

# Experience of People Living with Leprosy at Leprosy Settlements in Nigeria

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April 25, 2024

## Abstract

This research explores the experience of people living with leprosy at leprosy settlements in Nigeria. This is a concurrent mixed methods design whereby questionnaires, focus groups and interviews are conducted simultaneously. Seven leprosy communities were visited, one from Nigeria's six geographical zones and the Federal capital area. This study included 35 leprosy patients, 21 family members, seven community leaders, and seven officers in charge of the leprosy settlements. Also questioned were two heads of organisations involved with leprosy control in Nigeria. Majority (93.7%) of the respondents have access to healthcare in the health centres. Majority (95.2%) are interested in learning self-care practices for skin-related neglected diseases. About three-fourths (74.6%) receive free healthcare and accent that PLWL are admitted into the same ward as other patients. Whilst funding is a growing concern for leprosy control, the data from the interview confirmed that there is little support from the government but more from non-governmental organisations and implementing partners in Nigeria for people living with leprosy. Experts demonstrated that leprosy now ranks high among neglected diseases. The Nigerian government must work with partners to ensure the improvement and sustainability of leprosy control programs.

## Introduction

Leprosy remains a serious public health concern in Nigeria, with over 3500 people diagnosed each year and approximately 25% of these patients suffer from one form of disability or the other. Before Nigeria's independence in 1960, Nigeria had a leprosy prevalence of more than 20%. In conformity with existing global thinking and practice at the time, leprosy communities were developed to preserve public health and provide relief to men and women suffering from the disease.

Even though Nigeria achieved the national leprosy elimination target of less than 1/10,000 population in 1998

, some factors like culture, behavioural patterns, and social determinants, among others, are still contributing to more leprosy cases Tuberculosis and Leprosy Control Program (NTBLCP) started as a program in 1989 . Between 1991 and 2012, 111,788 leprosy patients were effectively treated with MDT (Multi-Drug Resistant Treatment), and the country was also able to meet another target which is the WHO eradication target of fewer than one case per 10,000 people in 2000 . With a case detection rate of less than 5% per 10,000 persons, Nigeria is currently classified as low endemic for leprosy, however, at the sub-national level, there are areas of “high endemicity” where leprosy prevalence remains at up to 1 instance for every 10,000 persons .

In 2019, 10% (20,205) of global leprosy cases were recorded in Africa with Nigeria and 12 other countries reporting 1000 – 10,000 cases . Studies from high leprosy endemic countries have shown that leprosy shows marked uneven geographical distribution even within the smallest community groups such as villages and households . This is one of the motivations for this research as people living with leprosy are mostly living in isolated communities outside main towns and cities.

Some other motivation for this study is the lack of publication and inadequate conversation about the level of care available for people living with leprosy in Nigeria. In Nigeria, we cannot compare the level of reporting tuberculosis gets to that of leprosy even by the National TB and Leprosy Control Programme (NTBLCP). The National Tuberculosis and Leprosy Control Program (NTBLCP) is an integral part of the Nigerian Ministry of Health with the role of coordinating and implementing national strategies, policies, and programs for the control and management of tuberculosis (TB) and leprosy in Nigeria. Some of the program’s responsibilities encompass policy development, strategic planning, program coordination, capacity building, monitoring and evaluation, advocacy and awareness, and research and innovation. Meanwhile, the level of stigma and disdain experienced by some people living with leprosy is so disheartening as leprosy is seen as the most terrible and despised disease in some areas of Nigeria .

The stigma has long-term negative consequences for people with disabilities, including loss of employment, social ties, and reputation, difficulties finding a life partner, divorce, and discrimination . As a result, leprosy is frequently referred to as a social killer The stigma associated with leprosy is sometimes more distressing than the disease itself . Some leprosy patients have frequently described how they are denied some social and economic opportunities. Some are also rejected by family members and society. These events have repercussions on their psychological health. Some because of stigma and disdain, therefore, postpone receiving treatment until difficulties appear .

