Leprosy Situation in Nigeria

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Summary  With an annual new case detection of 4000 people, a Grade 2 disability rate of 12%, and nearly 10% child ratio among new cases, leprosy remains a disease of public health importance in Nigeria. Faced with the reality of low endemicity; a declining budgetary allocation to leprosy control; and a pervasive loss of expertise; it is necessary for Nigeria to re-organise its leprosy control services to further reduce the burden of the disease and ensure quality care to people affected by leprosy.

Introduction

Nigeria is the most populous country in Africa with a 2012 projected population of over 170 million people. It occupies a land mass of approximately 923,768 km² and is made up of six geo-political zones comprising 36 States, a Federal Capital Territory (Abuja), and 774 Local Government Areas (LGAs). There are more than 250 ethnic groups with three predominant ones. The petroleum sector is the main stay of the Nigerian economy and contributes 36% to the annual GDP, 75% to government revenue and accounts for 95% of the foreign exchange earnings.¹

The health care delivery system in Nigeria consists of both orthodox and traditional health care delivery systems, and both systems operate side by side but with minimal collaboration. The goal of the National Health Policy is to bring about a comprehensive health care system based on Primary Health Care that is protective, preventive, restorative and rehabilitative to every citizen of the country.²

Historical Overview of Leprosy in the Country

In the pre-independence period, the average leprosy prevalence in Nigeria was over 20%. For example, one observer put the estimated prevalence in southern Nigeria at the time at an
astonishing 2–30%. In keeping with prevailing global concepts and practice at that time, leprosy settlements were set up to safeguard public health and provide relief to the unfortunate men and women who suffered from the disease. The first of these settlements was founded by the Presbyterian Church at Itu in present day Akwa Ibom state in 1928. The second settlement (Uzuakoli Leprosy Centre), once renowned for its global contribution to research in the chemotherapy of leprosy, is acknowledged by many as one of the Methodist Church’s most enduring legacies in Nigeria. Other notable settlements that sprang up in the segregation era include Okegbala in Kwara State; Osiomo in Edo State and Yadakunya in Kano State.

No historical account of leprosy in Nigeria can ignore the cultural and social dimensions. There were many stories of men and women in the settlements who defied overwhelming odds and distinguished themselves in various endeavours. One outstanding example is Ikoli Harcourt Whyte who left a legacy of enduring choral music as well as a shining example of leadership.

The National TB and Leprosy Control Programme (NTBLCP) was launched in 1989, but became fully operational in 1991. Between 1991 and 2012, a total of 111,788 leprosy patients have been successfully treated with MDT, and in the year 2000, the country achieved the WHO elimination target of less than 1 case per 10,000 population. With a case detection rate below 0.5 per 10,000, Nigeria may well be described as low endemic for leprosy. However, there remain pockets of ‘high endemicity’ at sub-national levels, where the leprosy prevalence is still >1 case/10,000 population.

Each of the 36 States and the Federal Capital Territory (FCT) has a State TBL Control Programme Manager who is the head of the State team and is mainly responsible for programme management and technical guidance to the LGAs. The LGA is the operational level of the programme and the LGA TBL Supervisor is responsible for day-to-day programme management at this level.

GEOGRAPHICAL DISTRIBUTION OF LEPROSY IN NIGERIA

Figure 1 highlights the significant geographical differences in the distribution of leprosy in Nigeria with notification rates higher in the North than in the South, and higher in the East than in the West. Five states namely Kebbi, Zamfara, Kano, Jigawa and Benue notified more than 200 new cases each in 2012.

Methods

The authors examined the following documents prepared by the Central Unit of the NTBLCP as available at March 2012. The documents are: i) NTBLCP Strategic plan 2010 to 2015; ii) NTBLCP Annual Reports of 2009; 2010; 2011; and 2012. Information from the above documentary analysis was supplemented with 11 key informant interviews and seven Focus Group Discussions (FGDs) consisting of eight people per focus group at the National, State and LGA levels. Among key informants interviewed were the Country Representatives and Medical Advisors of ILEP organizations (International Federation of Anti-Leprosy Associations), and the representatives of IDEA (Association for Integration Dignity and Economic Advancement).
Results

Policy

There is a combined National Strategic Plan (2010 to 2015) for tuberculosis and leprosy control in Nigeria. The leprosy component of this plan is well articulated and based on the ‘Enhanced Global Strategy for Further Reducing the Disease Burden Due to Leprosy.’ As a combined programme, the leprosy component competes for resources with a bigger burden partner. As such the attention given to leprosy control by policy makers and implementers is suboptimal and budgetary allocations for leprosy control at National and State levels are far below expectations.

There is a National Leprosy Technical Working Group (NLTWG) established in 2011. The overall purpose of the NLTWG is to support and monitor the implementation of the leprosy component of the NTBLCP strategic plan and advise the National Co-ordinator.
Although meetings are meant to occur quarterly, these have not been regular. For example, the NLTWG only met once in 2012.

