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# Quality of life and stigma among persons affected by leprosy or buruli ulcer in Nigeria: a community-based cross-sectional study

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### **Abstract**

**Introduction** Skin Neglected tropical diseases including leprosy and Buruli ulcer cause aesthetic and functional impairments due to late detection of the diseases. This study assessed the quality of life and stigma among persons affected by leprosy or Buruli ulcer in Nigeria.

**Methods** This was a community-based cross-sectional study. It involved 635 persons affected by leprosy or Buruli ulcers who were purposively selected from the endemic local government areas in six Southern States of Nigeria. The SARI Stigma Scale was used to assess stigma while the WHOQOL-BREF questionnaire was used to determine the Quality of life. Chi-square test, Correlation analysis, Mann Whitney U, Kruskal Wallis tests and multivariate analysis using binary logistic regression analysis were used in the study. The level of statistical significance was determined by a p-value of < 0.05.

**Results** The mean age of the respondents was  $43.8 \pm 17.0$  years. A higher proportion of the respondents, 78.9% were affected by leprosy. Less than one-third of the respondents, 29.3% had good quality of life. The mean overall stigma score was significantly higher for leprosy patients when compared with BU, (p = 0.042). There was a strong negative correlation between overall stigma and overall quality of life, (n = 635, r = -0.530, p < 0.001). There was a strong positive correlation between overall social support and overall quality of life, (n = 635, r = 0.558, p < 0.001). Predictors of good quality of life included having no formal education, (AOR = 0.4, 95%CI: 0.2 – 0.7), being unemployed, (AOR = 0.4, 95%CI: 0.2 – 0.7), having vocational training, (AOR = 2.1, 95%CI: 1.1 – 4.1), being affected by leprosy, (AOR = 4.3, 95%CI: 2.3 – 8.1) and having poor social support, (AOR = 0.1, 95%CI: 0.05 – 0.2).

**Conclusion** The quality of life of the individuals decreases as the level of stigma increases. Thus, the need to continue community health education campaigns to change the existing stereotypes about the diseases and provide strong social support for the affected individuals.

**Keywords** Quality of life, Stigma, Leprosy or buruli ulcer, Nigeria

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### **Background**

Leprosy, a skin-related Neglected Tropical Disease (NTD), is a debilitating chronic disease that occurs in more than 120 countries with 200,000 new cases reported yearly and about 2-3 million people are disabled [1, 2]. Although mortality associated with the disease is quite low it causes high morbidity especially in developing countries due to late detection of the disease [3]. Nigeria is categorised as a country with a 'high' burden of leprosy based on the Leprosy Burden Score by the World Health Organization, and this may be linked to high endemicity of the disease in some areas of the country. Although the country achieved the WHO leprosy elimination target of less than 1 per 10,000 population in 1998 [4,5], leprosy remains a health concern with approximately 3,500 new cases detected yearly and disability present in 25% of the patients [2]. The disease mostly affects the skin and peripheral nerves, resulting in neuropathy and long-term deformities and impairments [1].

Buruli Ulcer is another skin-related neglected tropical disease reported in 33 (mostly tropical) countries within Africa, the Americas, Asia and the Western Pacific [6]. The disease starts as a painless papule, nodule, plaque, or edematous lesion that eventually progresses to disfiguring skin ulceration occasionally involving the bone [7]. Recently, 2121 new cases of Buruli ulcer were reported from 11 countries and the African Region accounted for 84% of the disease [6]. Nigeria has recorded more than 500 new cases of the disease over the years with endemicity of the disease commonly seen in the southern region of the country [8, 9].

Leprosy and Buruli ulcers are the most common mycobacterial diseases in humans after tuberculosis and can affect any age group [10]. Due to the insidious nature of the diseases, it takes an average of five years for leprosy to manifest, while buruli ulcer presents between one-nine months [3, 7]. These attributes of the diseases contribute to the difficulty in identifying the infection for prompt treatment, leaving the patient with residual disabilities [3, 7]. The disabling sequelae of the diseases can lead to functional limitations of the affected limbs resulting in enormous physical and socioeconomic impacts on affected individuals [4, 9]. Also, these skin-related NTDs have societal consequences, including stigmatization, because they are highly visible diseases that alter a person's aesthetic appearance [11].