Nigeria through the Federal Ministry of Health and the National Tuberculosis and Leprosy Program and partners has successfully treated over 33,000 leprosy patients across the country since 2009 till date; this has been made possible through funding from donors and non-governmental organizations . International Federation of Anti-Leprosy Associations (ILEP) is a consortium of organisations that provides relief and rehabilitation services to persons affected with leprosy and their efforts are complemented by efforts from other organizations outside ILEP. ILEP organisations include; The leprosy mission, Nigeria (Coverage is nationwide), the Damien Foundation (Covers the South-Western states and Kwara state with a coverage population of over 56 million people), and DAHW German Leprosy and TB Relief Association (area of coverage is South-East and South-South, Nigeria) . Nigeria has made some level of progress in the fight against leprosy. However, to record tangible progress there is a need for the Nigerian government to increase its commitment to leprosy control and elimination by working alongside partners to ensure effective and sustainable leprosy control in line with the 2021-2025 global leprosy strategy .This study explored the experiences of people living with leprosy, the experiences of healthcare workers, and the conditions of living in the leprosy settlements.

## Methods

This is a concurrent mixed methods design whereby questionnaires, focus groups and interviews are conducted simultaneously. This is to ensure a synergistic approach to data collection. Both quantitative and qualitative data were collected concurrently, and analysis and interpretation of the data were done sep-

arately but at the same time. The quantitative was descriptive and cross-sectional. Two Focus Group Discussions (FGDs) and two key informant interviews were done at each leprosy settlement and participants for the qualitative were selected using purposive sampling. The officials in charge of the settlements were briefed about the objectives of the study, they then suggested Focus group discussions with participants who are able to answer the questions appropriately. The key informant interviews were done with the heads of the settlements appointed by the population themselves and the ones appointed by the government to be in charge.

The quantitative questionnaire provides baseline data on the research topic, while the focus groups and interviews delve deeper into participants' experiences and perspectives. This facilitates data complementarity, enhanced data integration, and triangulation of findings. There are 64 leprosy settlements in Nigeria and this number is unstable as some of these settlements are no longer functioning. The quantitative entails a cluster sampling whereby all the leprosy settlements were separated into respective geo-political zones and Federal Capital territory, and then one of these clusters is selected to represent the population in that zone. Seven leprosy settlements were selected including the only settlement in FCT. Questionnaires were administered to 5 People living with leprosy (PLWL), 3 family members who were randomly selected, and a community leader. The sample size was limited to 9 quantitative respondents for quantitative. Also, groups of 8 males and 8 females each were also engaged in a focus group discussion and the community leaders and persons appointed to be in charge were interviewed in the 7 leprosy settlements.

<b>Quantitative using questionnaires</b>	7 selected settlements	5 Persons living with leprosy	3 Family members	1 Community leader	1 Community leader
<b>Qualitative</b>		1 FGD with 8 male	1 FGD with 8 female	1 Key informant interview with the community leader	1 Key informant interview with the person assigned to the centre by the government
	2 representatives of the Damien Foundation, 2 representatives of The Leprosy Mission Nigeria (TLMN), and 2 representatives of TY Danjuma Foundation	2 representatives of the Damien Foundation, 2 representatives of The Leprosy Mission Nigeria (TLMN), and 2 representatives of TY Danjuma Foundation	2 representatives of the Damien Foundation, 2 representatives of The Leprosy Mission Nigeria (TLMN), and 2 representatives of TY Danjuma Foundation	2 representatives of the Damien Foundation, 2 representatives of The Leprosy Mission Nigeria (TLMN), and 2 representatives of TY Danjuma Foundation	2 representatives of the Damien Foundation, 2 representatives of The Leprosy Mission Nigeria (TLMN), and 2 representatives of TY Danjuma Foundation

### Summary of study participants

The 2 representatives of organisations interested in leprosy control were purposively selected based on their contributions to leprosy control within the region covered by their organisation. The agencies and organizations whose staff were interviewed include Damien Foundation, The Leprosy Mission Nigeria (TLMN), and TY Danjuma Foundation.

