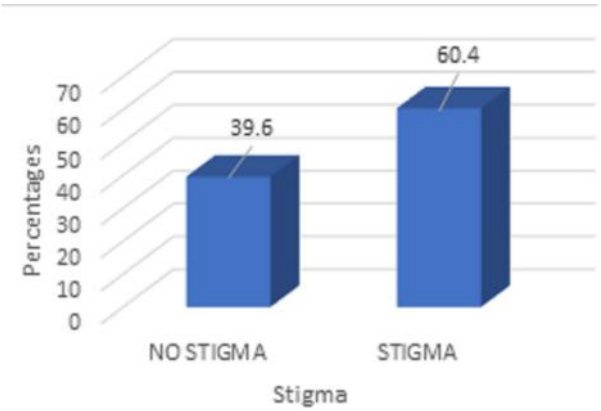

Fig 1: Prevalence of stigma among people living with leprosy

social welfare, and 58.5% were currently undergoing treatment for leprosy.

Regarding stigma and quality of life, 34% of respondents reported experiencing a low level of stigma, while 43.4% experienced a moderate level with 17% reporting a high level of stigma, and 5.7% experiencing a very high level of stigma. Overall prevalence of stigma among the participants was 60.4% (Figure 1). The majority (94.3%) of respondents reported a very poor quality of life, while the remaining 5.7% indicated a poor quality of life (Figure 2).

There were statistically significant associations between sociodemographic characteristics, stigma, and quality of life (Tables 1 and 2). However, the association between stigma and quality of life was not statistically significant (p = 0.239) Multivariate analysis using logistic regression, yielded no further association between selected sociodemographic characteristics and outcome variables of interest (Tables 3 and 4).

Table 1: Respondents' socio-demographic characteristics and quality of life

	QOL		(X^2)	P-value
	Poor n (%)	**Good n (%)**		
Age				
≤ 30	0(0.0)	0(0.0)	0.956	0.620
31-50	6(85.7)	1(14.3)		
51-70	18(66.7)	9(33.3)		
>70	13(72.2)	5(27.8)		
Gender				
Female	14(70.0)	6(30.0)	1.091	0.296
Male	23(69.7)	10(30.3)		
Marital Status				
Single	1(50.0)	1(50.0)	4.056	0.255
Married	23(67.6)	11(32.4)		
Divorced	3(100.0)	0(0.0)		
Widowed	10(71.4)	4(28.6)		
Religion				
Christianity	34(73.9)	12(26.1)	0.862	0.353
Islam	3(42.9)	4(57.1)		
Level of Education				
No formal	15(65.2)	8(34.8)	0.086	0.769
Primary	14(70.0)	6(30.0)		
Secondary	5(71.4)	2(28.6)		
Tertiary	3(100.0)	0(0.0)		
Occupation				
Farmer	17(63.0)	10(37.0)	0.012	0.913
Artisan	10(71.4)	4(28.6)		
Others	10(83.3)	2(16.7)		
Source of Income				
Begging	3(60.0)	2(40.0)	6.009	0.036*
Farming	8(61.5)	5(38.5)		
Government support	21(77.8)	6(22.2)		
Family support	4(57.1)	3(42.9)		