Stigma is a social process of interpretation that follows labelling, stereotyping, separation, resultant discrimination and the loss of status [12]. There are different forms of stigma, one of them is perceived stigma which refers to a person's understanding of how others may act towards, and think or feel about an individual with a certain trait [12]. Another form is enacted stigma which is an active experience of societal judgment and discrimination

against the affected people [13]. Societal discrimination causes a sense of insecurity and decreased self-esteem in the affected person leading to the other form of stigma (Internalized stigma) [13]. Stigmatization negatively impacts the health-seeking behaviour of the affected individuals resulting in increased disease transmission among family members, poor treatment outcomes, denial of employment opportunities and social limitations [10, 12]. Furthermore, their family members may be stigmatized by the community environment including denial of marriage relationships [3]. Thus, the consequences of stigma in people with leprosy or Buruli ulcer may outweigh the burden of physical afflictions [12]. Also [14], the residual, permanent, and unresolving physical disfigurements and painful neuropathy due to late detection of the disease continue to perpetuate the psychological, social, and economic impact which ultimately affects the quality of life.

There are several studies on the assessment of the quality of life in patients with leprosy, nevertheless, there is a paucity of research regarding the quality of life and stigma associated with persons affected with leprosy and Buruli ulcer in sub-Saharan Africa including Southern Nigeria where the diseases are endemic [2, 14]. The findings of this study will help policymakers in identifying and implementing social strategies aimed at reducing the burden of both diseases in the affected areas. Thus, this study assessed the quality of life and stigma among persons affected by leprosy or Buruli ulcer in Nigeria. Furthermore, it determined the correlation between the quality of life and stigma in the affected individuals which helps to identify areas for investment in stigma reduction and better quality of life.

### Methods

### Study setting

The study took place in southern Nigeria. There are three geo-political zones in southern Nigeria, including the southeast, south-south and southwest. The National Tuberculosis and Leprosy Control Program (NTBLCP) which is under the Federal Ministry of Health is the agency of government responsible for tuberculosis and leprosy and Buruli ulcer control program. NTBLCP is organized around the three tiers of government in Nigeria including the federal, state and local government areas. Nigeria achieved the WHO leprosy elimination target of less than 1 per 10,000 population in 1998 [15]. However, the country continues to have pockets of high endemicity of the disease in some States and Local Government Areas (LGAs) across the country. Two states (Anambra and Ebonyi) in the South-east and four states (Akwa Ibom, Cross river, Delta and Bayelsa) in the South-south geopolitical zones were included in the study. In these six states, ten LGAs were included in

the study. These include: Ebonyi LGA in Ebonyi state, Ogbaru and Anambra East LGAs in Anambra state, Etinan LGA in Akwa Ibom state, Calabar south, Ogoja and Obubra LGAs in Cross River state, as well as Ogbia LGA in Bayelsa state, and Ethiope East and Isoko South LGAs in Delta state.

### Study design

This was a community-based cross-sectional study that involved ten LGAs with the highest number of notified leprosy or BU cases between 2014 and 2018. They were purposively selected from 220 LGAs in the southeast and south-south geopolitical zones of Nigeria because they had the highest case load for leprosy or BU between 2014 and 2018.

### Study population

This included persons affected by leprosy or BU in the ten selected LGAs who were willing to participate in the study. All persons affected by leprosy or Buruli ulcer as identified by the officers of NTBLCP at the state and local government level gave consent to participate in the study.

### Sample size determination and sampling technique

This was a total population study of all persons (635) affected by leprosy or BU in the selected local government areas. Leprosy is a notifiable disease and the diagnosis and management of leprosy cases are under the auspices of NTBLCP. However after treatment for leprosy, the individuals are discharged to the communities, so while there are records of persons diagnosed and treated for leprosy in each of the selected LGAs, there is no way one may know the number of persons affected by leprosy who reside in the LGAs. However, with the assistance of the various state and LGA program officers, efforts were made to include all persons who met the inclusion criteria in the study.

### Study instrument

In assessing the quality of life of persons affected by leprosy or Buruli ulcer, the WHO QualBref [16] was used. The SARI Stigma Scale [17] was used to assess stigma among the respondents with Leprosy and was adopted for Buruli ulcer.

SARI Stigma Scale; this is a 21-variable questionnaire with 'a' and 'b' options. The b component is recorded when the object of interest is present in the individual which requires that a score of 1 represents Rarely/once, a score of 2 stands for Sometimes and a score of 3 which means Always/often was assigned. If the variable in question is not obtainable for any respondent, a score of zero was given. The scale has four domains, including experienced stigma, disclosure concerns, internalized stigma

and anticipated stigma. The higher the total score of the 21 variables for each respondent, the higher the stigma.