**Why 9 participants ?** This study was designed to make exploratory and qualitative submissions and no inferential analysis was intended. Quantitative data were used to describe and support qualitative responses and not to conclude, so representativeness was not considered. One FGD with a male population and one with a female population was thought to be appropriate since all persons lived in the same environment. Participants who were selected to be part of the quantitative were also part of the whole that was selected for the qualitative were selected.

### Study locations

1. South-West; The Lepers' Colony, Ogbomoso, Oyo state
2. South-South; The Lepers' Colony, Osio, Edo state
3. South-East; Uzuakoli Leprosy Colony, Abia state
4. North-Central; Chanchaga Leprosy Hospital, Niger state
5. North-East; RafinKada Leper Colony, Wukari, Taraba state
6. North-West; Lepers' Colony, kutareGusau in Zamafara state
7. Alheri community, Yangoji village, Kwali Area Council, FCT

The questionnaire assessment includes the state of health centres, water supply, sanitation, hygiene, human resources, and healthcare resources. The Focus group discussions and interviews with settlement leaders include descriptions of the quality of life of people living in leprosy communities and the amenities available. The questionnaire and interview questions were drafted after a literature review and were pretested first with 4 participants and the person in charge at the leprosy settlement in Abuja as pilot study participants. The two representatives of The Leprosy Mission Nigeria, Abuja were also part of the Pilot study. The questionnaire and FGDs were then consolidated with insights from the pilot. The Key Informant Interviews explore the contribution of non-governmental organisations to leprosy control and management in Nigeria.

The FGD sessions enabled exploratory and confirmatory questions to be asked to achieve a deeper understanding of their interests and needs. Focus groups were constructed in ways that will not hamper the discussion of sensitive topics due to differences in occupation, lifestyle, roles, and status in the community. This allowed participants to discuss topical issues in detail, and explore and clarify their points of view, thus enhancing in-depth discussions. The questionnaire and interview questions were translated into local languages before data collection. Two data collectors who understand local languages accompanied research assistants to the selected leprosy settlements. This study does not measure the expertise but explores the experiences of professionals working at leprosy settlements or that of representatives of organisations concerned about leprosy control in Nigeria.

**Data analysis:** NVIVO and IBM SPSS 25 were used for qualitative analysis and quantitative analysis of responses respectively. Quantitative data were entered into Microsoft Excel 2010 from where the dataset was imported into SPSS. Data were subsequently cleaned, coded and analysed. Quantitative data were presented as frequencies and proportions. For the qualitative data, transcripts and field notes were analysed using thematic analysis to provide an accurate reflection of participants' ideas. NVIVO 10 software was used for the systematic data coding to generate recurring themes by 2 data analysts. Another member of the team subsequently triangulated 10% of the transcripts to improve validity and draw up more perspectives which were compared with those generated by NVIVO analysis. This is necessary to reduce bias and revise the themes that might have occurred due to discrepancies and unexpected findings. The team subsequently reviewed the generated themes to ensure that they reflect respondents' ideas as opposed to the likelihood of bias often associated with a single analyst.

The outcomes of the study are listed below, no cause-effect relationship was measured. Also, outcomes were not measured but only described based on responses from respondents.

