Factors contributing to low leprosy case finding in Northern Gombe State, Nigeria

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Factors contributing to low leprosy case finding in Northern Gombe state, Nigeria

A thesis submitted in partial fulfilment of the requirement for the degree of

Master of Public Health

By

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Nigeria

Declaration:

Where other people’s work has been used (either from a printed source, internet or any other source) this has been carefully acknowledged and referenced in accordance with departmental requirements.

The thesis “Factors contributing to low leprosy case finding in Gombe state, Nigeria” is my own work.

Signature: ........................................

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ABSTRACT

Background

Although, Nigeria attained WHO leprosy elimination target of less than 1 case per 10,000 at national level, there is still a high number of leprosy cases in the county and pockets of high endemicity exist at sub national level. Gombe state is one of the high endemic states in Nigeria. Over the years the state Leprosy Case Detection rate (CDR) and Prevalence Rate (PR) has not improved appreciably, despite improved and intensified leprosy control activities at the state. There was also observed low case finding in the northern Local Government Areas (LGAs) of the state compared to the southern LGAs. This thesis aims to identify factors contributing to low case finding in Northern part of Gombe state.

Methodology

This study employs two approaches; first, a cross-sectional study approach utilizing questionnaires and Focus Group Discussion (FGD) to collect the perspectives from community, patients and health workers from MDT facilities. Second, a literature review was done to assess factors that contribute to low case finding in Nigeria and other countries. The findings were presented and analyzed using an adapted Piot Model.

Findings: This study shows that, community members have low knowledge and awareness about leprosy and leprosy services. It is likely that the information awareness campaigns are not reaching the community, or they are not having the desired impact. The majority of patients, who suspect that they have leprosy, first seek health care from alternative medicine practitioners. This leads to delay or non-reporting accounting to low case finding. Low case finding from demand side is a result of various social cultural, economic and health services barriers such as stigma, gender, travel cost to health facilities. Supply side barriers found include; insufficient knowledge health workers in leprosy diagnosis, lack of motivation, work overload, weak supervision and referral systems.

Conclusion: Low case finding in Northern Gombe State is due to low community knowledge and awareness, poor health seeking behaviour, low knowledge and motivation of health workers which is due to sociocultural, economic and health service barriers. This suggest that, an emphasis needs to be placed on health promotion activities, training of healthworkers and integration of leprosy to general health services.

Key words: Leprosy, case detection, Gombe, health seeking behaviours
# ACRONYMS AND ABBREVIATIONS

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Definition</th>
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<tbody>
<tr>
<td>ARI</td>
<td>Annual Risk of Infection</td>
</tr>
<tr>
<td>ACSM</td>
<td>Advocacy, communication and social mobilisation</td>
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<tr>
<td>CDR</td>
<td>Case Detection Rate</td>
</tr>
<tr>
<td>CHEW</td>
<td>Community Health Extension Worker</td>
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<tr>
<td>CI</td>
<td>Confidence interval</td>
</tr>
<tr>
<td>DG II</td>
<td>Disability grade 2</td>
</tr>
<tr>
<td>FCT</td>
<td>Federal capital Territory</td>
</tr>
<tr>
<td>FGD</td>
<td>Focus Group Discussion</td>
</tr>
<tr>
<td>FMOH</td>
<td>Federal Ministry of Health</td>
</tr>
<tr>
<td>GBSTBLCP</td>
<td>Gombe State Tuberculosis and Leprosy Control Programme</td>
</tr>
<tr>
<td>GHCW</td>
<td>General Health care Worker</td>
</tr>
<tr>
<td>GHW</td>
<td>General Health Worker</td>
</tr>
<tr>
<td>GLRA</td>
<td>German leprosy relief</td>
</tr>
<tr>
<td>ILEP</td>
<td>International federation anti-leprosy organizations</td>
</tr>
<tr>
<td>JCHEW</td>
<td>Junior community Extension worker</td>
</tr>
<tr>
<td>KIT</td>
<td>Royal tropical institutions</td>
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<tr>
<td>LEC</td>
<td>Leprosy elimination campaigns</td>
</tr>
<tr>
<td>LGA</td>
<td>Local Government Area</td>
</tr>
<tr>
<td>LGATBLS</td>
<td>Local Government Area Tuberculosis/Leprosy Supervisor</td>
</tr>
<tr>
<td>MB</td>
<td>Multibacillary</td>
</tr>
<tr>
<td>MDT</td>
<td>Multidrug Treatment</td>
</tr>
<tr>
<td>MoH</td>
<td>Ministry of Health</td>
</tr>
<tr>
<td>NDHS</td>
<td>Nigeria Demographic Health Survey</td>
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<tr>
<td>NGO</td>
<td>Non-Governmental Organisation</td>
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<tr>
<td>NLR</td>
<td>Netherlands Leprosy Relief</td>
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<tr>
<td>NPO</td>
<td>National Professional Officer</td>
</tr>
<tr>
<td>NTBLCP</td>
<td>National Tuberculosis and Leprosy Control Programme</td>
</tr>
<tr>
<td>NTBLTC</td>
<td>National TB / L Training Centre</td>
</tr>
<tr>
<td>PB</td>
<td>Paucibacillary</td>
</tr>
<tr>
<td>PHC</td>
<td>Primary Health Care</td>
</tr>
<tr>
<td>RFT</td>
<td>Released From Treatment</td>
</tr>
<tr>
<td>RR</td>
<td>Relative risk</td>
</tr>
<tr>
<td>ST</td>
<td>Sensory Test</td>
</tr>
<tr>
<td>STBLCO</td>
<td>State Tuberculosis/Leprosy Control Officer</td>
</tr>
<tr>
<td>STBLS</td>
<td>State Tuberculosis/Leprosy Supervisor</td>
</tr>
<tr>
<td>TBL</td>
<td>Tuberculosis and Leprosy</td>
</tr>
<tr>
<td>TBLS</td>
<td>TBL Supervisor</td>
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<tr>
<td>TOT</td>
<td>Train of trainers</td>
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<tr>
<td>TLM</td>
<td>Leprosy mission international</td>
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<tr>
<td>UNDP</td>
<td>United Nation development program</td>
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<tr>
<td>VMT</td>
<td>Voluntary Muscle Test</td>
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<td>WHO</td>
<td>World Health Organisation</td>
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Introduction

Leprosy is still of public health concern despite the international efforts that are aimed at reducing its burden. The World Health Organization (WHO) set the leprosy elimination target of prevalence of less than 1/10,000 population by the year 2000 (1); this rejuvenated the commitments of countries towards its reduction. Following this, many countries, including Nigeria initiated leprosy elimination campaigns; these efforts were spearheaded by WHO (2). This translated into the achievement of the target by Nigeria in 1998. However, Nigeria still contributes about 5000 new cases annually to the global burden of leprosy (2). Most of the patients are detected late often with advance deformities, therefore, leprosy is one of the leading causes of permanent disability in the country (2). Out of 36 states in the Nigeria, Gombe state along with 12 other states is considered leprosy endemic because high number of cases (above 200 cases) has been persistently reported annually (2). Wide disparities exist between the Northern and Southern LGA in terms CDR. On average the Northern LGA reported a CDR of 0.5/10,000 while the Southern LGA reported 1.4/10,000. In addition to this, there are differences in proportion of Multi bacillary (MB), proportion of Children and Disability grading (GD) among newly detected cases, with the Northern LGA reporting higher rates for these indicators (3). It is worth noting that the case detection intervention is similar for both regions. If that is left unchecked, it may undermine the leprosy control effort in the state. This prompted a health system research in the Northern LGAs which aimed at identifying the factors contributing to the low case finding in the region. However, the study completed the data collection stage but did not progress to analyse the data, because of technical and time constraints. This thesis aims to complete this study by analysing and interpreting the data collected, draw lessons from other studies by conducting a literature review and to draw conclusion and suggest recommendation. The author is interested in this topic because he has been working as a Programme Manager for the control of TB and Leprosy in Gombe state (GTBLCP) for more than five years, with a lot of challenges particularly the high leprosy endemic situation of the state. In addition to contributing to the strengthening of the program, this study also accords me the opportunity to widen my knowledge on leprosy control. The lessons learnt from this study would benefit other public health programs in Nigeria, particularly leprosy control programme in North-East region.
CHAPTER 1: Background

1.1 Geography and Demography

Nigeria located in West Africa, is the most populous country in the continent with estimated population of 169 million\(^1\) in 2009 (4). The country is operating a 3 tier federal system of government, consisting of 36 states and a federal capital territory. The states are further subdivided into LGAs; there are a total of 774 LGAs in the country. At each level of government a 3-arm system is maintained, consisting of legislative, executive and judicial arms. There is growing populations in slums around big cities due to rapid urbanisation (4). This may pose operational challenges in leprosy control.

Gombe State is located in the North Eastern part of the country and has 11 LGA, each having its own administration. There are 5 LGAs in both the Northern and Southern part of the state with state capital in the centre (annex 1). The state has estimated 2009 population of 2.6 million\(^2\) and population density of 128 persons per square km. The male to female ratio of 1.06:1. The state capital (Gombe) is crowded with the density reaching 275 persons per sq, but other LGAs are very sparsely populated (5). Overcrowding in the presence of leprosy reservoirs could lead to increased transmission of infectious disease in the state. Subsistence farming is their main source of income and more than 80% of the population live in rural areas (3).

1.2 Socioeconomic Indicators

The human poverty index (HPI) of the country is 37% (111 among 135 developing countries) in 2006 (6), reflecting the low socio economic situation of the country, despite the country is one of the world oil producers. The gap between the rich the poor is wide (Gini index 0.506) (6). Poverty is shown to be prominent in the North Eastern Nigeria, particularly in rural areas where 80% of the people are poor compared to the South West with 40% (7). Gombe state population is multi-ethnic, with a wide cultural and religious diversity. Gombe state population is young, 50% are under 15 years and level of education is low (Average,37.5%), female literacy rate of 25% (66% national) and males 50% (76%, national) (3).

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\(^1\) Projected from 2006 census(140M) at growth rate of 3.2%
1.3 Health Services

1.3.1 Organisation of Health services:
Health care services in Nigeria are provided at 3 levels namely primary, secondary and tertiary provided by local government, state governments and federal Government respectively. LGAs have PHC clinics and pay staff working in those clinics. However due to inadequate funding, the primary health care in the country is not functioning well. The private sector, Non-Governmental Organizations (NGO), and local communities also provide considerable services at all the levels of health care. The private sector accounts for about 50% of health care delivery in the country, they are poorly regulated and with some collaboration with NTBCP programme especially for the TB control but not with leprosy control (2). The structure and function of the health system in Gombe state is according to the National Health Policy. There are 10 general hospitals in the State with one serving as the referral hospital for leprosy and tuberculosis (Zambuk Hospital). Other health care facilities include, the Federal Medical Centre (tertiary care), 450 PHC centres, with 92 (22%) serving as MDT clinics (Annex 2) and 55 private health facilities spread over the State (3).