WHOQOL-BREF; this is a 26-variable questionnaire, and the response is on a five-point Likert scale. It is made up of four domains, including physical health, made up of seven variables and the psychological domain, which consists of six variables. Others include social relationships, which are made up of three variables, and environmental health, which is made up of eight variables. Two variables in the questionnaire are stand-alone. They include How do you rate your quality of life? and How satisfied are you with your health? All variables in the questionnaire are based on events of life in the last four weeks. Four variables in the questionnaire are reversed and scored. For each respondent, the higher the quality of life score, the higher the quality of life.

Social support was assessed using the Oslo Social Support Scale (OSSS-3) [18]. This is a 3-item self-reported measure of the level of social support. The focus of the questionnaire is on the availability of practical help. The three items in the questionnaire address relationship with neighbours, the number of close confidants and the sense of concern from other people. The total score for the three items ranges from 3 to 14. The higher the value, the higher the level of social support. The total score could be categorized into three categories: 3–8 signifies poor social support, 9–11 indicate moderate social support while scores of 12–14 represent strong social support.

### Data collection methods

Data was collected from persons affected by leprosy or BU by trained research assistants. The research team was accompanied by officers of the state and LGA program managers all through the study. The assistance of the various state and LGA program officers was useful in including as much as possible all persons who met the inclusion criteria into the study. The study was conducted in the communities and there are instances where individuals living in a neighbourhood came together at a particular place for the purpose of the study. However, privacy and confidentiality were taken into consideration in the collection of data.

### Data analysis

Data entry and analysis were done using IBM Statistical Product and Service Solution (SPSS) version 25. Continuous variables were presented using mean and standard deviation while categorical variables were represented using frequencies and proportions. The quality of life of the respondents was dichotomised into good and poor quality of life, a score of <78 represents poor quality of life and a score of  $\ge78$  represents good quality of life. The chi-square test was used to determine the difference in proportions between two categorical variables while

correlation analysis was used to determine the strength of linear relationship between two continuous variables. The level of statistical significance was determined by a p-value of < 0.05.

Multivariate analysis using binary logistic regression was used to determine the predictors of good quality of life among the respondents. Initially the outcome variable, good quality of life was cross-tabulated with the socio-demographic characteristics of the respondents and other variables that follow a logical sequence. Variables that had a p-value of < 0.2 at bivariate analysis were entered into the logistic regression model to determine

**Table 1** Socio-demographic characteristics of the respondents

| Variable                          | Frequency (n=635) | Percent (%) |
|-----------------------------------|-------------------|-------------|
| Age of respondents                |                   |             |
| Mean±(SD)                         | $43.8 \pm 17.0$   |             |
| Age of respondents in groups      |                   |             |
| < 30 years                        | 127               | 20.0        |
| 30–39 years                       | 122               | 19.2        |
| 40–49 years                       | 141               | 22.2        |
| 50–59 years                       | 112               | 17.6        |
| ≥60 years                         | 133               | 20.9        |
| Gender                            |                   |             |
| Male                              | 322               | 50.7        |
| Female                            | 313               | 49.3        |
| Marital status                    |                   |             |
| Never married                     | 196               | 30.9        |
| Married                           | 341               | 53.7        |
| Separated/Divorced                | 44                | 6.9         |
| Widowed                           | 54                | 8.5         |
| Religion                          |                   |             |
| Christianity                      | 607               | 95.6        |
| Islam                             | 1                 | 0.2         |
| Traditional religion              | 27                | 4.3         |
| Educational attainment of respond | lents             |             |
| No formal education               | 179               | 28.2        |
| Primary education                 | 268               | 42.2        |
| Secondary education               | 160               | 25.2        |
| Tertiary education                | 28                | 4.4         |
| Employment status of the respond  | ent               |             |
| Unemployed                        | 242               | 38.1        |
| Self-employed                     | 369               | 58.1        |
| Paid employment                   | 24                | 3.8         |
| Have had vocational training      |                   |             |
| Yes                               | 57                | 9.0         |
| No                                | 578               | 91.0        |
| Number of dependents              |                   |             |
| None                              | 177               | 27.9        |
| 1–4 individuals                   | 203               | 32.0        |
| ≥5 individuals                    | 255               | 40.2        |
| Disease entity                    |                   |             |
| Leprosy                           | 501               | 78.9        |
| Buruli ulcer                      | 134               | 21.1        |

the predictors of good quality of life. The results of the binary logistic regression analysis were presented using an adjusted odds ratio and 95% confidence interval and the level of statistical significance was determined by a p-value of < 0.05.