This year, the National Neglected Tropical Diseases (NTD) programme in Nigeria, launched its Multi-year (2013 to 2017) Master plan, which includes leprosy. The extent to which the combined National Strategic Plan for tuberculosis and leprosy (2010 to 2015) and NTD multi-year plan have been streamlined is unclear.

**PROGRAMME PERFORMANCE INDICATOR**

Analysis of case detection figures reveal that over 50,000 new leprosy cases were notified from 2001 to 2012 (See Figure 2).

In spite of the total number of new cases detected in the past 12 years, the annual case notification shows a steadily decreasing trend from 5981 cases in 2001 to 3805 in 2012. The key question is whether this is a true decline or a consequence of inadequate attention to leprosy control.

Compared to the decreasing trend of total new case detection, the proportion of people who already had visible deformities among newly detected cases has remained fairly stable at 12% between 1999 and 2012 (See Figure 3).

Similarly, the proportion of children amongst new cases averaged 10% over the same period, the stabilizing trends of visible deformities and child proportion among new cases suggest continuing late reporting and ongoing transmission of the disease respectively.

**MANAGEMENT OF MDT SUPPLIES**

MDT supply has been generally regular. The exact National MDT stock level could not be determined as at the time of writing this report. However, over the last 2 years, there have been occasional stock outs, particularly with PB Child MDT. Other drug supply challenges involve loose Clofazimine (Lamprene), used for the management of Erythema Nodosum Leprosum, which is sometimes not available.

![Figure 2. Showing trend of annual new cases of leprosy notified from 2001 to 2012.](image-url)
RECORDING AND REPORTING

The NTBLCP has issued uniform standardised formats and guidelines for recording and reporting cases of leprosy in Nigeria. These include individual patient cards and LGA Leprosy Central Registers. The individual patient card was updated and simplified in November 2011. The LGA TBLS, during routine supervision of health facilities, collect leprosy data from health facilities which are entered into the LGA Leprosy Central Registers. Quarterly, during State TB/Leprosy Programme Review meetings, these data are collated at State level, analysed and transmitted to the NTBLCP. Although done manually, this system has worked quite well over the years.

PREVENTION AND MANAGEMENT OF DISABILITIES

The NTBLCP promotes prevention and management of disabilities as a major pillar of patient care. In a bid to improve access to timely diagnosis and management of reactions, the NTBLCP introduced field management of reactions 10 years ago. Under this scheme, Local Government (or District) TBL Supervisors are permitted to diagnose leprosy reactions and prescribe appropriate treatment according to National guidelines. Although the premise of this approach is conceptually sound, supervision revealed that the quality of care offered by the LGA supervisors in this respect is less than satisfactory.

Formation of Self Care Groups is currently being promoted as an option for people affected by leprosy who choose to support one another through sharing experiences on wound
care and sundry matters. Additionally, everyone affected by leprosy is provided with appropriate footwear which is produced in a local shoe factory commissioned by the four in-country ILEP members (Damien Foundation of Belgium, German Leprosy and Tuberculosis Relief Association, Netherlands Leprosy Relief and The Leprosy Mission Nigeria).

There are more than 20 leprosy referral centres in the country. Some of these centres are owned by Faith Based Organizations, e.g Holley Memorial Hospital in Ochadamu, Kogi State; Qua Iboe Church Hospital in Ekpene Obom, Akwa Ibom State. Others are owned by State Governments, e.g Leprosy Referral Hospitals in Kano, Sokoto and Niger States. These Hospitals were developed to provide quality services for the management of leprosy complications, including septic and reconstructive surgery. However, overtime, most of them have evolved into providing general health care services, with increasingly less emphasis on leprosy services. This trend has been encouraged by a myriad of factors including, the reducing case load of leprosy; weak referral systems; loss of leprosy expertise; dwindling funding for leprosy services; a policy of reverse integration; and a drive by some of these hospitals, to be self-sustaining.

Generally, there is little appreciation that disability is fundamentally an issue inextricably linked to and rooted in human rights. The common perception, held by policy-makers and the public, is that disabled people and disability issues are a matter of charity and welfare. However this is not the case with leprosy-related disability, an issue which is supported primarily by ILEP members and the national chapter of IDEA. It is a deliberate policy of in-country ILEP members to encourage and challenge people affected by leprosy through the platform of IDEA to stand up for their rights by building their capacity in Rights-Based Approaches and Advocacy, while also challenging Governments at various levels to live up to their responsibilities.

The Ministry of Women Affairs and Social Development is the lead government department for general disability issues in Nigeria. However, the services they provide are based on a charity/welfare approach to disability issues, with demand for such services far outstripping supply. There are some international NGOs that provide services to disabled people, but their geographical coverage is very limited. Although there is a plethora of disabled people’s organizations (DPOs) operating at the national, state and local levels, there are two national umbrella DPOs, namely, the Joint National Association of Persons with Disabilities (JONAWPD), and the Association for the Comprehensive Empowerment of Nigerians with Disabilities (ASCEND). However, the great deal of conflict between these two organisations impacts negatively upon their ability to effectively lobby the Nigerian Government to implement a rights-based agenda to disability issues. Although Nigeria is a signatory to the United Nations General Assembly resolution on the ‘elimination of discrimination against persons affected by leprosy and their family members,’ it is yet to be formally adopted and domesticated.