1.3.2 Health Indicators
Nigeria’s overall health system is weak and grossly under-funded as a result of which the country has one of the worst health indices in the world (8). Most of Nigerians’ disease burden is due to preventable diseases. Maternal and under Fives mortality ratios are one of the highest in the world (800 and 230/100, 0000 live births respectively in 2007) (9). Gombe state and other North Eastern states have the worst health indicators compared to other regions of the country. Maternal and under Fives mortality is 1,728 and 260 /100,000 (9). Malaria, diarrhoeal, measles, upper respiratory and malnutrition are the major causes of under Fives mortality in the state while HIV and TB are the major infectious causes of mortality and morbidity in adults and leprosy is one of the leading causes of morbidity in the state (10) (See annex 3).
1.3.3 Health Work Force:

There is general shortage of Human resources for health in the country with wide geographical variation. North East where Gombe state is located and rural areas are shown to have the worst number and lowest qualified health workers (4), this seriously affect the delivery of health services including leprosy. Previously, TBL supervisors with MDT assistance ran leprosy clinics in the LGAs once monthly for all the patients, however with integration into the general health system, leprosy staffs in the PHC clinics conduct the clinics and TBL supervisors supervise their activities. Hence availability of trained staff at PHC clinic could influence leprosy case finding in the area. In Gombe state the number and distribution of health workers is not known, but evaluation reports showed, they are not adequate and poorly distributed with concentration at LGA Headquarters (see annex 4). About 276 different categories of health workers from PHC facilities have been trained on leprosy in the last five years (3). Medical officers and TBL supervisors from states and LGA are trained at National Tuberculosis and Leprosy Training Centre (NTBLTC) for the effective implementation, monitoring and management of the programme in the country (2).

1.3.4 Health Care Financing:

The three levels of Government in Nigeria have responsibilities for financing health care delivery. The sources of health care funding are mainly government budget, user fees, loans and multi-lateral and bilateral development aid including support from NGOs. Public health expenditure on health in 2007 is less than $22 per capita compared to the US$34 recommended internationally, so most (80%) of the health expenditure rely on out of pocket payment despite the endemic nature of poverty (11). As such, leprosy victims who are mostly beggars could experience catastrophic expenditure from common illnesses like malaria and perceived cost at PHC facilities may deter patients from accessing leprosy services. The leprosy programme funding for the state is mainly from the State Government and Netherlands Leprosy Relief (NLR), however Federal Government and LGAs are also giving additional support (3).
1.4 The National TB and Leprosy Control Programme (NTBLCP)

1.4.1 Organizational Structure:

The NTBLCP is located within the directorate of PHC and Disease Control of Federal Ministry Of Health (FMOH); it is responsible for coordination and policy formulation of TBL activities in the country. At State level, the State TBL programme is vested with the responsibility of operational management of TBL programme with the assistance of TBL supervisors. At LGA level, TBL supervisors (LGTBLS) of each LGA are responsible for supervising General Health Workers (GHW) and overall management of the programme at LGA level. At country level NLR, GLRA, TLMI and WHO provides technical and financial assistance to the programme. Gombe state control TBL programme is supported by NLR financially and technically while the zonal WHO TBL officers provide technical assistance to the State. (See annex 5).

1.4.2 The Leprosy Situation:

The implementation of the MDT as the strategic intervention for Leprosy elimination in Nigeria has resulted in a rapid decline of the number of registered leprosy cases from nearly 200,000 cases in 1989 to 5398 by 2007 (2). This success is attributed to the reduction treatment duration from 24 to 12 month by WHO and general improvement in provision of leprosy services due to government commitment and the involvement of NGOs (1). The WHO elimination target at the national level, but high leprosy cases are still registered yearly. However, both national rates of prevalence and case detection remained below 0.5 per 10,000 population hence, Nigeria is considered low endemic for leprosy (2). All Zones except North East and North West Zones have reached this low endemic situation. A total of 23 (62.2%) States have attained low endemic level. The remaining 13 states report high number of leprosy cases annually, with pockets of endemic areas (see annex 6). The country registered more than 5,000 leprosy cases annually and more than 1 in every 10 new patients already having visible physical disabilities at diagnosis. At the end of 2007 nationally, 5,381 leprosy cases were registered, 87% were MB cases, 12% with DG II, 43% females and 9% children (2). The leprosy situation in Gombe state is summarised in (figure 1 &2 below and annex 7, 8 &9) which show the key leprosy statistical indicators between 1999 and 2007 and LGA distribution of cases. About 200 leprosy cases are registered annually in the state, majority MB cases with high pecentage of Children and DGII, the details is described
below. Primary Preventive of disability (POD) activities (nerve function assessment and steroid treatment of reactions) is being done but the quality of the assessment leaves much room for improvement. There are Self Care Groups (SCGs) both in the field and around the TBL referral hospital. Treatment completion rate for in MB and PB were 95% and PB 100% respectively for patients registered in 2007.
2.1 Problem Statement

Early case finding and treatment with Multi Drug Therapy (MDT) is the WHO recommended strategy for reducing leprosy transmission and leprosy control (1). Data from the leprosy programme in Gombe State between the period (2005-2008) showed that, there is low case finding in the Northern LGAs, alongside high leprosy indicators (proportions of MB, Children and DGII among new cases) when compared to the Southern LGAs of the State. The reason for the low case finding in the Northern LGA is the central focus of this thesis.

2.2 Setting of the Problem

In Gombe state, the prevalence of leprosy has been fluctuating over the years, it dropped slightly below 1 case per 10,000 while case detection rate rose slightly above 1 case per 10,000 at end of 2007 (see figure 1). Although, there is slight effect due to increasing population over the years, however the trends of PR and CDR have not appreciably changed, despite improved and intensified leprosy control activities at the state. Further, there is persistently high proportion of MB, children and DG II among new cases as shown in figure 1. High MB (greater than 80%), children (more than 5%) and DG II (5%) among new cases (see figure 2). These are suggestive that there is presence of a reservoir, ongoing transmission and late detection respectively (23). High reservoir of leprosy in the community and low case finding implies that, control leprosy may be difficult to achieve. Similarly, late detection leads to nerve damage that results into deformity, which in turn leads to stigma and socioeconomic to the patients and the community at large (12).

Figure 1: Trends of prevalence rate and new case detection rate in Gombe state 2001-2007
Figure 2: Trends of % MB, % children and % DG II among new cases detected in Gombe state 2001-2007

Individual LGA data revealed that, case finding is low in the Northern LGAs (CDR 0.5) as compared to the Southern LGAs (CDR 1.4). This pattern was observed over the period 2005 to 2008. It also true for other indicators, for instance the Northern LGAs had MB of 80% compared to the Southern LGAs 74%. The northern LGA had a higher Child proportion (14%) compared to the Southern LGA (9%). Disability rate among new cases is important indicator of leprosy activity in which high value indicates delayed case reporting (12), the Northern LGA almost had double DG II (15%) compared to the Southern LGA (7%). Finally, the proportion of women amongst new cases is almost similar in both cases (see table 1).

Table 1: Comparison of Northern LGAs versus Southern LGAs of Gombe state against demographic and leprosy indicators of new cases registered from 2005-2008

<table>
<thead>
<tr>
<th></th>
<th>Northern LGAs</th>
<th>Southern LGAs</th>
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<tbody>
<tr>
<td></td>
<td>N (%)</td>
<td>N (%)</td>
</tr>
<tr>
<td>Average population</td>
<td>1.15 million</td>
<td>1.34 million</td>
</tr>
<tr>
<td>Characteristics of patients</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>108 (55%)</td>
<td>373 (54%)</td>
</tr>
<tr>
<td>Female</td>
<td>88 (45%)</td>
<td>317 (46%)</td>
</tr>
<tr>
<td>Age (years)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;15</td>
<td>27 (14%)</td>
<td>86 (9%)</td>
</tr>
<tr>
<td>&gt;15</td>
<td>69 (85%)</td>
<td>604 (91%)</td>
</tr>
<tr>
<td>Total number of cases registered</td>
<td>196</td>
<td>690</td>
</tr>
<tr>
<td>CDR classification</td>
<td>0.5</td>
<td>1.5</td>
</tr>
<tr>
<td>MB</td>
<td>156 (80%)</td>
<td>510 (74%)</td>
</tr>
<tr>
<td>PB</td>
<td>40 (20%)</td>
<td>180 (26%)</td>
</tr>
<tr>
<td>Disability grading among new cases</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DG 0 &amp; 1</td>
<td>85%</td>
<td>93%</td>
</tr>
<tr>
<td>DG 2</td>
<td>15%</td>
<td>7%</td>
</tr>
</tbody>
</table>

Source: Authors compilation
Although interventions to improve CDR seems to be similar in both regions in terms of health education, radio messages, and outreach campaigns. There may be underlying factors behind the observed difference such as variation in local government activities, financing levels, program organisation, management and support, human resources as well as socio-cultural characteristics. The differences could as well be due over diagnosis of cases in the southern LGAs but this was rule out during routine supervision. In effort to gain insight into the problem, a health system research was conducted in 2008 with the aim of identifying some of these factors, but this activity was not concluded due to limitations in technical capacity and time.

2.3 Problem Analysis

Case detection and effective treatment are recognised by WHO as the keys to breaking the chain of leprosy transmission and subsequently leprosy elimination (12). Poor knowledge and awareness among community members is likely to be associated with low case detection (13). This is because; community members are not able to recognise the early signs and symptoms for leprosy. The early symptoms of leprosy could easily be confused with other simple skin disease such as ring worms, this may cause suspected cases to be lax and not seek care early enough. Several studies that have been conducted in Nigeria on knowledge and awareness about leprosy (14;15;16), but no such study has been conducted in Gombe State which could be a contributing factor to low case detection at the State. Although, awareness campaigns are ongoing at the State, little is not known about the impact of such intervention. Studies have shown that cultural beliefs, stigma and misconception have an influence on leprosy health seeking behaviour (15). Gombe State has a multi ethnic and diverse culture, it likely that beliefs misconception could be acting as barrier to early leprosy health seeking. The informal health sector such as traditional healers, herbalists and street drug vendors are also present in Gombe state, particularly in rural areas, it is likely that patients suspecting they have leprosy may seek health care from this sector thereby affecting the case finding. Although about 98 facilities that offer leprosy care are integrated into general health service and these are distributed throughout Gombe State, but the issue of accessibility in terms of distance, cost, time due to poor roads, and acceptability is not yet determined. This may be a contributing factor to the low case finding. The knowledge and awareness amongst health workers in a key issue to ensuring early diagnosis of leprosy, a suspected case may be misdiagnosed and that could lead poor case finding (17). In Gombe State the health workers have been trained on leprosy diagnosis, but their level of knowledge has not been evaluated. Health worker performance is also influenced by his / her motivation,
supportive supervision as well as other human resources issues such as remuneration levels, promotion mechanisms (18). This information is important as it may contribute to the problem, or if known, it may be used to strengthen future interventions. The study made attempt to assess both the demand (patient related barriers) and supply (health service barriers) as they relate to the factors that influence low case finding in the context of Gombe State.

2.4 Thesis Objectives

2.4.1 General Objectives

To identify factors contributing to low case finding in northern LGA of Gombe State in order to make recommendation for improvement.

2.4.2 Specific Objectives

1. To assess leprosy knowledge, awareness and health seeking behaviour amongst leprosy patient and community members in northern part of Gombe State.

2. To determine leprosy knowledge and attitude of the Health care workers and how this affects case finding.

3. To describe factors influencing leprosy case finding in Nigeria and other developing countries.

4. To critically review the study design and methodology of HSR study conducted in 2008 in northern Gombe.

5. To use the findings to make appropriate recommendations for the improvement of case finding in the state.

2.5 Research Questions

1. What is the leprosy knowledge and awareness amongst leprosy patients and community members in Gombe State?

2. What is the knowledge and attitudes of health workers towards leprosy in the State?

3. What is the health seeking behaviour on leprosy amongst patients and community members?

4. What are the factors influencing leprosy case finding in Gombe state?

5. What are the strengths and weakness of the HSR study conducted on low case finding in northern Gombe state in 2008?
2.6 Methodology of the thesis

The methodology of this thesis is in two parts. The first part is the methodology of the HSR study conducted in Northern Gombe state 2008 and it was described in the next chapter (chapter 3). The part answered questions 1, 2 & 3 of the thesis. The second part involves review of relevant literature and documents from Nigeria and other developing countries answering question 4 of the thesis (methodology described in chapter 3). Modified piot model (described below) is used as framework for presenting and discussion of findings of the study and the literature review. This was then followed by critical analysis of the field study methodology and based on that conclusion and recommendations are finally made.