- Experiences of people living with and affected by leprosy in Nigeria

- Challenges faced in leprosy settlements in Nigeria
- Experience of medical professionals working at leprosy settlements
- Reasons for abysmal financing and reporting measures of health financing
- State of health at leprosy settlements
- State of the settlements and recommendations for improvement
- Recommendations for leprosy control in Nigeria

**Ethical Considerations:** Ethical approval was gotten from the Health research ethics committee of Federal Capital Territory, Nigeria, and consent was gotten as appropriate for all the data collection steps. The anonymity of respondents' identity was guaranteed. Approval Number: FHREC/2021/01/137/8-12-21

## Results

*The tables are in the annex*

### **Table 1: Socio-demographic and standard of living of respondents living in leprosy settlements in Nigeria**

This shows that the majority (66.7%) of the respondents were males; mostly (87.2%) older than 25 years (adults); with more than one-third (38.1%) with no formal education. More than half are married (57.1%); half (50.8%) are traders and farmers but about a quarter (23.8%) are unemployed. Almost half (47.9%) of the residents have lived in the settlement for more than 20 years; with most (74.6%) of the residents earning less than the minimum wage (N 30,000).

### **Table 2: Leprosy Knowledge and Perception of respondents living in leprosy settlements in Nigeria**

Majority (76.2%) of the respondents do not know the cause of Leprosy. Less than a quarter (22.2%) knows how it is transmitted. Half (52.4%) know that it is difficult to treat; with most (69.8%) of the respondents knowing the signs and symptoms of the disease. About two-thirds (69.8% and 68.3%, respectively) indicated that leprosy causes shame, disdain or embarrassment and leprosy is a source of problems in intimate relationships. About half (87.3%) perceived that people dislike trading with persons living with leprosy; almost two-thirds (61.9%) think that leprosy status will make finding employment difficult.

### **Table 3: Evaluation of health services for people living with leprosy in leprosy settlements in Nigeria**

Majority (93.7%) of the respondents have access to healthcare in the health centres. About a third (31.7% and 36.5%, respectively) reported leprosy symptoms at a health facility only when home treatment did not work. Majority (95.2%) are interested in learning self-care practices for skin-related neglected diseases. About three-fourths (74.6% and 74.6%, respectively) receive free healthcare and accent that PLWL are admitted into the same ward as other patients. Majority (95.2%) think that government should take special care of PLWL.

## Qualitative Data

**Tables 4a and 4b** report the qualitative analysis which includes the themes and references based on quotes from responses to Focus Group Discussions and Key Informant Interview.

### **Table 4a:**

1. The experiences of people living with and affected by leprosy in Nigeria  
2. Roles Organisations play in leprosy control  
3. Challenges faced in leprosy settlements in Nigeria

### **Table 4b:**

4. What can be done differently in leprosy control in Nigeria?  
5. Recommendations

## Theme 1: The experiences of people living with and affected by leprosy in Nigeria

People living with Leprosy shared their experiences during the key informant interviews. Their experiences were summarized into sub-themes as follows:

### Available funding provisions;

Whilst funding is a growing concern for Neglected tropical diseases, the data from the interview confirmed there is little funding support from the government and other implementing partners in Nigeria for people living with leprosy.

*“I’m not sure but there’s an allocation for drugs”* - PLWL Taraba State

*“I have no idea except for the #5000 monthly payment from the Local Government council”* - PLWL from Oyo State

The budgetary allocation of funding from the government to support people living with leprosy is buttressed by supporting organizations who are non-governmental organisations

*“I can’t say exactly how much the government has budgeted but I can say that there is a fund set aside for PLWL. There’s a body for TB and leprosy control (NTBLCP) and the body runs a budget but it’s minimal because most people focus on TB but yes there’s funding but I can’t say how much is budgeted exactly ”* - Program officer, Damien Foundation

Despite the current treatment support and complementary financial assistance for patients in Oyo state, there is still out-of-pocket expenditure. An interview with the head of programs at TLMN revealed patients spend on managing complications. This gap is now being bridged by non-governmental organizations.