### **Ethics approval**

Ethical approval for the study was obtained from the Health Research and Ethics Committee of the University of Nigeria Teaching Hospital, Ituku Ozalla, Enugu. (NHREC 0501-2008B). The respondents signed or thumbprinted a written informed consent form before participation in the study. The extent of their involvement in the study was made known to them. For respondents who were less than 18 years of age, the parents/ guardians of the respondents signed a written informed consent form, while a verbal assent was obtained from the respondents, which was witnessed by the parent/ guardian. Respondents were assured that there would be no victimization of respondents who refused to participate or who decided to withdraw from the study after giving consent. Participation in the study was voluntary, and respondents were assured that all information obtained was for research purposes only. The study was done according to the Helsinki Declaration.

### **Results**

### Socio-demographic characteristics of the respondents

Table 1 shows the socio-demographic characteristics of the respondents. A total of 635 respondents were enrolled in the study. The mean age of the respondents was  $43.8\pm17.0$  years. The highest proportion of the respondents, 22.2% were in the age group 40-49 years while the least proportion, 17.6% were between 50 and 59 years. A higher proportion of the respondents, 50.7%, were males. The majority of the respondents, 58.1% were self-employed. A higher proportion of the respondents, 78.9% (501), were affected by leprosy, while 21.1% (134) were affected by Buruli ulcer.

### Prevalence of good quality of life among the respondents

Table 2 shows the prevalence of good quality of life among the respondents. Less than one-third of the respondents, 29.3% had a good quality of life. More than one-third of the respondents affected leprosy, 33.7% had good quality of life, while 12.7% of the persons affected by BU had good quality of life.

### Relationship between quality of life scores and stigma among the respondents

Table 3 shows the relationship between the scores of quality of life and stigma among the respondents. There was a strong negative correlation between the total stigma score and the overall quality of life score of the

**Table 2** Prevalence of quality of life among the respondents

| Variable  | Frequency<br>(n=635) | Per-<br>cent<br>(%) |
|---|----------------------|---------------------|
| Quality of life                                 |                      |                     |
| Good  | 186                  | 29.3                |
| Poor  | 449                  | 70.7                |
| Quality of life for persons affected by Leprosy | (n = <b>501</b> )    |                     |
| Good  | 169                  | 33.7                |
| Poor  | 332                  | 66.3                |
| Quality of life for persons affected by BU      | (n=134)              |                     |
| Good  | 17                   | 12.7                |
| Poor  | 117                  | 87.3                |

respondents. Thus, increases in quality of life correlated with decreases in stigma and this was found to be statistically significant. (n = 635, r = -0.530, p < 0.001). There was a weak negative correlation between quality of life (social domain) and experienced stigma, increases in experienced stigma correlated with decreases in quality of life (social domain), and this was found to be statistically significant (n = 635, r = -0.456, p < 0.001).

### Relationship between overall stigma scores and characteristics of respondents

Table 4 shows the relationship between overall stigma scores and characteristics of respondents. The mean overall stigma score for persons diagnosed with leprosy,  $26.8 \pm 14.7$ , was significantly higher than that of persons diagnosed with Buruli ulcer,  $26.1 \pm 16.4$  (p = 0.042). Similarly, the mean overall stigma score for unemployed respondents,  $37.5 \pm 19.2$ , was significantly higher than that of those who were employed,  $23.6 \pm 14.6$  (p < 0.001). The respondents who had no formal education had the highest mean overall stigma score,  $33.1 \pm 18.5$ , while those who attained secondary education and above had the least,  $25.5 \pm 16.8$ , and the mean difference was found to be statistically significant (p < 0.001). The respondents who were 50 years and above had the highest mean stigma score,  $31.0 \pm 18.3$ , while those aged 40-49

years had the least stigma score,  $26.3 \pm 17.0$  and the difference in mean was found to be statistically significant (p = 0.036).

Similarly, the respondents who had poor social support had the highest mean overall stigma score,  $34.5 \pm 18.1$ , while those who had strong social support had the least and the difference in mean was found to be statistically significant, (p<0.001). There was no significant difference in the mean stigma score between males and females (p=0.547).