2.7 Description of the Framework

Piot model\textsuperscript{3} was adapted to serve as a framework for presenting findings and analysis (19). The model was first used to assess the control of TB and subsequently for other communicable diseases. It shows how proportion individuals in the community with the disease pass through several steps to the time they become cured of the disease, some individuals are lost at each steps due to operational factors as indicated in the steps (showed in figure below). But, for the purpose of this thesis, only step 1 to step 5 are considered which are concerned with case detection. However, the model did not look at other factors that may have influence on cases detection such as family and societal factors that influence health seeking behaviour as discuss in Andersen’s 3 factor model of health which looked at predisposing, enabling and need factors (20). Other issues considered in the framework are management and support such as training, supervision and human resources. The basic epidemiological model (Agent, environment and host factors) as it relates to burden of leprosy in a community was briefly discussed.

\textsuperscript{3} The model described case finding and treatment of tuberculosis in simple mathematical form
Figure 3 Framework of Analysis

Proximal/Distal determinants

- Support and management by control programme
  - Human resources
  - Training and supervision
  - Logistics & supplies
  - Financing, Govt
  - NGO

- Service delivery
  - Integration
  - Community outreaches (LEC/Surveys)
  - Posters
  - Health education by health workers

- Health seeking behavior:
  - Education level
  - Income/SES
  - Social norms, stigma
  - Gender
  - Traditional healers
  - Myth & Misconceptions

Epidemiological factors
- Agent:
  - Virulence of M. leprae.
  - MB Proportion
- Environmental: socioeconomic, household contact, clustering,
  - Host: immunity, BCG vaccination

Pilot Model

- Patients released from treatment
- Patient adhered to treatment
- Patient started on correct treatment
- Patients correctly diagnosed
- Patients identified as suspect in MDT health facilities

Case finding
- Those people with leprosy that seek care at health facilities (Motivation to consult health services)
- Those people with leprosy having Knowledge and awareness in the community
- All leprosy patients in the community

Source: Authors compilation
CHAPTER 3: DESCRIPTION OF STUDY AND STUDY FINDINGS

This chapter is divided into two sections. The first section presents the methodology and findings from primary study while second section describes methodology and findings from literature review on factors contributing case finding. The findings were presented based on the steps of Piot adapted framework.

3.1 Factors influencing leprosy case findings from Primary Study

3.1.1 Description of the Study
The aim of the study was to identify the factors responsible for low case finding in Northern LGAs. The study was first proposed by the state programme with the assistance of NLR medical advisor and funding obtained from NLR. The research team comprised of the four members and led by the author of this study. Data collection lasted for three months (May to August 2008), as it was done alongside other routine work.

3.1.1.1 Description of Study area
The study area consists of five of the eleven LGAs which constitute about 46% of the population. Although Gombe LGA is centrally located, in this study it was included in the Northern LGA because they share similar social cultural beliefs and religion (annex 1). The population is predominantly Hausa/Fulani and Muslims. The area is semi-arid with good network of roads and most communities are accessible except during the rainy season when some areas are difficult to access. When compared to the Northern LGA, the Southern LGA has better infrastructure, however there are some hard to reach places because of mountainous topography. The inhabitants are also relatively more educated as compared to the Northern LGA.

3.1.1.2 Methodology of the Study
It was a cross-sectional study and the study population comprised of: community members, leprosy patients and Health workers. The total sample size was 140 participants and 2 FGDs of 10 participants. The semi-structure questionnaire was planned to include 25 patients 80 community members and 35 health workers. This was achieved except for the number of patient, which fell short by one patient.
The questionnaire was piloted and adjusted with the assistance of the medical advisor. Five LGA supervisors were recruited and trained on data collection for two days by the team. Patients were recruited from the five LGAs in the region, in each LGA 5 patients were selected from leprosy register using purposeful sampling method in which only clinics with patients were selected, leaving out clinics without patients. This sampling was done by the local government supervisors from each of the five LGAs. However, where there were no up to five patients in the register, patients who had been treated and released 2 years earlier were selected as in the case of two LGAs. Health workers from the clinics where the selected patients were being treated were recruited into the study. Seven health workers from each LGA were recruited making a total of 35 Health workers. Where ever there were less than seven, health workers from the neighbouring clinics were recruited and this happened in three LGAs. Community members were also interviewed from the same localities in which the patients were residing. A total of sixteen community members were selected from each LGA.

The two FGDs were done in two LGA one in each. The LGAs were also purposefully selected, the first two LGA where data collection was conducted were the ones where FGDs were conducted. The participants of the FGD were selected by the district head of the respective villages. The two groups were comprised of all males and the venue was the palace of the village head.

At the start of the research activities, the Ministry of Health was informed of the study and they gave a go ahead for the study to proceed. No written consent form was administered to the participants during the study. During the data collection phase, two patients were replaced because they did not turn up. The clinics were used for the data collection and in some cases the data was collected under the tree. The data was checked for completeness and consistency after coming from the field, that was done by one person. The data was coded and entered into SPSS. The FGD was transcribed and the data carried along, and was analysed in this thesis.
3.1.2 Study Findings

3.1.2.1 General Information:

The number of Males was more than that of females across the groups included in this study. Majority of the respondents were in the age bracket 30-45 years. Most of the patients were classified as MB (83%) which may indicate the presences of high reservoirs of infection in the community. 92% of the patients had DG II which may indicate late detection. Farming is the commonest occupation among male respondents, both for the community and the patients. Majority of the women were Housewives, 23% of the women among the community members were traders. Among the patients, all were married except 3 males and 4 females. 60% of the patients were detected by active case findings (See table 2 below). Most of the health workers were Junior Community extension workers (JCHEW) and few number of nurses (see figure 4 below).

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<tr>
<th>Table 2 Demographic Characteristics of the Respondents</th>
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3.1.2.2 Magnitude of leprosy in the Community
This aspect of piot model was not covered by our study.

3.1.2.3 Knowledge and awareness of leprosy patients and the community on leprosy

I. Community’s Knowledge and awareness
Almost all the respondents have seen or heard about leprosy patients but only 28% relate it with germ, 52% believed the cause is hereditary while 10% said it is due to eating goat meat or black fish and 10% did not know the cause. Only 20% cited skin patch as the early symptoms of leprosy. 74% believed leprosy is curable, 10% believed it is incurable and the rest did not respond (figure 4). Only 23% of the respondents knew where to access leprosy services within the community while 30% cited the major referral hospital and the remaining did not know. On information about leprosy, 50% of community members acknowledged that they have heard information on leprosy before, 71% of them through the radio, and 21% from health workers and the remaining from community members. This is supported by the fact that only few participants in FGD reported receiving information on leprosy mainly through radio, health workers or other means. However, most could not remember the type or frequency of the information they had through the radio. Majority of the participants from FGD had poor knowledge on cause, transmission
and location of leprosy services, but most believed leprosy is curable and that modern treatment was effective. Early signs and symptoms could not be mentioned by the community members, many cited deformity as a sign of leprosy infection. Myths and misconceptions were common; some opined leprosy is transmitted via sexual contact, by flies, hereditary, eating goat meat, evil spirit and bewitching.

“They simply throw the evil spirit inside water, when one mistakenly drinks or bath with the water then he becomes infected leprosy”
(one member of FGD in Ashaka Gari)

Figure 5: Knowledge of community members on leprosy

II. Patients’ Knowledge and Awareness:

Knowledge before Diagnosis:

Most (84%) of the respondents were aware of leprosy before diagnosis, the rest did not know. Their sources were mainly radio, family members and members of the community. All knew the disease they were suffering from, 29.2% of the patients associated skin patch with early manifestation of leprosy while remaining 70.8% mentioned body pains, body weakness, insensitive hands/feet, and redness of eyes, fever and headache. This implies that only the late manifestation of leprosy is known by patients prior to diagnosis.
Knowledge after Diagnosis:

Only 37.5% (77% men and 23% women) knew that leprosy is caused by germs; 33% attributed it to God, 4.2% to evil spirits and 16.7% did not know the cause. Only 30% of the patients knew the correct route of transmission, 15% mentioned that leprosy is transmitted through the blood and 45% did not know. Most believed leprosy is curable with modern treatment alone but 20.8% believed in combination of both modern and traditional (prayers), 7% did not respond and 4% believed is not curable. Most indicated health workers as their major source of knowledge through monthly health education and few mentioned ex-patients and family member as their sources. This was most typical with in Funakaye LGA where there is a lot of ex-patient.

Figure 6: Patients' knowledge on leprosy

Generally, patients and the community members have inadequate knowledge on the cause, early symptoms, and transmission and most members of the community do not know where to access leprosy services within their communities; however they have a good knowledge on its curability and the effectiveness of the modern treatment. Radio is main source of information in the communities while health workers, ex-patients and community members are also important source of information to both patients and the community. This was also supported by health workers in which 37% of them felt that leprosy awareness in the community is inadequate.
3.1.2.3 Motivation to consult Health services

Self-medication is the first action taken by most patients when they notice leprosy symptoms, 42% tried drugs or creams from drug stores and 23% went for traditional care or used herbs. This pattern cuts across all the health facilities. Lack of knowledge and awareness about the symptoms and where to access care was the common reason given for such actions but some mentioned that alternative medicine was cheaper and convenient as compared to formal treatment. It was noted that, there was time lag between the manifestation of symptoms in patients and their presentation at the Health facilities, the delay range from 1 to 3 years on average. When the question “where would you go for treatment when you have leprosy?” and “where would you go when you had another skin disease?” was posed. Only 25% reported that they would go to a PHC facility when they suspected they had leprosy and 15% reported they would if they had a skin disease. Majority of the respondents prefer visiting a hospital for both leprosy and skin disease. This may be indicative of perceived poor quality of PHC services. This is supported by the views of some participants in the FGDs in which they mentioned doubt regarding the ability of PHC staff to treat leprosy hence they prefer visiting referral hospital where they can be seen by experts. In addition, probably because people consider leprosy as a severe disease many would go to both hospital and PHC compared to when they suspect other skin diseases, 5% reported they would do nothing if they had a skin disease and 27% of patients said they would visit a chemist if they had other skin diseases. That was the common opinion from one of the FGDs. However, with low knowledge and awareness, they may find it difficult to differentiate the two, hence may end up self medicating in the chemists. This is illustrated above, where most patients delayed treatment due to self medication. Interestingly, about a quarter of the respondents reported they would visit a traditional healer if they suspected they had leprosy, while 9% would do the same if they had other skin diseases. Similarly, some participants from the FGDs indicated that they would use traditional herbs when they suspected leprosy. One of the participants from FGD said

“If I go to hospital they would waste my time and make me to pay a lot of money for drugs, so for me the herbalist is cheaper”.