*“there’s no specific funding targeted at providing healthcare or a health insurance scheme. Even referral centres owned by the government that only offer leprosy-related services suffer neglect, although leprosy treatment is free. Medications are provided by WHO and it’s supplied to the Healthcare centres. Medications that are used to manage complications due to the use of drugs for treatment like prednisolone are not free so the leprosy mission step in to provide these drugs for the hospitals”* - Head of Programs TLMN

*“We receive support, the support comes from philanthropists, organizations like NNPC, and well-meaning individuals. The support is always in kind, mostly food items. For education, the Daughters of Charity help our children through secondary education and provide working tools for this who have picked one vocation or another. We receive food donations from NGOs and people that visit. The government of Edo state have been giving us #5000 every month and it has been consistent. Sometimes, we also contribute money amongst ourselves to take care of minor things.”* - PLWL Edo State

*“People here get about #6000 per month from the FCT council but it’s not regular like before. We also get funding from NGOs and some multinational companies ”* - PLWL FCT

*“Funding is a continuous thing here in our organizations and PLWL gets a huge portion of our annual operational budget. We also have a reconstructive centre in ogbomoso where they go for pro bono surgeries”* - Program manager, Damien Foundation

*“From my organization, the leprosy settlements that we cover get support from us regularly like the medical, educational, and rehabilitation support ”* - Program officer, Damien Foundation

### Condition of inmates at the leper settlements and the state of the settlements

Living with leprosy was widely regarded as a difficult condition by the respondents. The camps lack basic amenities and thus make it unconformable for the patients in the camp.

*“Been in the camp for few years, there’s no indication of time to leave the camp. Lifestyle in camp is not encouraging ”* - PLWL Abia

*“Living in a leprosy camp has not been easy, although the people are friendly and our directors are trying, there’s a shortage of basic amenities like water, food and electricity ” - PLWL Zamfara*

*“The people in the community are good but our condition of living is bad ” - PLWL Taraba*

### **Renovating and equipping leprosy settlements**

*“The damages are reported and it is looked into. mostly, private organizations help with renovations and maintenance - PLWL Taraba*

*“Our preference as an organization isn’t to keep settlements. We encourage patients to go back to their communities and come for ambulatory care. However, we won’t deny that some people live in these settlements and we make fairly decent renovations that will ease their living there and efforts are supported by civil society organizations like Lion’s club and Rotary club ” - Staff of DAHW*

*“For shelter, this settlement was built by the government but is being renovated by the ”Daughters of Charity”, and an organization from Germany ” - PLWL Edo State*

### **Stigmatization**

*“We can’t even go out for any business, because people are afraid to buy from us - PLWL Niger State. A respondent replied, ” I have been living here for 30 years”. It has not been easy, we face a lot of stigmatization and there are no jobs” - PLWL Zamfara*

## **Theme 2: Roles Organizations play in leprosy control**

### **Welfare of PLWL**

*“I work with the Methodist church, we try to improve their welfarism and help them resettle after being treated” - Staff, Abia*

### **Research, Media Advocacy and Service Delivery**

*“We are here to support the national response as far as leprosy and other NTDs are concerned. We support the South Eastern and South Southern states in particular. Also, at the federal level, the central unit feels free to approach us for support for one thing or the other. We do help them to plan, we attend meetings. If you look at the other components of the central unit, the health workforce, we do capacity building, and service delivery which is the first component of the WHO health system and the building blocks. We do research, we pride ourselves in the operation of research. We ask questions together with our colleagues from the University and we try to answer the questions together. So we frame the research questions and try to answer them together ”-Staff of DAHW*

*“We also do public awareness and sensitization via traditional and modern media. Another thing we’ve done is to bring up advocacy to the level in which the rights of persons affected with leprosy are protected in line with the goals of WHO of which Nigeria is a signatory. We also research to gather facts and get clarity on Leprosy control” - Staff of DAHW*