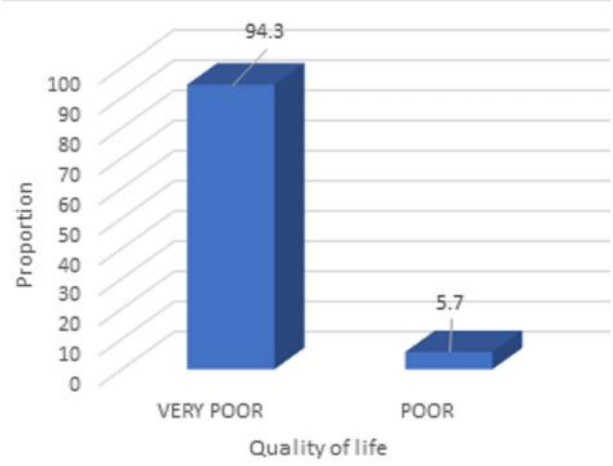

Fig 2: Quality of life among people living with leprosy

Table 2: Association between socio-demographic characteristics and stigma

	Stigma				X^2	P-valu
	Low stigma n (%)	Moderate stigma n (%)	High stigma n (%)	Very high stigma n (%)		
Age						
≤ 30	0(0.0)	0(0.0)	0(0.0)	0(0.0)	3.791	0.705
31-50	2(28.6)	3(42.9)	2(28.6)	0(0.0)		
51-70	10(37.0)	13(48.1)	3(11.1)	1(3.7)		
>70	6 (33.3)	6(33.3)	4(22.2)	2(11.1)		
Gender						
Female	8(40.0)	6(30.0)	4(20.0)	2(10.0)	2.935	0.402
Male	10(30.3)	17(51.5)	5(15.2)	1(3.0)		
Marital Status						
Single	0(0.0)	1(50.0)	1(50.0)	0(0.0)	9.687	0.376
Married	11(32.4)	16(47.1)	6(17.6)	1(2.9)		
Divorced	0(0.0)	1(33.3)	1(33.3)	1(33.3)		
Widowed	7(50.0)	5(35.7)	1(7.1)	1(7.1)		
Religion						
Christianity	14(30.4)	21(45.7)	9(19.6)	2(4.3)	4.894	0.180
Islam	4(57.1)	2(28.6)	0(0.0)	1(14.3)		
Occupation						
Farmer	7(25.9)	15(55.6)	3(11.1)	2(7.4)	16.815	0.010*
Artisan	8(57.1)	5(35.7)	0(0.0)	1(7.1)		
Others	3(25.0)	3(25.0)	6(50.0)	0(0.0)		
Duration of diagnosis of leprosy						
0-20	3(30.0)	5(50.0)	1(10.0)	1(10.0)	7.242	0.841
> 20	15(34.8)	18(41.9)	8(18.6)	2(4.7)		
Duration of Stay in Leprosy Settlement (years)						
0-20	8(47.1)	6(35.3)	2(11.8)	1(5.9)	5.037	0.831
> 20	10(27.8)	17(47.2)	6(16.7)	3(8.3)		

*(*P<0.05)*

Table 3: Multivariate analysis of source of income, quality of life, occupation, and stigma among respondents.

	QOL				P-value	OR	CI
	Very poor n (%)	Poor n (%)	Fair n (%)	Excellent n (%)			
Source of Income							
Begging **(ref)**	5(100.0)	0(0.0)	0(0.0)	0(0.0)			
Farming	13(100.0)	0(0.0)	0(0.0)	0(0.0)	0.952	0.94	0.114-7.728
Government support	26(96.3)	1(3.7)	0(0.0)	0(0.0)	0.408	0.43	0.058-3.186
Family support	5(71.4)	2(28.6)	0(0.0)	0(0.0)	0.921	1,13	0.109-11.595
	Level of stigma				**P-value**	**OR**	**CI**
	Low stigma n %	Moderate stigma n %	High stigma n %	Very high stigma n %			
Occupation							
Farmer **(ref)**	7(25.9)	15(55.6)	3(11.1)	2(7.4)			
Artisan	8(57.1)	5(35.7)	0(0.0)	1(7.1)	0.223	0.44	0.118-1.644
Others	3925.0)	3(25.0)	6(50.0)	0(0.0)	0.465	1.77	0.385-8.087

*(*p<0.05, OR=Odds Ratio, CI= Confidence Interval)*

DISCUSSION

In this study, we tried to understand the association between leprosy related stigma and the quality of life among people living with leprosy. Our study revealed that a larger percentage of the respondents were between the age of 51-70 years and predominantly male (62.3%) which is consistent with findings by Peters and Eshiet in Enugu, Nigeria and Ramos in Ethiopia[29,30].