### Factors associated with good quality of life among the respondents

Table 5 shows the factors associated with good quality of life among the respondents. The respondents who had no formal education were 2.5 times less likely to have a good quality of life when compared with those who attained secondary education and above (AOR = 0.4, 95%CI: 0.2-0.7). Similarly, the unemployed respondents were 2.5 times less likely to have a good quality of life when compared with those who were employed (AOR = 0.4, 95%CI: 0.2-0.7). The respondents who had vocational training were twice more likely to have a good quality of life when compared with those who had no vocational training (AOR = 2.1, 95%CI: 1.1-4.1). The respondents who were affected by leprosy were four times more likely to have a good quality of life when compared with those who were affected by Buruli ulcer (AOR = 4.3, 95%CI: 2.3–8.1). The respondents who had poor social support were ten times less likely to have a good quality of life when compared with those who had strong social support (AOR = 0.1, 95%CI: 0.05–0.2). Also, the respondents who had moderate social support were 3.3 times less likely to have a good quality of life when compared with those who had strong social support (AOR = 0.3, 95%: 0.3 (0.2-0.6).

### Correlation matrix of variables

Table 6 shows the correlation matrix of variables for all respondents. There is a very weak positive correlation between age in years and overall stigma score, increases

**Table 3** Relationship between quality of life scores and stigma among the respondents

| Stigma dimensions | Correlation co-efficient r, p-value, (n = 635) |                            |                       |                                   |                                   |  |  |
|-------------------|--|----------------------------|-----------------------|-----------------------------------|-----------------------------------|--|--|
|                   | QOL (Physical domain)                          | QOL (Psychological domain) | QOL (Social domain)   | QOL (Environmental domain)        | QOL<br>(Overall)                  |  |  |
| Overall stigma    | r=-0.448<br>p < 0.001                          | r=-0.372<br>p < 0.001      | r=-0.473<br>p < 0.001 | r=-0.489<br>p<0.001               | r=-0.530<br>p < 0.001             |  |  |
| Experienced       | <i>r</i> =-0.398 <i>p</i> < 0.001              | r=-0.339<br>p < 0.001      | r=-0.456<br>p < 0.001 | <i>r</i> =-0.451 <i>p</i> < 0.001 | <i>r</i> =-0.488 <i>p</i> < 0.001 |  |  |
| Disclosure        | r=-0.285<br>p < 0.001                          | r=-214<br>p < 0.001        | r=-0.281<br>p < 0.001 | r=-0.297<br>p<0.001               | r=-0.319<br>p < 0.001             |  |  |
| Internalized      | <i>r</i> =-0.442 <i>p</i> < 0.001              | r=-0.401<br>p < 0.001      | r=-0.473<br>p < 0.001 | r=-0.479<br>p<0.001               | r=-0.530<br>p < 0.001             |  |  |
| Anticipated       | r=-343<br>p < 0.001                            | r=-0.249<br>p < 0.001      | r=-0.308<br>p < 0.001 | r=-0.363<br>p < 0.001             | <i>r</i> =-0.382 <i>p</i> < 0.001 |  |  |