**Programme Implementation** *“Currently, we’re in about 11 states, the Leprosy mission only. The head of programmes will answer this question best. As the head of business, my job is to go into the communities, see what the people need and present their needs to funders, get funding and work with the people to implement. At the state level, we have a project implementation and advisory committee that coordinate the activities. At the community level, we have community management committees formed by the community leader, women leader and youth leader. We also work with them to get data to send to the funders. The leprosy mission commits her funds to the programmes also.” - Head of Business, TLMN*

### **Support PLWL with empowerment and capacity-building projects**

*“We support the NTBLCP in the care and management of persons affected with leprosy. Our area coverage is the South Western part of Nigeria and Kwara state. Apart from case finding, we also support affected*

persons with lots of empowerment projects, we also set them up to start a vocation or a trade. Some are even employed to work with Damien Foundation and we pay them” - Program Manager at Damien Foundation

“Majorly, we offer care after-cure services. We provide capacity building for health workers, we offer educational support to persons affected with leprosy and their children via the Damien Foundation scholarship scheme, and we support people that are interested through school up to the university/polytechnic level) and the Back To School” project, we distribute the usual school pack that involves sandals, school bag, writing materials to every kid in the settlement, we also provide rehabilitated living quarters for them to enjoy a better living condition, we also provide pro bono surgeries for people with complications due to leprosy, we have a reconstructive centre in ogbomosho” - Program Officer Damien Foundation

### **Research and Health services support**

“It happens in the form of treatment, capacity building, research (we have ongoing research that costs about #80M which will happen over 4years, and providing materials for people infected. We also fund leprosy referral centres and fund reconstructive surgeries”- Staff of DAHW

“WHO also supports patients with chemotherapy. A leprosy patient undergoing chemotherapy can come down with complications and visible deformities so we provide corticosteroids to help them manage these complications. We also provide appropriate footwear for infected persons, we also provide rehabilitative surgeries and make sure they learn how to walk. We also provide care after cure for patients” - Staff of DAHW

“We have been training personnel and building the capacity of Nigerian health workers to help them make diagnoses, manage cases, do some reconstructive surgeries, and take care of the social care aspect. We also help with the reintegration of persons affected into society. We also provide assistive devices. We also provide educational support for persons affected and their children” - Staff of DAHW

“We also provide mobile ulcer care project, so that we can go into houses of people affected to ”dress” their wounds; interestingly, people that ride the bikes and go around are people affected with leprosy. We also run a quarterly project called Back 2 School project (we provide basic school items for them). We also provide better living conditions by renovation and providing basic amenities” - Program manager, Damien Foundation.

### **Theme 3: Challenges faced in leprosy settlements in Nigeria**

#### **Abysmal financing**

“There’s no money to start a business and because of the disease, activities to engage in have been limited. A respondent answered that she’s been living with leprosy for about 30 years. Another respondent answered that ”there’s no money to take care of herself and her family and she’s been with leprosy for over 35 years” - PLWL Niger State

“We stopped getting proper funding after the Obasanjo regime” - PLWL FCT

“The major factor and cause of our lapses here is funding” - PLWL Abia state

#### **Inadequate Water Supply**

“There’s a problem with water, there’s a borehole before but it has spoilt. Another answered ”There’s not enough resources but they are content with whatever God provides for them” - PLWL Niger State

“Living here hasn’t been easy because we are not being provided with adequate shelter, food and water” - PLWL Zamfara State

#### **Irregular Support from Government**

“support and resources are not regular. Most resources are provided by people” - PLWL Abia

“Only the missionaries take care of them, their basic needs are neglected. Health information is gotten from people around. What happens when the missionaries leave, what will happen to us?... The government

isn't doing anything and therefore the education of the children is in shambles because there's no money to pay. Also, a big challenge in the settlement is food" - PLWL Niger State.