This shows that traditional healers may still be relevant in the leprosy treatment in these communities and could be a barrier to case finding.
Majority of the patients have fear of being stigmatised by members of the community, 63% of the patients informed their spouse or parents and only 2 (8%) informed neighbours and none informed friends or other members of the community. Sixteen (16.7%) of the patients had experienced some discrimination in the form of isolation or being barred from attending important community function while 30% declined to respond to this question. Among Community Members, 57% feared they would be discriminated and isolated from the society or work place if they had leprosy. Women appear to be more concerned about stigma, 18 respondents majority women were concerned that leprosy could affect their relationship with other family members or their partner while 12 said they don’t fear that leprosy would affect their relations and 5 declined to respond to this question. Only 27.5% said they would not mind marrying from family which had a leprosy case while 72.5% declared they would not marry from a family which had a leprosy patient. Most of the participants in the FGDs expressed that they don’t associate with leprosy patients due fear of contracting the disease, most would not eat, shake or inter marry with families that had cases. However a minority believed that whether one had leprosy or not was subject to God’s will.

“They are human beings like us and it can happen to any one of us, I invite them for wedding ceremony and shake hands with them provided they don’t have wound in the hands prevent catching the disease” said by one participant from FGD in Nafada.
When asked about people with leprosy symptoms that are hiding in the community, 18% of the respondents acknowledged that, there are people hiding due to fear of being stigmatized. This opinion is also shared by 31% of health workers. Therefore, stigma may act as an important barrier to health seeking, amongst leprosy suspects in this communities. When patients were asked if they experienced any problems with accessing leprosy services, most of the patients reported that they did not face problems in terms of travel cost, time and distance. However, 30% were living at a distance of more that 5km away, 70% spent between 150-300 naira (1 -2US$) for monthly fares and 30% take between 1 to 2 hrs on the road to reach health facility. Two women stated that most of the time they had to be accompanied by somebody, this then doubles the amount that has to be spent on transport which could be a barrier. Availability of transport and poor terrain was also mentioned as one of the problems associated with access.

**Figure 8: Distance, time and cost of accessing Leprosy Services by patients in Northern Gombe state**
Majority of the community members (87%) preferred that leprosy services be integrated as compared to when they were vertically delivered, because of the stigma attached to attending services that were entirely dedicated to leprosy. But in the FGD, someone mentioned that he was not comfortable attending maternity clinics where women deliver. This may prevent people from going to these facilities when they suspected they had leprosy.

“*How can I go to clinic where women go for delivering when we go there we are usually asked to wait outside*” Said by one participant in Ashaka Gari

When asked on privacy, 80% mentioned that they did not have a problem with privacy while 10% reported they had and 10% did not respond. Ninety (90%) indicated that they were satisfied with the attitude of the clinical staff; as a matter of fact they acknowledged the staff have been supporting them morally.

3.1.2.4 Patients identified as suspect in Health Facilities

Out of the 35 health workers, 14 were not trained on leprosy. About half of the staffs were trained more than five years ago and no refresher course had been given. Half (47.5%) of the staff who had not been trained on leprosy, although, some claimed that they received on the job training from LGTBLs. Most of the facilities (77.1%) were being run by one staff, but surprisingly, 4 trained staffs were found in the same clinic in the LGA head quarter implying uneven distribution. On the aspect of their knowledge and awareness, the study found insufficient knowledge on recognising early sign of leprosy and diagnosis. It is worth noting that the knowledge of the respondents on duration of treatment, transmission, and classification was impressive (see figure 9). However, it is likely that untrained staffs were the ones who gave striking responses in this study, for instance, leprosy is caused by hereditary factors (16%), or transmitted by flies (8%), or by sharing clothes / contact with sweat or other secretions from patients (4%). Therefore, poor knowledge of GHW is likely to be associated with low case finding in the northern LGA.
3.1.2.5 Patient correctly diagnosed with leprosy

Out of the total respondents, 34% could explain how to use cotton wool to examine patient. The rest either did not know or gave wrong responses. But, only 20% of the respondents have made a diagnosis before while 34% had suspected and referred patients to LGTBLs for confirmed diagnosis. Some of the reasons given for their inability to make a diagnosis include: lack of adequate training or work overload, or patient denial of diagnosis. When asked about community health education, 77% stated that they educated community members about leprosy, however, very few (5) had conducted contact tracing before. This implies that contacts of MB patients are not examined which may have contributed to increase case finding in the area. For the question seeking to examine the attitude of staff towards leprosy and patients, 62.9% did not mind attending to leprosy patients, while 17% were uncomfortable attending to them. Some of the reasons cited for this discomfort include: fear of contracting infection, stigma both by the health workers and other patients. This means that a positive attitude towards leprosy is common amongst health workers, however, a notable proportion is still stigmatized and exhibit negative attitude about leprosy. This is likely from the untrained staff among
the respondents. This has implications in that; it may affect the health seeking behaviour negatively and result in low case finding. When the health workers were asked about the problems that prevented them from performing leprosy activities, majority (72%) of them mentioned work overload as the challenge to carrying out their duties. About half of the leprosy patient cards were not correctly completed. This may indicate the low skills of the health workers in recording and reporting. Drugs and necessary diagnostic materials were available in 65% of the health facilities. However, only 2 of the 27 health facilities had workers manual. Majority of the patients (80%), reported that they had no delay in diagnosis, that is their diagnosis was reached within two days while 20%, had a delay of one week to one month mainly due to referral to LGTBLS. 30% of the patients stated that they waited for more than two hours, to get their drugs. Similarly, in one of the FGDs some participants corroborated that because of long waiting and uncertainty in meeting health workers in the PHC clinics they prefer going to a chemist or a hospital. Therefore, the quality of care may be important contributory factor to case low case finding in this communities.
3.2 Factors influencing leprosy case findings from literature review

3.2.1 Methodology

3.2.1.1 Search Strategy:
The databases were searched using the search terms listed in Box 3.1. Following a search, returned results, were selected after reading the title of the paper, thereafter, their abstracts were read to select articles for full review.

Box 3.1: Search terms, data bases and other sources

<table>
<thead>
<tr>
<th>Search Terms: “leprosy” AND:</th>
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<tr>
<th>Databases: Pubmed, Science Direct, Embase and Google scholar</th>
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| Other sources: Websites: WHO, ILEP, TLMI and UNFPA. KIT, infolep and VU catalogues. Reports from NTBLCP, GSTBLCP, NLR GSTBLCP and lecture note from ICHD. |

3.2.2 Findings on factors influencing Case Detection

3.2.2.1 Magnitude of Leprosy in the Community
The burden of leprosy within a community is measured by its incidence which is the rate of occurrence of new cases during a defined period usually one year. Leprosy incidence is practically difficult to measure due to its long incubation (2 to 10 ten years) and the lack of tools to study the transmission levels in the community (22). Also the exact onset of leprosy is difficult to determine because of its insidious onset. Hence, CDR and PR are use as proxy indicators of burden in the community, although they are affected by many operational factors (23), such as intensity of case finding activities.
Various factors are shown to influence the incidence of leprosy within a community which include; duration and closeness of contact, presence and number of reservoirs of infection, the number of susceptible contacts, infectiousness of M.lepra. and genetic and/or environmental factors. The duration of contact is in turn influenced by early detection and treatment, self cure and to lesser extent by migration or death (23;24). Contact between infected persons and healthy persons lead to leprosy transmission. It is generally believed that leprosy transmission occurs via nasal droplets, although prolonged close contact as well as transmission through other indirect means are proposed (25), but the exact mode of transmission of leprosy is still unknown. However, most people don’t develop the disease even if they are infected due to natural immunity (24). Genetic defect in cell-mediated immunity is suggested to causes susceptibility to the disease and that could be reason for clustering nature of leprosy among some families in the populations (26). Untreated MB cases are the main sources of leprosy infection in the community, infection rates among contacts of MB varied from 6.2 per 1000 per year to 55.8 per 1000 per year from various incidence studies (27;28). Another cohort study from Malawi reported 5 to 8 times (RR 4.9, 95% CI: 2-10.3) increased risk among household contacts of MB patients (29). Neighbours and other social contacts of leprosy patients especially MB are also at increased risks compared to non contacts (30). Although, little evidence shows high risk among social contacts but involving them in contact examination could contribute to increase case detection. Shetty VP et al. concluded from their study that high proportion of MB cases and children among new cases is indicative for a high number of undetected cases in the community (31).

The age and sex of the individual have been identified as a risk factors contributing to increase susceptibility to leprosy, however contradictory findings have been reported by different studies. For instance, one study reported males are 22 times (CI: 1.2-4.1) higher risk than females (32) while another did not show significant sex difference in the risk ( RR for men 0.8 CI:0.7-0.96 ) (33). In addition, children (5-15 years) have been reported to have a higher risk of contracting leprosy than adults (33). Further, infection with mycobacterium has been cited to confer some protection against leprosy infection (34). Household size is also associated with increased risk of leprosy incidence, household with more than 7 members are 3 times (CI: 1.3-7.3) more likely to developing leprosy than house hold with less than 4 members (32). This implies that individual characteristics could be important factors influencing in leprosy incidence within the community.
Incidence of leprosy is also found to be related to environmental and socioeconomic determinants, which make exposure to M.lepra. sufficient to cause leprosy. This was supported by ecological studies from Malawi, India and Brazil, which reported that the risk of leprosy decreased by increasing education level and housing quality, settlement, malnutrition, population and growth (33;35;36). However, their role in the transmission of leprosy is considered vague due to insufficient evidence. BCG vaccination has proven to have a protective effect against leprosy an average protection of 26 % ( 95% CI: 14–37%) and the protection increases with additional dose (37). There is low (22% national 60%) BCG vaccination coverage in Gombe state (84). Equally, dapsone and rifampicin when use as chemoprophylaxis are shown to prevent leprosy. Dapsone was shown to have efficacy of about 60% and even higher among household contacts of MB, however its major disadvantages are, high rate of resistance and need to be administered for long time (38). Rifampicin was reported to reduce leprosy incidence among contacts of index cases in the first two years of diagnosis by 0.57 (95% CI: 0.33 to 0.72) and it has the advantage of shorter duration of administration (39). Hence rifampicin could be use as protective measures against leprosy in the future.

3.2.2.2 Knowledge and awareness of leprosy patients and the community on leprosy

Only proportion of the people with leprosy symptoms in the community would have the knowledge and awareness about leprosy based on the adapted model. The number is usually determine by the prevailing belief, myth and misconceptions about leprosy within the population which are perpetrated by traditional healers for economic gain, the level of health promotion activities in the area and individuals factors such as education level (15;19). Alubo et al. in their study Northern Nigeria reported poor awareness regarding leprosy in the community; people believed leprosy is due to breaking of food taboo like eating goat meat or fish, leprosy incurable and by supernatural (16). Other studies attributed leprosy to evil spirit, witchcraft, violation of religious or social norms, poor hygiene, a sexually transmitted disease, back magic or divine punishment from God (19;40;41). People with this knowledge and beliefs would most likely seek care from traditional healers and that will affect case finding. However, compared to general population family members or other associate of ex patient are reported to have better knowledge and awareness on leprosy (42). Knowledge and awareness about leprosy is shown to be associated with literacy level, illiterates had poor leprosy compared to literate (43).
Besides awareness about the disease itself, it is equally important to know where leprosy services can be accessed within the community, study in Nigeria found low awareness among community members regarding leprosy service location and people were reported seeking care at distance clinics despite existence of services in the nearby PHC clinics due to lack of awareness (44). Similarly, poor knowledge and awareness among leprosy patients is associated with delayed which increases the risk of nerve impairment, deformity and stigma, 71% of leprosy patients exhibited poor perception about causation and prevention of deformity from study in Nepal (45). Early manifestation of leprosy with skin patches or weakness and loss of sensitivity of limbs require sound knowledge for early recognition by suspects. The symptoms resemble common illnesses like ringworm that may be regarded harmless and then ignore or even seek a different care(16), Kolappan et al. also pointed out the difficulty in recognizing skin patch even among professional (46), therefore, inability community members to recognize early symptoms of leprosy due low knowledge could lead to low case finding. Health promotion activities about leprosy through community mobilization activities, media and materials, drama and the health education activities by health workers in the community such as outreach programs are reported to have influence on case detection (47). The messages aired through the media are meant to counteract false beliefs and raised awareness about leprosy in the community (48), identifying and reflecting local belief in the messages would improve its effectiveness (48). However, the used of posters, leaflet along are found to be less effective in improving community knowledge and awareness (49). Higher knowledge and awareness was demonstrated among community members with health education interventions compared to community without intervention (13). Non-involvement of religious leaders, community leaders and traditional healers in health education activities was shown to make health education less effective (48). Ebenson et al. in Nigeria, found increased in community awareness and participation following LEC activities in that area and subsequently increased early case finding (51). Low level of education, rural residence, older age, female gender and Moslem religion were found to be associated with poor knowledge and awareness as well as poor attitudes in the community from study in Tanzania (52).
3.2.2.3 Motivation to Consult Health services

Among those patients aware of leprosy symptoms in the community, only a proportion would progress to seek care at health facility, in addition to the knowledge and awareness, this is also influence by various individual, behavioural, socio cultural, economic factors and health services related factors (36). Cultural beliefs and norms of the community are shown to influence health-seeking behaviour of leprosy in the community (53). Self medication using drugs, creams and herbs from informal sector such as chemist, drug vendors and traditional healers were common and first health care behaviour found from study in Northern Nigeria (54). Most patients delayed for average duration of 1-3 years before reaching health facilities (54).