The study also revealed that most of the respondents were married with only 3.8% who have never experienced marriage. 50.9% and 28.3% of the respondents have been diagnosed with leprosy for over 21-40 years and 41-60 years respectively. There is a likelihood of the respondents getting married before they got diagnosed since only 13.2% of the respondents are aged below 50 years which is consistent with findings from Peters as earlier cited in the text.[29] The larger percentage of married men living with this illness is inconsistent with findings from Scott in South Africa who reported many cases of partners leaving the respondents after they have been diagnosed.[31] Also, 43.4% and 37.7% of the respondents have no formal education and primary education respectively. This can play a major role in their poor quality of life as their low level of education can be as a result of their illness. Their illness can predispose them to lack of standard jobs and low-income levels. This is also evident based on findings carried out by Singh in India.[20] It can be seen from our study that most of the respondents are farmers and may only be producing enough food for their families alone, only a few are artisans and it is in line with a study in Bangladesh by Feenstra who reported that most of the respondents were involved in subsistence farming.[32]

Furthermore, findings from our study indicated that 94.3% of respondents had a very poor quality of life. This is consistent with results from studies conducted by Rahman in Egypt and Dako-Gyeke in Ghana, which reported very poor quality of life among people living with leprosy.[17,33]

Factors such as marginalization, low education, negative public perception, lack of employment opportunities and socio-economic conditions significantly influence the quality of life of individuals with leprosy, shaping their perceptions and satisfaction with life. We found that the occupation of the respondents was statistically significant with stigma. This association between occupation of respondents and stigma is consistent with findings from a study by Brakel which reported that most respondents are stigmatized and are therefore restricted to low-income jobs.[34] This is due to the fact that people do not want to employ them and some lose customers as a result of the condition. Additionally, only the source of income of respondents had a statistically significant association with their quality of life. The other factors have no association with the respondents' quality of life. The association between the source of income of respondents and their quality of life is consistent with findings from the study by Chatterjee in India which indicated that the source of income plays a huge role in determining the quality of life of respondents.[35] Most of the respondents in this study are being supported by the government and some family members and although this may not aggressively affect their mental health, it is not helping with their quality of life.

There was no statistically significant association between stigma and quality of life of respondents. This is consistent with findings from a study by Chatterjee in India who reported that stigma has no relationship with the quality of life of the respondents.[36] These findings can be attributed to other factors such as community support, clinical involvement and educational status of people in the community which were absent in our own communities. However, findings from studies in India show a strong association between stigma and quality of life.[37] Also, another study by Tsutsumi in Bangladesh reveals further association on multiple regression between stigma and quality of life. This study reported that stigma is a predictor of the lower levels of quality of life of respondents.[38]

On multivariate analysis, we found no statistically significant association between the source of income of respondents and their quality of life. This is consistent with findings from a study conducted by Mankar in India who reported that quality of life remained poor despite the different sociodemographic factors of the respondents.[39] This was not consistent with findings from You in China who indicated that there is an association or link between the source of income of respondents and their quality of life.[40] Also, there was no association found between occupation of respondents and stigma. Stigma toward leprosy is primarily driven by misconceptions and local beliefs rather than occupation, which is consistent with Dahiru's findings in Kano, Nigeria.[41] However, this did not align with findings from Kinanti in Indonesia who reported that individuals affected by leprosy faced significant challenges in employment due to stigma. Participants reported difficulties securing jobs and experienced discrimination from employers based on their leprosy.[42]

CONCLUSION

This study revealed a high prevalence of leprosy-associated stigma and poor quality of life outcomes among participants, though interestingly without statistically significant correlation to stigma levels. The findings underscore the critical need for multifaceted interventions including enhanced community engagement, government initiatives for accessible healthcare and anti-discrimination policies, and structured educational campaigns to challenge persistent myths about leprosy. Comprehensive approaches addressing both social stigma and quality of life determinants, supported by further qualitative

research, are essential to ensure full societal integration of people affected by leprosy with dignity and opportunity.

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