**Table 4** Relationship between overall stigma scores and characteristics of respondents

| Variable                                     | Sample size (n = 635) | Overall stigma score Mean ± SD | Man Whitney U       | <i>p</i> -value |
|--|-----------------------|--------------------------------|---------------------|-----------------|
| Gender                                       |                       |                                |                     |                 |
| Male   | (322)                 | $29.3 \pm 18.4$                | 0.602               | 0.547           |
| Female                                       | (313)                 | $28.5 \pm 17.2$                |                     |                 |
| Marital status                               |                       |                                |                     |                 |
| Married                                      | (341)                 | $29.3 \pm 18.0$                | 0.703               | 0.482           |
| Single*                                      | (294)                 | $28.3 \pm 17.5$                |                     |                 |
| Disease entity                               |                       |                                |                     |                 |
| Leprosy                                      | (501)                 | 29.6 ± 18.1                    | 2.040*              | 0.042           |
| Buruli ulcer                                 | (134)                 | $26.1 \pm 16.4$                |                     |                 |
| Employment status of the respondent          |                       |                                |                     |                 |
| Unemployed                                   | (242)                 | $37.5 \pm 19.2$                | 9.653               | < 0.001         |
| Employed                                     | (393)                 | $23.6 \pm 14.6$                |                     |                 |
| Have had vocational training                 |                       |                                |                     |                 |
| Yes  | (57)                  | $26.8 \pm 14.7$                | 1.100               | 0.275           |
| No   | (578)                 | 29.1 ± 18.1                    |                     |                 |
| Age of respondents in groups                 |                       |                                | Kruskal Wallis test | p-value         |
| <40 years                                    | (249)                 | $28.3 \pm 17.6$                | 3.351               | 0.036           |
| 40–49 years                                  | (141)                 | $26.3 \pm 17.0$                |                     |                 |
| ≥50 years                                    | (245)                 | $31.0 \pm 18.3$                |                     |                 |
| <b>Educational attainment of respondents</b> |                       |                                |                     |                 |
| No formal education                          | (179)                 | $33.1 \pm 18.7$                | 8.848               | < 0.001         |
| Primary education                            | (268)                 | $28.5 \pm 17.3$                |                     |                 |
| Secondary education and above                | (188)                 | $25.5 \pm 16.8$                |                     |                 |
| Number of dependents                         |                       |                                |                     |                 |
| None   | (177)                 | $28.8 \pm 17.9$                | 1.490               | 0.087           |
| 1–4 individuals                              | (203)                 | $26.8 \pm 16.6$                |                     |                 |
| ≥5 individuals                               | (255)                 | $30.6 \pm 18.5$                |                     |                 |
| Social support                               |                       |                                |                     |                 |
| Poor social support                          | (365)                 | $34.5 \pm 18.1$                | 52.785              | < 0.001         |
| Moderate social support                      | (178)                 | $23.0 \pm 14.4$                |                     |                 |
| Strong social support                        | (92)                  | 17.9 ± 13.2                    |                     |                 |

in age correlate with increases in overall stigma and this was found to be statistically significant (r=0.081, p=0.042, n=635). There is a weak negative correlation between overall stigma score and overall social support score, increases in social support correlate with decreases in overall stigma and this was found to be statistically significant (r=-0.476, p<0.001, n=635). There is a strong positive correlation between overall quality of life score and overall social support score, increases in social support correlate with increased quality of life and this was found to be statistically significant (r=0.558, p<0.001, n=635).

### Discussion

Leprosy and Buruli ulcers have the potential to worsen the overall health status of the affected individuals by limiting their living capacity, productivity, and functionality in society which ultimately may affect their quality of life [19]. Assessment of the quality of life can help promote the treatment, care, and rehabilitation programs for these individuals. This study determined the prevalence of quality of life, the relationship between quality of life of the patients and stigma as well as socio-demographic characteristics associated with good quality of life.

The findings of our study showed that less than one-third of the respondents (29.3%) had a good quality of life and this was similar to the reports of other researchers [14, 20]. However, another study in Indonesia revealed that 45% of the respondents had a good quality of life [21]. The disparities in the findings between our study and the study from Indonesia may be attributable to the relatively low number of disabilities among the respondents in Indonesia due to good monitoring of the treatment program. Nevertheless, the quality of life of these individuals is still poor and calls for early detection of the diseases by the community health workers to prevent debilitating conditions leading to individuals being physically and socioeconomically unempowered in society [22].

The quality of life of patients with leprosy or Buruli ulcer, including the physical, social, economic and psychological aspects, is strongly affected by the existence