Mode of presentation of leprosy has been shown to influence health seeking behaviour, people with symptoms of lepra reaction due it association with fever and pains make them to seek care early and first at health facility (14). Health seeking behaviour is shown to correlate with educational level and socioeconomic variables of the individual such as his/her of level income, illiterates due lack of access to health education materials are shown to delay seeking leprosy services care from study in India (36).

3.2.2.3.1 Stigma

Leprosy stigma, shame and fear of rejection were the major causes of delayed and low case finding reported from the study by Ebenso et al in Nigeria (40). Families with deformed leprosy patient were shown to experience stigmatization by members of the society refer to as “courtesy stigma” as such community member don’t not marry from families of leprosy patients (55). Hence leprosy is often kept as a secret thereby leading to delay presentation or non-reporting (56). Another study in Nigeria found that due to fear of stigma some patients prefer to attend clinics in different location far from their communities (54), hence for those that can not afford travel cost would either not seek care or seek alternative care. Cured deformed leprosy patients are reported to be more stigmatised and discriminated by the community compared to non deformed patients because people belief they are highly contagious (57). Patients are shown to experience difficulties in getting employment or force out of their jobs, as such patients hide their diagnosis in order to avoid these consequences (41). On the contrary, stigma was showed to motivate early seeking of care among women from study in Nigeria, because women fear disfigurement associated with delayed which lead to serious social consequence on them such as divorce and rejection by the families (16).
3.2.2.3.2 Gender

Gender inequality is shown to influence leprosy case finding and early reporting for treatment, more men registered for leprosy treatment than women from most program reports and studies (2;3;16). Although, it has been suggested that women are less susceptible to leprosy than men but there may be hidden leprosy cases among women in the community. This ia due to various socio cultural and economic barriers face by women that prevent them from accessing care (15;16,58). However, there are studies in Nigeria that reported equal number or even more women than men reporting for treatment, despite men suffered from more severe form (MB) of leprosy (16;54). Other factors found to influence women health seeking behaviour include, their low status in the community, low level of education, limited mobility, religious and cultural tradition (54;58).Decision about where and when they seek care often lies in the hands of their husbands, hence leading to low case finding. A study in Nigeria show that women have poor access to information on leprosy as most of the health education activities are not gender sensitive (51). Study in Botswana, reported higher delayed among women leprosy patients than their men counterparts due their lower knowledge and awareness (59). Most health facilities staffed by male leprosy workers females with leprosy symptoms find it difficult to go there for examination leading to hidden cases among females thereby affecting case finding (60).

3.2.2.3.3 Alternative treatment

Traditional healers and other health providers such as drug sellers contribute to delayed diagnosis of leprosy and low case finding, as they are usually the first contact (16;40). This is because; they are usually readily available, cheap, and culturally accepted and often provide privacy to leprosy patients (60). Studies in Nigeria and, Ethiopia reported that most patients delayed treatment because they had consulted traditional healers and other alternative care as such leading to high deformity among newly detected patients (54;59). The studies found that beliefs and misconceptions attached to leprosy such as, cause by supernatural forces or witchcraft make people to consult traditional healers believing that cure can only be obtained through that means. However, introduction of MDT has changed most peoples’ beliefs and perception about leprosy has changed. Most leprosy patients are now cured with less number of deformed patients, hence people consider traditional treatment of leprosy less effective (60). Study in Nigeria reported that, if traditional healers are trained and encouraged can suspect and refer leprosy cases (54).
3.2.2.3.4 Health Services Barriers

Health seeking behaviour could be influenced by previous experiences with seeking help in health services; Person with leprosy symptoms is less likely to consult health services when he or she had bad experience with the facility (62). Perceptions regarding access and quality of the services also influence motivation to seek care, when individual perceived the poor quality or distance of health services will be less motivated to go there for treatment even if the clinic is within his/her reach (63). Provision of accessible and good quality leprosy services are shown to enhanced early case finding, good patient’s compliance (16). Integration of leprosy to general health has improved the service availability although, its impact on case detection is yet to be determine but it is apparently clear that, it has made leprosy services more accessible to users (64). Geographical access was shown to be a barrier to early health seeking which could be due to uneven distribution of health facilities, bad roads or difficult to reach areas like mountain or rivers (65), lack of available transport in some rural areas is another factor that could make access to care difficult (65). Although, leprosy care is given free of charge but travel cost and opportunity cost are identified a major barriers to accessing leprosy services (16;54). Long distance between patients’ homes and clinics and the cost of repeated visits to health clinics make the travel cost high thereby discouraging people from visiting health facilities and could result in impoverished of the household (62). This is shown to be worse for the poor, women and rural communities. Poor access is also associated with patients’ delay and poor compliance (62). Perceived cost of care is also found to contribute to the delay or non-reporting to leprosy care in Nigeria (54). Patient’s motivation is also influence by the culture and norms of the society that is its acceptability, for instance women due to cultural and religious restriction were shown to stop attending clinics where only male health workers were working (66). Culture, education, language differences between health provider and community members were also reported to affect acceptability of leprosy services which would ultimately affect case finding (65).

The motivation of individual to consult health services can be influenced by the quality of care which can be viewed in terms of structure, process and outcome as proposed by Donabedian⁴ (67). Structural factors such as state facilities (dilapidated), staff numbers in relation to workload, their qualification and the way services are organized, the convenience of the services such as clinic opening hours, appointment systems and waiting time. Others include;

⁴ 1980s, Avedis Donabedian created a framework for measuring quality of Health care.
examination procedure, availability of drugs, recording materials, staff attitude, interpersonal relations, for instance how health education is deliver to patients. (66). These factors could influence people’s decision to seek care or not, thereby affecting case finding. Similarly lack of privacy in public health facilities was reported as one of the barriers to utilisation of public health services as such people visit private health facilities which provide privacy(63,65).

3.2.2.4 Patient identified as suspect and correctly diagnosed in Health facilities

Although, in piot model the two (identify patient as suspect and correct diagnosis) are recognised as distinct steps, in reality the line of separation is very thin especially in the case of leprosy. Therefore, for more clarity the two are discussed together. In addition most distal factors that influence the steps are common. Only proportion of people with symptoms of leprosy that presented to health facilities will be suspected and subsequently diagnosed as leprosy and that depend on the knowledge, skills and motivation health worker as well as enabling environment (18). Identification and diagnosis of leprosy in resource limited settings like Nigeria, is based on history of skin patch identified by its insensitivity using cotton wool test and nerve enlargement detected by palpation (68). Studies in different parts of Nigeria reported that, poor knowledge and awareness of leprosy among health workers could lead to misdiagnosis and prescription of different treatment, hence ultimately resulting in delayed treatment (17;34). Study in Brazil, identified lack of knowledge and awareness of health workers as one of the obstacle to the early diagnosis of leprosy (70). Similar studies show that, lack of community awareness activities through health education and community outreaches by health workers contribute to low case findings (54;69). Rao et al. show that, training increased high index of suspicion of health workers leading increase in case detection (71), however, field worker after initial training were found to be missing up to 35% leprosy of cases, mostly those with early manifestations, but after gaining experience and on-job training during supervision the value dropped down to about 20% (72). Therefore, lack of supportive supervision could also result in low case finding as skills acquired during training might not be sufficient and therefore require more emphasis during supervision.
The use of good-quality leprosy poster and leaflets at PHC clinics was shown to maintained and improved health workers’ knowledge and awareness on leprosy (73). Availability of Standard operating procedures (SOPs), guidelines, diagnostic charts in the clinic as a reference is demonstrated to increase knowledge and awareness of health workers (74). Where they are not available could affect the skills of GHW in leprosy diagnosis leading to low case finding. The skills of health workers in conducting cotton wool examination, voluntary muscle testing (VMT) and sensitivity testing (ST), classification of leprosy and recording and reporting are important in making correct diagnosis of leprosy (75). GHW without skills in carry out these procedures is less likely to make leprosy diagnosis and report cases. Conductive atmosphere with good illumination and privacy are essential for making correct leprosy diagnosis (75). Similarly, proper patient exposure was reported as one of the crucial step for patients’ examination and correct diagnosis, otherwise, skin lesions can easily be missed leading to wrong diagnosis or miss classification (75). Although, diagnosis of leprosy based on clinical grounds is difficult even in experience hands because of its subjectivity leading to inter observer variation. Eliciting and Interpretation of nerve enlargement is shown to be difficult and subjective. This because nerve enlargement could be normal findings in farmers or people that use their limbs for strenuous activity and can be caused by other forms of neuropathies (76;77), hence this may affect the ability of a fairly trained GHcw to make reliable diagnosis of leprosy.

The knowledge of GHW is also influenced by level of leprosy cases in the community; staff will be less familiar when the prevalence is low. A study in Madagascar found high rate of false-positives among registered cases in low endemic areas and attributed that to staff incompetence due to lack of familiarity with sign and symptoms of leprosy (78).

The extent of basic training on TB and leprosy by health workers determined the quality and sustainability of integrated leprosy services (18), in most developing countries leprosy have been incorporated in training curriculum of physicians, nurses and community health officers however, in Nigeria leprosy is in the curriculum of doctors and nurses but not in most curriculum of schools of community workers, even where it is included has never been updated. Lack of pre-service training of GHW on leprosy could affect their knowledge and attitude to leprosy while on service (18).
Inadequate communication skills and poor attitude of GHW were reported as a barrier to TB and leprosy case finding and poor patients’ compliance in Madagascar (79). Poor attitude and fear of GHW towards leprosy and patients are shown to have negative effect on integration process, thereby affecting case detection and case management (81). Negative attitude expressed by staff is because of fear of infection and stigma associated with leprosy and leprosy patients and mainly attributed to lack knowledge about leprosy (81). Shortage of trained staff could harm the provision quality leprosy care thereby affecting case finding, the shortage is worse with female workers and in rural population (71). Lack of sufficient staff couple with multiple responsibilities in integrated settings and high work load especially in rural facilities is associated with of poor diagnosis and poor quality of TB and leprosy services (71). This occurs due to failure to recruit and retain staff, uneven staff distribution or as result high staff attrition. Low motivation health worker is shown to contribute to poor performance, thereby affect the quality of services and case detection. Some of the factors found to have effect on staff motivation include inadequate remunerations, lack of career structure, poor working condition, lack of materials and supplies (80). In Nigeria, most health workers attend training for the financial incentives due to poor remuneration which lead to poor performance after training (17). Staff absenteeism due to continuing participation in training from various programmes has been shown to affect delivering of health services in Nigeria. Likewise, GHWs residing at distance away from health facilities where they are working were reported to experience problem with delivering of leprosy services such as conducting of contact tracing and community education(16).