#### **Theme 4: Lessons Learned and Recommendations**

##### **Reintegration is now the best practice**

*"It is fundamental to note that the settlements are no longer in existence. It's now best practice that persons affected are integrated back into the community so that they can live among their family members"* – Staff of DAHW

*"Treatment has been good but rehabilitation has not been good, it's difficult for people that have been healed to get back into society. The state of the settlements has been bad and our children need education or vocational training also"* - PLWL Edo State

##### **Advocacy and Human rights efforts should be improved.**

*"Promoting and protecting the rights of persons affected with leprosy by public education which can be done by the stakeholders in the media"* - PLWL Edo state

##### **Leprosy has become neglected even among neglected diseases.**

*"I will say it's a situation of neglect, not just because the government decides to neglect it because it's still neglected even among other neglected tropical diseases. It's neglected probably because the government is overwhelmed, there are lots of competing demands in the health budget like COVID-19, Tuberculosis. The leprosy control programmes have been joined with the tuberculosis control programme but attention is given more to TB because of how infectious it is. Nigeria achieved the elimination target of WHO years ago but we're seeing a resurgence of leprosy. The current security issue in the country is also making control more difficult because health workers have to go into the communities to find infected persons and they are not able to go because of the security risk so we have a possibility of a resurgence."* - Head of Programs, TLMN

##### **Need for government commitment and support**

*"We the NGOs are just here to support, the leprosy control programme is the government's. We demand increased commitment from the state government such that the only form of funding available will not be from the NGOs. The funding for case search from the NGOs to curb ongoing transmission is prohibited and limited hence the need for government intervention. Over the last 12 years, it has always been what the NGOs bring to the table. The government needs to show more commitment backed up with cash and understand that Leprosy is still a major public health problem."* - Head of Programs, TLMN

*"Government should improve funding for the colony."* - PLWL Zamfara.

**Summary of findings:** This study provides an overview of the socio-demographic characteristics of study participants, knowledge and perception of leprosy, and the description of health services in leprosy settlements in Nigeria. Majority of the participants are male and a considerable proportion have no formal education. Additionally, the findings underscore a lack of comprehensive understanding of leprosy, with a substantial percentage of respondents unaware of its cause and transmission, though a majority recognize its symptoms and associated social challenges. Majority of respondents have access to healthcare, but some report delays in seeking professional help for skin conditions.

The qualitative data provide a deeper perspective on the challenges faced by people living with leprosy, the roles of various organizations, and the lessons learned. The experiences shared by respondents reveal a lack of consistent government funding for individuals affected by leprosy, leading to dependence on non-governmental organizations and philanthropic support. The inadequate living conditions and lack of basic amenities in leprosy settlements further contribute to the challenges faced by PLWL. The crucial role of supporting organizations is highlighted through themes such as welfare enhancement, research, media advocacy, and service delivery. However, these efforts, while valuable, cannot replace sustained government commitment and financial support.

## Discussion

This study aimed to explore the experiences of people living with and affected by leprosy in Nigeria. Using data and statistics gotten from all six geo-political zones of Nigeria. The findings from this study showed that the majority of participants were familiar with the signs and symptoms of the disease, while just above a tenth revealed a good knowledge level about the cause of leprosy. The low knowledge level of causes might be attributed to lack of awareness programs which can be somewhat attributed to the effectiveness of leprosy control initiatives and awareness campaigns. This study showed that most of the participants did not know how leprosy was being transmitted, and this differs from a similar study in Eastern Ethiopia where more than half of study participants who are PLWL knew about leprosy transmission in Eastern Ethiopia. Poor knowledge of the cause of leprosy, and its mode of transmission among people living with leprosy pose a public health challenge, because these individuals would not be exercising the needed precautionary measures to prevent disease transmission.