**LEPROSY EXPERTISE**

The loss of expertise in leprosy is real and pervasive in Nigeria. As many of the ‘old guard’ of committed leprosy workers exit the stage by retirement or death, it has become increasingly apparent that newer generations are unwilling to take over the torch. A recent survey of over one thousand final year medical students and young medical doctors (interns) in the south-east of the country found worryingly poor level of knowledge and attitude amongst the respondents. The major leprosy referral centres are run by the few remaining experts and in some cases assisted by retired experts on special contracts.
The NTBLCPR has a federal training institution dedicated solely to TB and leprosy. This institution (called the National TBL training centre Zaria) receives financial and technical support from ILEP, for training and re-training LGA supervisors, State control officers (programme managers), physiotherapists, laboratory scientists/technicians and other personnel essential for effective programme implementation. Although the National policy is for programme staff to be retrained at 3-yearly intervals to ensure they stay abreast with new developments in the field, this policy has not been implemented as desired.

LEPROSY RESEARCH IN THE COUNTRY

The leprosy situation in Nigeria is grossly under-researched. While this is partly a reflection of the perception of leprosy as a neglected disease, it is also a failure of stakeholders to find creative ways to make leprosy research attractive. In early 2007, a Health Systems Research (HSR) Workshop was organised for State TB and Leprosy programme managers to stimulate their interest in research. This led to a transient increase in operational research in leprosy in the country. Unfortunately, no deliberate effort has been made at national level to promote research since 2007. No other HSR workshops have been conducted. However, in recent years, some research has been carried out by some ILEP members. For example, a study of Knowledge Attitude and Practice of leprosy among final year medical students and young medical doctors (interns) in south-east Nigeria was conducted by GLRA. Also NLR assessed the feasibility and effectiveness of community dermatology approach in leprosy control in Northern Nigeria. Abstract of the GLRA survey has been accepted for presentation at the forthcoming International Leprosy Congress in Brussels in September 2013.11

Nigeria continues to express interest in participating in international studies where issues of strategic importance are explored. One example is the multi-centre study on emerging rifampicin resistance.

Discussion

SUMMARY OF CURRENT SITUATION

Despite achieving the elimination target of <1 case per 10,000 population in the year 2000 through implementing WHO recommended policies and strategies, leprosy remains a disease of public health importance in Nigeria. With an annual new case detection of 4000 people; a Grade 2 disability rate of 12%; and nearly 10% child ratio among new cases, it is necessary to maintain leprosy control measures to further reduce the burden of leprosy and ensure quality care to people affected by the disease. It is crucial that services are re-organised to take into account the new setting of low-endemicity and the uneven distribution of leprosy in Nigeria.

MAIN CHALLENGES

● There is inadequate Government financial commitment to leprosy. This is largely due to difficulty in convincing National Finance Ministers and State Health Commissioners to continue investing in an ‘eliminated’ disease in the context of competing interests from diseases such as HIV/AIDS, TB and Malaria.

● There is a gradual loss of leprosy expertise in the country. This may not be unconnected to the reduced funding for leprosy and arguably low endemicity of leprosy. In addition,
interest in leprosy work among newly qualifying doctors and general health professionals is low due to the perceived lack of career prospects in the field of leprosy.

- Beyond clinical care, the physical and social rehabilitation of the thousands of people with leprosy-related disabilities remains a challenge. So also is the longstanding issue of stigma and discrimination.

**Recommendations**

(1) In light of the current status of leprosy as a low endemic disease, its focalised occurrence, and dwindling resource allocation by government, it is imperative that the programme be re-organised to take these emerging realities into account. To optimise efficiency and effectiveness, there is need to undertake careful mapping of the disease at the LGA level across the country. This will help in resource allocation as well as rational targeting of special interventions like periodic intensified case-finding exercises (mini-LECs).

(2) The integration of leprosy into the NTD programme provides an opportunity to leverage resources for its control and needs to be maximised.

(3) The National Leprosy Technical Working Group needs to be strengthened and made more functional.

(4) Zonal referral centres should be identified and strengthened with competent teams and budgetary provision for running costs. These centres could be responsible for specialised care including rehabilitative and reconstructive surgery. Setting appropriate and patient-friendly referral systems should be negotiated in consultation with representatives of people affected by leprosy under the platform of IDEA.

(5) All stakeholders must continue to facilitate the empowerment of the various IDEA chapters while constantly reminding government of the unfinished business of leprosy control in the country.

(6) Other measures with potential benefit for leprosy control include improved engagement of dermatologists as well as creative pre-service orientation of medical students, nursing students and students of schools of health technology.

(7) To improve quality of care in the short and medium term, the national TB/leprosy guidelines should be revised to incorporate validation of diagnosis of new cases, relapsed cases and cases of reaction. Using the ubiquitous mobile phone technology for registration of new patients and follow-up of treatment should be explored.

(8) All stakeholders must continue to support the training and retraining of National, State and LGA TBL staff and other health workers in the diagnosis and proper management of leprosy.

**References**


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