**Programme Funding**

Funding influences implementation of programme activities, hence absence of fund can affect case detection activities leading to low case finding. In Nigeria with declined number leprosy cases, it is now low on the political agenda attracting low funding from Government, most activities are funded by NGOs which may not be sufficient to implement desired activities, hence the need to advocate to key decision makers to pay more attention leprosy control activities.
CHAPTER 4: DISCUSSION AND CRITICAL ANALYSIS OF THE STUDY

This chapter discusses the findings of this study, and critically analyses the strengths, weaknesses and limitations of HSR study design and methodology.

4.1 Discussion and analysis of Study findings

4.1.1 Burden of leprosy in the Community

The findings of this study shows that there is high leprosy reservoir in the community. The majority of the patients that were interviewed had MB leprosy which is in conformity with the data that was recorded in the programme data. Studies have shown that patients with MB leprosy are the most effective transmitters of leprosy in the community(27,28). On average the respondents delayed between one to three years, although this may be an underestimate as it is difficult for them to recall accurately. This is consistent with findings from study in Nigeria, Ethiopia and India (16;62;31), has conforms to the high (92%) disability II found among patients. This has implications to Gombe State as the high reservoir of patients with MB is increasing the burden of leprosy within the community. Contact examination of MB a recommended strategy The reports indicate disparities in contact examination in the two regions While the health workers in the Southern LGS are reported to perform contact tracing, the situation is a complete opposite in Northern LGAs where health worker are not empowered by the LGTBL to carry out contact examination of MB patients (3). This could help account for the low case detection in the Northern LGAs. Study shows that BCG vaccination offers protection against infection by leprosy bacilli (37). Therefore, when BCG immunisation rates are higher, then future generation are protected against infection, thus bringing reducing the burden due to leprosy in the community. However, BCG vaccination rate in Gombe State is far too low compared to the national rates, considering that national coverage rates are lower than the WHO recommendation. The implication of this finding is that if immunisation (BCG vaccination) coverage and leprosy case finding are improved this will act synergistically to control leprosy. The social structure of in Gombe State may contribute to ease of transmitting leprosy. This is because many families are extended, therefore most family units tends to be crowded particularly in the rural areas.
4.1.2 Knowledge and awareness of leprosy Patients and the  
community on leprosy

Community Knowledge and awareness about leprosy in important  
factor influencing early case finding and adequate treatment (17). Our  
study found myths and misconception are present amongst community  
members. Many did not know where to seek health care when they  
suspected they had leprosy. In addition, most community members  
did not know the early signs of leprosy. It is possible that when the  
first signs of leprosy show up, most patients pass it off as a simple  
skin disease and do not seek health care. Even, if the suspected that  
the skin lesion may be a sign of leprosy, they still do not know where  
to seek health. This is may account for the low case finding in the  
area. This is supported by the knowledge level of patients before they  
were diagnosed as they could only mention the late signs of leprosy.  
Similar findings have been reported in studies conducted in Nigeria  
(13;16;54). Despite poor knowledge about leprosy, study findings  
show that many community members believed that leprosy is curable,  
through modern medicine. This means that with improvements in  
knowledge, many people who suspect leprosy are more likely going to  
seek care at health facility. Women had lower knowledge levels  
compared to men. This finding has also been reported in other studies  
(15,16). The disparity in knowledge levels could be expained by the  
low access to information by women. Women generally rely on their  
husbands for information, and the culture imposes certain restrictions  
to women. For instance, women are not allowed to go out of their  
households unless when they are sick or important ocassion. Thus,  
the second major source of information is the health centres.  
Therefore, if health facilities do not conduct health education, women’s  
knowledge on leprosy will remain low. Varkevisser et al. also reported  
similar findings in Plateau State of Nigeria (16). The state TBL  
program is weak when it comes to targeting women, this is yet  
another contributory factor as studies have shown that gender  
targeting intervention improves case finding. The level of education  
has been associated with the increased knowledge about leprosy (40).  
In Gombe State, there is low level of education, further, literacy rates  
are even lower amongst women. There is also difference in general  
literacy levels in the two regions of the state, with the Northern LGA  
having lower rates than the Southern LGAs. This will contribute to their  
low knowledge and low case detection in the region.

The major communicating channel in Northern Gombe is radio,  
Hausa/Fulani tribes are known with attachment to their radio even in  
the farms while in the South is mainly television and other printed  
materials. The major channel the programme uses for information  
dissemination is radio. However, about half the respondents reported
that they had not received information about leprosy from any of the channel that are used in the TBL program namely: radio, health workers, and the activities of ACSM committee. Even those that reported ever receiving information about leprosy from any of these channels could not give correct information about leprosy or remember the messages. This could indicate that the information is either not effective or adequate. Mutatkar et al observed similar findings in their review of health education in which inaccurate knowledge was found among both community members and patients and attributed that to ineffectiveness and inadequacy of the message (85). Studies show that media campaign should be context and culture appropriate and developed with the full involvement of the community (86). However, this has not been done in Gombe State. In addition, the jingles are only done once per day and lasts for one minute. There are other factors that could hamper the effectiveness of the radio campaigns. First, the timing when the campaign is aired could be inappropriate. Two, there is power ration currently ongoing in Gombe State, could be that when the campaign is aired, most households are out of electricity and miss the message. Third, language barriers, Gombe State has over five major languages but campaigns are only delivered in one language. The program established a committee, but their activities are funded by the local government, which has never provided funding, as such few if any committee is functional. Thus, this initiative is not contributing to the improvement of knowledge awareness as originally intended.

4.1.3 Motivation to Consult Health Services

The findings from this study shows that, the first action taken by most patients when they first noticed leprosy symptoms was self medication from alternative medicines like traditional healers or chemist. Kumaressan and Magaru noted that in areas where leprosy awareness is low, the influence of alternative medices on case finding may be high (59).

In this study, the main reasons given by the respondents to explain their visit to traditional practitioners were: that it was cheaper, accessible, convenience. It is likely that they were not open about other reasons behind visiting traditional practitioners possibly due to interviewer bias. From my personal experience, leprosy patients take traditional concoctions with the belief that it is going to cure the disease. This is consistent with the findings reported in other studies that were conducted in Northern Nigeria, that the community has similar culture and religion with the study population in the current
study (16;54;87). These studies report that they believe that leprosy is from God and so they tend to accept patients who are suffering from leprosy, while the belief amongst Christians is that, contracting leprosy is punishment for sins committed. These beliefs, affect health seeking behaviour of the of leprosy suspects (89). This is contrary to the findings of this study, because in Northern LGA, the majority of residents are Muslim, but it appears that their health seeking behaviour and attitude towards leprosy do not support the findings of these studies. Religion may not be an important factor but confounded by another variable, hence there may be other underlying factors behind health seeking behaviour. Furthermore, there are many chemists and other drug sellers across the state especially in rural areas and northern region. Hence, the programme needs to collaborate with these providers, so that can refer cases to MDT facilities.

The findings show that stigma against leprosy and patients is high in the community. Most patients conceal their diagnosis either to themselves or to close family members and did not want community to know, this is common among the non deformed patients as they cannot be early identified. This affects other aspects of socio-economic aspects for example, people will not marry or buy products sold by families that had leprosy patients. Because of these fears of people who suspect they had leprosy, may not seek health care but hide their symptoms resulting to low case finding.

Although, gender was not exhaustibly evaluated in our primary study, it is an important barrier to case finding considering the peoples’ culture and religion in the area. In Northern LGA, most women rely on their husbands for their livelihood, while in the Southern LGA women are engage in trading , farming and trading as a result they are not heavily dependent of their husband which may influence their health seeking behaviour as well. In addition, the culture in Northern LGA men and women are reluctant to expose their bodies to opposite sex. This affects the diagnosis of leprosy. However, in the Southern LGA this is not a problem.

MDT facilities in Gombe state are sparsely distributed as they were not established based on population size or distance away from community (see annex 4). It is likely that many patients have problems accessing leprosy care in the state. But, this study respondents reported that they did not have a problem with access either due to cost or distance. However, this finding may be biased, because it is likely that the participants who were interviewed in this study were residing near health facilities. But from experience, I know that access is an
important barrier to seeking health care in Gombe state due uneven distribution of facilities, bad roads, cost or lack of transportation. Perceived cost could also be an important barrier.

From our study, long waiting time, lack of privacy and absence of staff were indicated as a barrier. In contrast, most patients expressed satisfaction with the privacy, waiting time and staff attitude, however, if we had used observation or exit interview technique we could have confirmed the contribution of quality of care. From experience, the quality of PHC services in Gombe state is poor; for instance, most facilities don’t have screens, equipments, supplies and shortage of staff in rural areas lead to long waiting time. Therefore, quality of care is an important barrier.

4.1.4 Patient identified as Suspect and correctly diagnosed in Health facilities

The findings from our study shows that the skills of the GHW in diagnising leprosy is not adequate. Even though the leprosy program has been training GHW, 40% reported that they had no previous training on leprosy. This could be attributed to staff attrition, it is possible that the GHW that are getting transferred in MOH programs are the ones who have already recieved training from the TBL program. The new personnel who are transferred into the MDT clinics may not be skilled to make a diagnosis on leprosy. It is likely that participants who are not working in the target clinic attend the training offered by TBL because of the financial incentives that are associated with training workshops (per diem). The findings show that some of the GHWs were trained more than five years ago and have not had refresher course since then. This could be compounded by the absence of supportive supervision which could have detected any areas of weaknesses.