**Table 5** Factors associated with good quality of life among the respondents

|                                       | Quality of life(n=635) |                   | <i>p</i> -value** | AOR (95%CI)*** |  |
|---------------------------------------|------------------------|-------------------|-------------------|----------------|--|
|                                       | Good N (%)             | Poor <i>N</i> (%) |                   |                |  |
| Age of respondents in groups          |                        |                   |                   |                |  |
| < 40 years                            | 70 (28.1)              | 179 (71.9)        | 0.267             | NA             |  |
| 40–49 years                           | 49 (34.8)              | 92 (65.2)         |                   |                |  |
| ≥50 years                             | 67 (27.3)              | 178 (72.7)        |                   |                |  |
| Gender                                |                        |                   |                   |                |  |
| Male                                  | 110 (34.2)             | 212 (65.8)        | 0.006             | 1.3 (0.9- 2.0) |  |
| Female                                | 76 (24.3)              | 237 (75.7)        |                   | 1              |  |
| Marital status                        |                        |                   |                   |                |  |
| Married                               | 116 (34.0)             | 225 (66.0)        | 0.005             | 1.4 (0.8–2.3)  |  |
| Single*                               | 70 (23.8)              | 224 (76.2)        |                   | 1              |  |
| Educational attainment of respondents |                        |                   |                   |                |  |
| No formal education                   | 42 (23.5)              | 137 (76.5)        | 0.004             | 0.4 (0.2-0.7)  |  |
| Primary education                     | 72 (26.9)              | 196 (73.1)        |                   | 0.5 (0.3–0.8)  |  |
| Secondary education and above         | 72 (38.3)              | 116 (61.7)        |                   | 1              |  |
| Employment status of the respondent   |                        |                   |                   |                |  |
| Unemployed                            | 31 (12.8)              | 211 (87.2)        | < 0.001           | 0.4 (0.2-0.7)  |  |
| Employed                              | 155 (39.4)             | 238 (60.6)        |                   | 1              |  |
| Have had vocational training          |                        |                   |                   |                |  |
| Yes                                   | 28 (49.1)              | 29 (50.9)         | 0.001             | 2.1 (1.1–4.1)  |  |
| No                                    | 158 (27.3)             | 420 (72.7)        |                   | 1              |  |
| Number of dependents                  |                        |                   |                   |                |  |
| None                                  | 36 (20.3)              | 141 (79.7)        | 0.003             | 1.6 (0.8–3.1)  |  |
| 1–4 individuals                       | 74 (36.5)              | 129 (63.5)        |                   | 1.6 (0.9–2.6)  |  |
| ≥5 individuals                        | 76 (29.8)              | 179 (70.2)        |                   | 1              |  |
| Disease entity                        |                        |                   |                   |                |  |
| Leprosy                               | 169 (33.7)             | 332 (66.3)        | < 0.001           | 4.3 (2.3–8.1)  |  |
| Buruli ulcer                          | 17 (12.7)              | 117 (87.3)        |                   | 1              |  |
| Social support                        |                        |                   |                   |                |  |
| Poor support                          | 50 (13.7)              | 315 (86.3)        | < 0.001           | 0.1 (0.05-0.2) |  |
| Moderate support                      | 73 (41.0)              | 105 (59.0)        |                   | 0.3 (0.2–0.6)  |  |
| Strong support                        | 63 (68.5)              | 29 (31.5)         |                   | 1              |  |

**Table 6** Correlation matrix of variables

|                           | Correlation co-efficient r, p-value, (n = 635) |                                    |                    |                                |  |
|---------------------------|--|------------------------------------|--------------------|--------------------------------|--|
|                           | Age in years                                   | Overall<br>Stigma                  | Overall<br>QOL     | Social<br>support<br>(overall) |  |
| Age in years              | 1  |                                    |                    |                                |  |
| Overall stigma            | r = 0.081<br>p = 0.042                         | 1                                  |                    |                                |  |
| Overall QOL               | r = 0.011<br>p = 0.775                         | <i>r</i> = -0.530 <i>p</i> < 0.001 | 1                  |                                |  |
| Social support<br>Overall | r = 0.006<br>p = 0.873                         | r= -0.476<br>p < 0.001             | r=0.558<br>p<0.001 | 1                              |  |

of stigma. Our study revealed an inverse correlation between perceived stigma and quality of life, meaning that as perceived stigma increases, the quality of life decreases. This supports the findings of other studies done in Indonesia, Bangladesh and Iran [23–25] and emphasizes the importance of implementing stigma reduction strategies such as community awareness and health education [4, 13]. These strategies have been

shown to reduce stigma, minimise disease burden, and help encourage the affected individuals to seek help and participate in self-care [4].

Despite some advancements made over the years in the treatment of leprosy, our study noted that individuals affected by leprosy were more stigmatized compared to those affected by Buruli ulcer. This was similar to the report of another study which stated that Buruli ulcer is less stigmatized because of community acceptance and sympathy towards the affected individuals [26]. This may be linked to the fear of infection due to the deteriorating physical appearance, beliefs and misconceptions about leprosy [27]. In this study, respondents who were 50 years and above were more stigmatized compared to those below the age group, which was similar to other studies and may probably be linked to the unchanged historical misconception about the diseases [28, 29]. Furthermore, participants who were unemployed and had no formal education were associated with a higher level of stigma compared to their counterparts who were employed and had formal education. These are associated with stigma in many other studies and underscore the importance of socioeconomic rehabilitation in the affected individuals [26, 29, 30]. The rehabilitation will help them live with dignity as useful self-supporting members of the community [26]. Also, it will lead to an increase in the overall knowledge of the diseases and an increased ability to resist the negative stereotype attached to the diseases [29]. Respondents with poor social support were more stigmatized compared to those with strong and moderate social support. This shows that stigma is commoner among affected individuals with poor social networks [13, 26] and calls for a supportive environment, including equal acceptance of these individuals and providing the necessary care, which can help them build self-esteem and improve their mental well-being [26].