In this study, the majority of respondents believe that leprosy is treatable. This result tallies with that reported in Southeast Ethiopia where respondents believe that leprosy can be treated with pharmaceutical drugs, and is in sharp contrast with another study in Mexico where a majority of PLWL do not know if leprosy is treatable or not. According to these findings, two-thirds of participants believed leprosy to be a source of shame, disdain, and embarrassment. This is similar to those observed in Thailand and Ethiopia where respondents would deliberately avoid leprosy patients

Although results from this study mentioned that stigmatization has been reduced greatly because of the interventions by Nongovernmental organizations, people living with leprosy still mentioned that there is still stigmatization against leprosy in Nigeria. This has also been reported by India in 2019 where people living with leprosy mentioned that if they had known they would not have sought help concerning their condition because of shame and stigma from people in their surrounding environment

Similar to our findings on stigmatization faced by people living with leprosy, a systematic review done in 2022 (Abdul et al., 2022), revealed that people living with leprosy are often concerned about their physical appearance which limit their ability to socialize with other people. The study also identified the economic burden of the disease on the patients who have to pay for their transportation to the health centres to access the free treatment. Further, the physical disabilities associated with leprosy and its symptoms limit their abilities to work, causing loss of income and unemployment. This supports the findings of our research, where a respondent stated that they can't freely go out to do business because people are afraid to buy from them.

Although NGOs have been at the forefront of the fight against leprosy in Nigeria and they have been doing very well, the government needs to take their front row in the fight. One way this can be done is to separate National TB and Leprosy Agency into two because the government has given a lot of attention has been given to Tuberculosis over leprosy over the years. This has been reported by Ogbeiwi, 2005 who indicated inadequate reporting due to less attention on leprosy compared to tuberculosis in recent years by the National Tuberculosis and Leprosy Control Programme has shifted the whole burden of care and management of people with leprosy to ILEP members ILEP is the federation of autonomous anti-leprosy non-governmental organizations. This will provide more oversight, centralization of care, improved policy implementation, clear government funding at national and sub-national levels, and ensure coordination This study recommends the empowerment of Persons affected with leprosy, increasing the awareness of leprosy, improved intervention from government and Organizations, and provision of basic amenities by the government.

## Conclusion

Overall, this study sheds light on the complexities of leprosy control in Nigeria, revealing the need for enhanced government involvement, increased funding, and improved living conditions for people affected by leprosy. The findings emphasize the importance of comprehensive education, awareness campaigns, and the promotion of human rights to counter stigmatization and improve the quality of life for those living with leprosy. Furthermore, the study underscores the evolving approach of reintegration as the best

practice, advocating for individuals affected by leprosy to be integrated back into their communities for improved societal inclusion and well-being. In the face of challenges and opportunities, this study calls for a concerted effort from the government, non-governmental organizations, and society as a whole to address the multifaceted issues surrounding leprosy control in Nigeria.

**Conflict of interest:** “Don Eliseo Priso” is Editor-in-Chief of the journal and co-author of this article. They were excluded from the peer-review process and all editorial decisions related to the acceptance and publication of this article.

**Limitation:** Despite multiple attempts, we were unable to secure participation from representatives of The National Tuberculosis and Leprosy Control Program (NTBLCP) and The National Leprosy Eradication Programme (NLEP) within the allocated data collection period. Scheduled interviews were postponed on multiple occasions, and our attempts to conduct virtual interviews were also unsuccessful.

**References**

**Annex 1: Tables**

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Variable

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**Table 1: Socio-demographic of respondents living in leprosy settlements in this study** Variable Frequency (%)

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Variable

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**Table 2: Table 2: Leprosy knowledge and perception of respondents living in Leprosy settlements in Nigeria**

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Variable

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**Table 3: Evaluation of health services for people living with leprosy in Leprosy settlements in Nigeria. N=6**

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**Qualitative Data**

**Table 4a and 4b: Qualitative Thematic Analysis including themes and references based on quotes from responses to Focus group discussions and Key Informant Interviews**

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Theme

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**Table 4a: 1. The experiences of people living with and affected by leprosy in Nigeria 2. Roles Organisations p**

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Themes

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**Table 4b: 4. What can be done differently in leprosy control in Nigeria? 5. Recommendations Themes Refe**

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