Further, only 2 facilities out of 27 were using guidelines and workers manual that aid the diagnosis of leprosy and TB. This has implications in that diagnosis of leprosy, will be difficult for the health workers, hence affecting case finding negatively. Leprosy is not incorporated within the curriculum of training of GHWs in Gombe State.and the three day training that is offered by the programme is based on the premise that the trainee has already some background knowledge and skills on leprosy aquired during pre-service training. As such the in-service that is offered may not be sufficient for this GHWs to be able to make leprosy diagnosis.
Shortage of staff and uneven distribution were noted in this study. This is because most GHW don’t want to work rural areas and there are no incentives to attract and retain GHWs in rural areas. As a result, the GHWs that are working in MDT facilities cope with large workloads. This affects the quality of services that they deliver and also their motivation for instance, they have less time to examine patient properly, give adequate health education, contact examination or community outreach activities as such leading to low case finding. It is worth noting that the ratio of heath workers to population is more in the Southern LGAS as compared to the Northern LGAS (see Table 4.2). however, MDT assistants with vast experience in leprosy who were drop out of the programme with the start of integration are available particulary in the northern LGAs .therefore the staff shortage can be partly overcome by doing task shifting through involving them in refferal or awareness creation activities. The current study shows that more than half of the GHWs were comfortable and were in support of the integration of leprosy services into general health services. But this may not be reflect the real situation on the ground. From our experience we found out that GHWs are not really interested in the leprosy control program. In Nigeria, GHWs in the rural areas area allowed to sell drugs and keep the proceeds from such sales as form of incentives to attract them to work in the rural areas. Thus they do not feel that they will benefit from being involved in leprosy programs as drugs for leprosy are not for sale. If incentives is given to the GHWs, this could motivate them to get interested in taking full part in leprosy programs. The LGTBLS supervisors may be lacking in skills in general. However, the Southern supervisors are more experienced in leprosy work as compared to the Northern LGAs. This could be a contributory factor to the low skills of GHWs in diagnosis of leprosy.
## 4.2 Findings from Northern and Southern LGAs of Gombe State

<table>
<thead>
<tr>
<th>Background variables</th>
<th>Northern LGAs</th>
<th>Southern LGAs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Housing condition/ overcrowding</td>
<td>Compound houses in extended family settings and crowded</td>
<td>more nuclear family settings, less crowded</td>
</tr>
<tr>
<td>Communication Channel</td>
<td>Radio</td>
<td>TV, posters</td>
</tr>
<tr>
<td>Socioeconomic status (SEC)</td>
<td>low</td>
<td>Low but relatively higher than the north</td>
</tr>
<tr>
<td>Geography</td>
<td>Flat lands / Semi arid</td>
<td>Mountainous</td>
</tr>
</tbody>
</table>

### Demand side

<table>
<thead>
<tr>
<th></th>
<th>Northern LGAs</th>
<th>Southern LGAs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Educational level</td>
<td>low</td>
<td>Low but higher than the north</td>
</tr>
<tr>
<td>Gender</td>
<td>Women are restricted</td>
<td>Women are not restricted</td>
</tr>
<tr>
<td>Religious</td>
<td>Predominantly Muslims</td>
<td>Majority Christians</td>
</tr>
</tbody>
</table>

### Supply side

<table>
<thead>
<tr>
<th></th>
<th>Northern LGAs</th>
<th>Southern LGAs</th>
</tr>
</thead>
<tbody>
<tr>
<td>PHC Health facilities</td>
<td>157 (35%)</td>
<td>293 (65%)</td>
</tr>
<tr>
<td>Ratio of Health facilities to population</td>
<td>1:7,324</td>
<td>1:4,573</td>
</tr>
<tr>
<td>MDT facilities</td>
<td>35 (36%)</td>
<td>62 (64%)</td>
</tr>
<tr>
<td>Ratio of MDT to population</td>
<td>1:32,857</td>
<td>1:21,612</td>
</tr>
<tr>
<td>Health worker in PHC facilities</td>
<td>423 (39%)</td>
<td>651 (61%)</td>
</tr>
<tr>
<td>Ratio of health worker to population</td>
<td>1.929166667</td>
<td>1:2,000</td>
</tr>
<tr>
<td>Number of trained health workers on leprosy</td>
<td>137</td>
<td>139</td>
</tr>
</tbody>
</table>
Source: Authors compilation (GSTBLCP, 2006)

4.3 Critical analysis of Study Design and Methodology

This section critically analyses the primary study; its strength, weaknesses, and limitation and how it could have been done better.

4.3.1 General information

The Sex distribution of the respondents in the study favoured males because convenient sampling employed in the study. Lack of adequate representation of females’ leprosy patients might affect the overall outcome of the study. Like wise male community members are over represented in the sample, this may affect the responses regarding gender and socioeconomic factors that hinder the uptake of leprosy services as it might be different between males and females’. Equally more males GHWs were interview than their female counterpart so issues related to female workers may be under represented. The educational level of respondents was not included, we could have relate it to knowledge and awareness as studies show that, beliefs and stigma attached to leprosy are shown to be enhanced by low education, gender, religion and rural residence (52). The fact that 60% of the patients were detected through active case finding shows the low passive finding in the area.

4.3.2 Study Designs and Study area

The study is the first step to explore the barriers to case finding in Gombe state, it provided useful information for evidence based interventions for the improvement of case finding in the state. It started with good plan and research protocol. This has guided the implementation of activities during the study, although the time table was not strictly adhered to and was not developed with participation of stakeholders particularly community members. If the study were conducted with relevant stakeholders it would have increase its ownership, thus implementation of recommendations would have been better.

The study focused on 5 of the 11 LGAs in Gombe with assumption that, they are the areas with the problem. The study would have involved the southern LGAs, so that comparison can be made, lessons can be learnt on how case finding can be improved. Also, literature review was not done before starting the study, thus making the study less focused and omitting important variables such as educational
levels. Literature review would help to give insight to the problem, what is already known and where there is a gap which the study will attempt to contribute into the knowledge about the topic. Some key informants such as traditional healers, alternative health providers (traditional, chemist, private), and LGTBLS and PHC coordinators of the LGAs were left out in the study. Their opinion and suggestions would have enriched our findings and help in the implementation of recommendations. The involvement of ex patients in the study could bring about recall bias as they may not remember most of issues related to research questions especially related to health services or knowledge thus leading to wrong conclusion.

4.3.3 Study type

The study was cross sectional description, however since little is known about the cause of the problem in the state and by looking at the research questions, it would have been more appropriate if exploratory qualitative study was conducted, that would help to explore the situation better and further study can then follow.

4.3.4 Sampling

The convenient sampling techniques used in this study by involving only MDT clinics with patients, made us to missed information from MDT clinics without patients which would have helped us in answering our research question (low CDR), that is why they don’t have patients. Extreme case sampling would have been used which will give us the opportunity to look at both high and low reporting areas. The recruitment was also faulty and was associated with a lot of biases such as selection and information, thereby decreasing the quality of our study. This is because LGTBLS who manage the program at the LGA were part of the data collectors and they were allowed to recruit participants and health facilities for the study. Similarly, selection of participants for FGD and community members was done without any standard procedure by the community leaders and LGTBLS. The participants for FGD should have been homogenous groups (socio-economic status, age, education level) of both male and females but our study used only men in the FGD which heterogeneous group where some participants were not free to talk. FGD should have been conducted with health workers; more issues would have been discussed and reduced the chances of interviewer bias.
4.3.5 Research Objectives, Variables and Instruments

The objectives was not well formulated because it was not based on problem analysis, hence variables were poorly selected. Although, many important variables related to case detection were included but due to lack of proper problem analysis some important variables were missed such as education levels and gender issues, income level etc.

Questioners and interview guide were used in the study and were pretested prior to study which helped in improving the clarity of questions and interview techniques; however tools should have been translated to local language by expert, this would the ease of administration and make it uniform. The questioners contained names, dates signature of the interview and quality check box that made clarification easier.

4.3.6 Data Collection techniques

Various techniques were employed during the study such as interview, FGDs, records checking and triangulations was done, however other techniques such as observation, exit interview, projectile techniques should have improve the quality of the of our information. Research assistants were trained on the techniques which had improved the quality of the study. Some probing questions were not probed e.g. we asked about referral after they answer, we did not explore further for challenges that may affect case finding and some questions were not very clear and valuable information could have been missed.

Cultural norms of the communities were followed through involvement traditional leaders. Verbal consents were obtained from respondents prior to their participation, although ethical approval was not obtained and privacy was not adequately observed during data collection. The data collection was wrongly timed because it was done at peaked of raining season where respondents who mostly farmers are hardly at home. Data was cross checked by one person from the team at home after data collection. This should been done in the field so that missing information could be immediately obtained and double checked by another person.

4.3.7 Data Analysis

This was done long after data collection. It would have been better it was done currently with data collection, so that areas requiring further information can be obtained. Conclusively, despite the observed pitfalls in this study, the findings would contribute to improvement of leprosy case finding in the state and indeed in other NLR supported states.
CHAPTER 5: Conclusion and Recommendations

5.1 Conclusion
Gombe state is one of the high leprosy endemic states in Nigeria with relatively stable PR and CDR over the years. There is low case finding in the Northern LGAs and poor indicators of leprosy (proportions of MB, Children and DGII among new cases) when compared to the Southern LGAs. This is because of low knowledge and awareness among community members. The communication campaigns are not disseminated frequently, and the content is not achieving the desired effect. Socio-cultural and economic factors influence community members and patients to consult traditional practitioners and/or chemists as their first line of action. Health workers in Northern LGAS lack the capacity to diagnose leprosy, this attributed to low motivation level and high workload. Referral system and supervision are weak.

5.2 Recommendations
Based on the above conclusions, the following recommendations are made to the relevant stakeholders

- There is need for prompt release of counterpart funding by state and LGAs for increase coverage of leprosy services in the state and LGAs.
- LGAs in northern part of the state should ensure even distribution of staff particularly females.
- Leprosy should Integrated into the curriculum of all Health Institutions.
- Technical support to states and LGAs programmes by NTBLCP should be strengthened.
- TOT training should be organize for some members of the state team and LGA Health workers in all NLR states on communication skills, so that GHW will be trained on that to facilitate and improve the quality of health education given to patients and the community.
- NLR should increase support for integration of leprosy to general health services with particular focus to endemic areas. This will improve access and improve early case finding and community awareness activities.
- Increase public awareness by conducting situation analysis of the traditional beliefs and knowledge in the whole state and use that to develop health education messages.
- Increase frequency of airing the message.
• The State programme together with LGA supervisors should identify alternative medicines providers, collaborate with them and sensitize them on the importance of referring cases.

• Knowledge and skills of GHW in Northern LGAs of Gombe state should be enhanced through retraining and intensified supervision by state and LGA supervisors.

• The bi-directional referral system should be strengthened in the state. The MDT assistants who are experience in leprosy can be employed to strengthen referral.

5.3 Suggestions for Further Research
Further research is required to further understand the influence of the factors that influence late reporting and client satisfaction. This will provide sound evidence to policy and decision makers on how best to design and roll out interventions.
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Annexes:
Annex 1: Gombe state Map with LGAs in the northern and southern region

Source: Authors compilation (GSTBLCP)
Annex 2: A dot-density map of Health facilities and MDT by LGAs in Gombe State

Source: Authors compilation (GSTBLCP)

Note: The location of the health facilities in the map do not correspond with the real location of the health facility
### Annex 3: Important health indicators in Gombe state

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population</td>
<td>2,506,938</td>
</tr>
<tr>
<td>Under five mortality</td>
<td>260/100,000 live birth (230 national)</td>
</tr>
<tr>
<td>Maternal Mortality rate</td>
<td>1,728/100,000 (800 national))</td>
</tr>
<tr>
<td>Infant mortality rate</td>
<td>103/1000 live birth (Northeast region)</td>
</tr>
<tr>
<td>No. of Health facilities</td>
<td>521</td>
</tr>
<tr>
<td>Nurse population ratio</td>
<td>1: 3,885 Gombe WHO 1:4</td>
</tr>
<tr>
<td>Doctor population ratio</td>
<td>1:18,424 Gombe WHO 1:10,000</td>
</tr>
<tr>
<td>HIV Prevalence</td>
<td>4.9% (4.0 national)</td>
</tr>
<tr>
<td>Illiteracy rate male</td>
<td>49.6% (25% female, 50% male)</td>
</tr>
<tr>
<td>Urban/Rural ratio</td>
<td>20:80</td>
</tr>
<tr>
<td>Child Immunization Coverage</td>
<td>60%</td>
</tr>
<tr>
<td>State life Expectancy at birth</td>
<td>47 years (National 48 years)</td>
</tr>
</tbody>
</table>