Regarding the predictors of good quality of life, the respondents who had no formal education and were unemployed were 2.5 times less likely to have a good quality of life compared to their counterparts. This was the experience of other researchers [24, 31] as individuals with poor education may have some difficulty in seeking the right treatment and providing self-care which can impact their quality of life. Also, employment plays a central role in providing financial income and nonfinancial gains, including fulfilment of a social role, physical and mental well-being [32]. Thus, unemployment has a negative effect on the experiences and social status of an individual, leading to poor quality of life [32]. The respondents who had vocational training and strong social support were more likely to have a good quality of life compared to their counterparts with no vocational training and poor social support. Strong social support towards the affected individuals can motivate them to be involved in vocational training. Vocational training enables people to have productive employment, resulting in improved self-esteem, skills acquisition and financial independence [33]. This ultimately leads to a better quality of life among individuals affected by leprosy or Buruli ulcer. Although leprosy patients were more stigmatized than those with Buruli ulcer, the study showed they were four times more likely to have a good quality of life compared to individuals with Buruli ulcer. This may be attributable to the different interventions from international organisations involved in leprosy management aimed at preventing disabilities and promoting inclusiveness [34]. These lines of action potentially contribute to achieving a good quality of life as individuals can regain their physical strength, engage in their daily activities and become productive [34].

The study noted that as age increases in years the stigma increases, which was the reports of other researchers [29, 35]. The older a patient becomes, the higher the difficulties found in socializing, both due to

the history of prejudice and disabilities linked to the disease which interferes with the patient's daily life, leaving an indelible mark on the individual's mental well-being [29]. Furthermore, an increase in social support correlates with decreases in stigma, while an increase in social support leads to an increase in quality of life. This re-emphasizes the importance of including good social support as one of the stigma reduction strategies in the management of patients with leprosy or Buruli ulcer [25]. It leads to an improvement in self-esteem, social acceptance and ultimately to a better quality of life.

Strength and limitation The strength of this study stems from the inclusion of two skin-neglected tropical diseases, as it enabled comparison of quality of life across the two diseases, assessed the different types of stigma, and analyzed the relationship between the quality of life and stigmatization in these patients. The findings will help in the implementation of stigma reduction strategies and promote integrated interventions for neglected tropical diseases. A potential limitation of the study might be the problem with obtaining a homogenous sample which are free from other co-morbidities and these can influence the outcome of the quality of life. Also, the study is prone to recall and information bias due to the use of a self-reported tool. The LGAs included in the study were purposively selected based on the number of cases of leprosy and BU notified between 2014 and 2018. Thus, there could be a possibility of a selection bias since a probability sampling technique was not used in selecting the respondents, and there is no evidence that all persons affected by leprosy or BU in the selected LGAs were included in the study.

### **Conclusion**

People affected with leprosy or Buruli ulcer experience a very poor quality of life which worsens with poor social support and as the level of stigmatization increases. Also, the higher level of stigma is associated with lower levels of education, unemployment and poor social support necessitating the need for stigma reduction strategies for better quality of life. The strategies include community health education campaigns to change the existing stereotypes about diseases, improvement in employment opportunities and the provision of strong support groups to help them realize that they can avoid the negative consequences of stigmatization, which will eventually contribute to their higher self-esteem and better quality of life.

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#### **Author contributions**

AE, NE, IE, EO, NM, FC, OI, CA, and JC were involved in the conceptualization of the manuscript. The design of the study was done by: AE, NE, IE, EO, PH, CN, MN, AM, CA, and JC. Data was collected by: PH, FC, OI, and MN. The data analysis and interpretation were done by: AE, NE, IE, EO, CA and JC. The drafting of the manuscript was done by: AE, NE, IE, EO, CA and JC. All authors read and approved the final manuscript.

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### Data availability

Data is available and can be provided on request from the corresponding author

### **Declarations**

### Ethical approval and consent to participate

The ethical approval to conduct this research was obtained from the Health Research Ethics Committee of the University of Nigeria Teaching Hospital, Enugu (Reference number: NHREC 0501-2008B). Written informed assent and consent were obtained respectively from the respondents less than 18 years and those above 18 years of age after they had been duly informed of the purpose of the study and their rights to refuse to participate.

#### Consent for publication

Not applicable.

### **Competing interests**

The authors declare no competing interests.

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