Source SMOH, 2006

### Annex 4. Distribution of Health Professionals in Gombe State

<table>
<thead>
<tr>
<th>Health Professionals</th>
<th>Primary</th>
<th>Secondary</th>
<th>Tertiary</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical Doctors</td>
<td>4 (NYSC)</td>
<td>42</td>
<td>65</td>
<td>111</td>
</tr>
<tr>
<td>Nurses/Midwives</td>
<td>82</td>
<td>657</td>
<td>150</td>
<td>889</td>
</tr>
<tr>
<td>Community Health Workers</td>
<td>792</td>
<td>600</td>
<td>72</td>
<td>1,464</td>
</tr>
<tr>
<td>Pharmacist</td>
<td>-</td>
<td>12</td>
<td>11</td>
<td>33</td>
</tr>
<tr>
<td>Laboratory staff</td>
<td>17</td>
<td>47</td>
<td>33</td>
<td>97</td>
</tr>
<tr>
<td>Professional Health Planners</td>
<td>-</td>
<td>3</td>
<td>-</td>
<td>3</td>
</tr>
</tbody>
</table>

**Total** 965 761 343 2597

Source SMOH, 2006
Annex 5: Organization of TB and leprosy services in Nigeria

<table>
<thead>
<tr>
<th>LEVELS</th>
<th>INSTITUTIONS</th>
<th>TBL STRUCTURES</th>
<th>RESPONSIBLE OFFICER</th>
</tr>
</thead>
<tbody>
<tr>
<td>Federal</td>
<td>Federal ministry, depart. of disease control (DC)</td>
<td>Central unit of TB and leprosy control</td>
<td>National coordinator reporting to the director disease control</td>
</tr>
<tr>
<td>Zonal x 6</td>
<td>WHO</td>
<td>TB Zonal professional officers and medical adviser of NLR and 2 other ILEP organisations</td>
<td>Reporting to WHO country office/NGO Head quarters</td>
</tr>
<tr>
<td>State x 36</td>
<td>State ministry, depart. of DC</td>
<td>State TBL unit</td>
<td>State TBL control officer reporting to director disease control and national</td>
</tr>
<tr>
<td>LGA x 774</td>
<td>Department of PHE</td>
<td>LGA TBL unit</td>
<td>LGA TBL supervisors reporting to PHE coordinators</td>
</tr>
<tr>
<td>Community</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: Authors compilation (NTBLCP)

Annex 6: Map of Nigeria showing States yet to reach a low endemic situation of leprosy as at the end of 2007

Source: NTBLCP, 2007
Annex 7: Leprosy Case detection rate (CDR) by LGAs in Gombe state in 2007

Source: Authors compilation (GSTBLCP)
Annex 8: Percentage of Children among new cases in Gombe State) by LGA (2005-2008)

Source: Authors compilation (GSTBLCP)
Annex 9: Percentage disability grade II among new cases in Gombe State) by LGA (2005-2008)

% DGII among new cases

- < 5%
- 5-10%
- 10%
- 15%

Source: Authors compilation (GSTBLCP)
Dear respondents,
We are conducting Research on leprosy; we wish to ask you some questions which will help us improve the services in this community. The interview will take some minutes. Also, I want to assure you that the information will be handled confidentially.
Thank you

Date of Interview___________________________________________________________
Name of Interviewer________________________________________________________
LGA of Interview___________________________________________________________

1.0 Demographic Data
1.1 Age (in years) (a) <15 (b) 15-24 (c) 25-34 (d) 35-44 (e) 45 and above
1.2 Sex (M/F)
1.3 Occupation
   a) Farming
   b) Civil servant
   C) Artisan
   (d) Others (specify)……………………………
1.4 Educational background
   (a) Non-formal education
   (b) Primary education
   (c) Tertiary education
   (d) Others (specify)
1.5 How long on treatment? ________________________

2.0 Knowledge before diagnosis?
2.1 How did this disease start (symptoms) ________________________________
2.2 What did you do when you discovered the symptoms?
2.3 Which treatment did you go for?
2.4 Did you ever try going to a clinic or hospital when you first notice the symptom? Yes No
   If yes give details of advice or treatment given?
2.5 Where were you diagnosed?

2.6 What made you go for diagnosis (probe symptoms? advise of whom)?______________
2.7 Do you know the disease you have?
2.8 What did you know about it before you were diagnosed?______________________
2.9 What is your source of information?________________________________________
2.10 Did you know any of your family member or community members having the disease?  
Yes  No  

3.0 Patients Education.  
3.1 Were you told what disease you are suffering from?  Yes  No  
3.2 Were you told about the importance of completing treatment?  Yes  No  
3.3 Were you told about the duration of treatment  Yes  No  
3.4 If yes, How long? ____________________________  
3.5 Were told about curability of the disease  Yes  No  
3.6 Were you told of how to take care of your self?  Yes  No  
3.7 Were you told on how to educate other members of community on early sign of leprosy  
Yes  No  
If yes, how many people did you educate?  
(a) <10  
(b) 10-20  
(c) 21-50  
(d) >50  

4.0 Knowledge on leprosy.  
4.1 What do you think causes leprosy?  
4.2 How is it transmitted?  
4.3 Do you think leprosy is curable  Yes  No  

5.0 Attitude of community  
5.1 Do your close neighbours know anything about the disease?  Yes  No  
5.2 If yes, how do they react to you?________________________________________________  
5.3 How do the community members or relatives behave to you when they release you have leprosy?___________________________________________________________  

6.0 Treatment  
6.1 Where are you at present taking treatment? _________________________________  
6.2 What is the distance to your home?  
< 1km  
1 – 5km  
6 – 10km  
>10 km  
6.3 How much do you spend on transportation?  
< ₦200  
₦200- ₦500  
₦500- ₦1000  
₦1,000  
6.4 Did you take your drug regularly?  Yes  No  
6.5 Do you have any difficulty in coming to clinic?  Yes  No  
6.6 What is your advice on how to improve early leprosy case finding?_______________
Dear respondents,

The Gombe State Tuberculosis and Leprosy Control Programme is conducting a study on certain key aspects of the programme. The main objective is to assess the performance of the programme in respect of its key functions of early case detection and treatment of leprosy. You are hereby requested to participate by responding to this questionnaire, which is aimed at providing us with the necessary information to improve the programme performance. We look forward to your cooperation. All information provided will be treated strictly as confidential and only for the purpose of this study. Your name is optional in this regard please.

Bio data

Name (optional)_______________________________________________________
Age_________(Years)    Sex   M [ ] F [ ]
Name of community ____________________LGA________________________
Occupation _________________________________________________

Community Knowledge about Leprosy

What is leprosy?_____________________________________________
What do you think causes leprosy
In your opinion what are the early symptoms of leprosy?
Skin patch with loss of sensation   [ ]
Headache               [ ]
Abdominal pain     [ ]
Tingling sensation                              [ ]
Loss of fingers                                    [ ]
Other, specify____________________________________________

4. Do you think leprosy can be cured?   Yes   [ ] No   [ ]
If yes how .................................................................................................................................

5. Are you aware of modern (Orthodox) way of treating leprosy?   Yes   [ ] No   [ ]
If yes, How .................................................................................................................................

6. Do you know where these services are rendered? Yes   [ ] No   [ ]

7. Did you receive any information on leprosy from the health worker in the community?
   Yes   [ ] No   [ ]
If yes, what information?....................................................................................................................

How often-  
2 weeks
1 month
3 months
6 months
1 year

8. Did you receive any information on leprosy through the local radio?   Yes   [ ] No   [ ]
If yes, what information .................................................................................................................................
9. Did you receive any information on leprosy through the local TV station?  Yes [ ]
   No [ ]
   If yes, what information
10. Do you receive any information on posters about leprosy?  Yes [ ]
    No [ ]
   If yes, what information

Health seeking behaviour and attitude
11. Where do you go when you notice changes in colour in your skin, weakness and loss of
    feeling?
   Traditional healer [ ]
   Chemist [ ]
   Hospital [ ]
   Other (specify)_______________________
12. How long will somebody wait before going to a health facility or see Doctor?
   Less than 6 months [ ]
   Between 6 month to one year [ ]
   More than one year [ ]
   Other, Specify___________________________________________________
13. Do you think people suffering from leprosy should hide their diseases?  Yes [ ]
    No [ ]
   Why?...........................................................................................................
14. Do you think that there people in the community with symptoms of leprosy hiding the
    disease
   Yes  [ ]
   No [ ]
   If yes why_____________________________________________________________
15. If your neighbour has leprosy will it affect your relationship with him?  Yes [ ]
    No [ ]
   Please Explain
16. In this community can a man with leprosy marry woman without leprosy or vice versa
    Yes [ ]
    No [ ]
   If yes or No, Please explain
17. In your opinion is health education on leprosy given to the community members adequate?
    Yes [ ]
    No [ ]
   If yes, by whom...........................................................................................
   What information is given?...........................................................................
18. Leprosy patients were seen by LGTBLS before and now by GCHW, in your opinion
    which one do you think patients would prefer: ..............................................
19. Suggest ways you think early leprosy case finding be improved in your community?
Dear respondents,

The Gombe State Tuberculosis and Leprosy Control Programme is conducting a study on certain key aspects of the programme. The main objective is to assess the performance of the programme, in respect of its key functions of early case detection and treatment of leprosy. You are hereby requested to participate by responding to this questionnaire, which is aimed at providing us with the necessary information to improve the programme performance. We look forward to your cooperation. All information provided will be treated strictly as confidential and only for the purpose of this study. Your name is optional in this regard please.

Worker Health administrative data:
Name (optional)________________________________________________________
Age_________(Years)
Sex M [ ] F [ ]

Information on the Health Facilities:
How many staff is there in the clinic:

<table>
<thead>
<tr>
<th>No</th>
<th>No in the health facility</th>
<th>No involve in TBL services</th>
</tr>
</thead>
<tbody>
<tr>
<td>I/C</td>
<td></td>
<td></td>
</tr>
<tr>
<td>GHCW</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Leprosy Attendant</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Are you trained in leprosy care? Y [ ] N [ ]
When (in years)____________

How many staff are train in leprosy in the facility?______________.

Health worker Knowledge about Leprosy:

What is leprosy?................................................................................

What causes leprosy?............................................................................

How is leprosy transmitted?.................................................................

List the cardinal signs of Leprosy:

5. How can Leprosy be confirmed? .......................................................

6. What part of the body is commonly affected by Leprosy?

7. Mention the types of Leprosy you know...........................................

8. How can you differentiate the types based on skin patches?

9. What modern drugs is used in treating leprosy?.................................
10. How long does it take to treat leprosy? .................................................................

11. How many skin diseases did you see in your clinic in the last three months? -------
12. Did you suspect leprosy out of them?     Y [ ]     N [ ]

13. What action did you take?.....................................................................................

14. How many leprosy patients did you diagnosed since your training?............... If none, why?..........................................................................................

15. Did you refer any suspect for diagnosis to other health facilities or LGTBLS in the last one year?     Y [ ]     N [ ]
If yes, how many .................................................................................................

16. Are TBL drugs available?           Y [ ]     N [ ]

17. Are patient cards kept in the clinic?     Y [ ]     N [ ]

18. How often do TBLS visit your clinic?
Once in three months
Once in six months
Once in a year
Once in a month
None

*Health education to community:*
What is your role on leprosy in this community?-------------------------
---------------------------------------------------------------------
Do you educate the community on leprosy?  ?     Y [ ]     N [ ]

What information do you normally give? ----------------------------
---------------------------------------------------------------------
What is your opinion concerning the level of awareness about leprosy in this community
........................................................................................................
Do you think there are people with signs of leprosy who are not presenting for treatment in this community?     Y [ ]     N [ ]

If yes, why are they not presenting at the health facility for treatment...
........................................................................................................................

22. Do any leprosy patient presented to you health education message received from Radio Gombe?     Y [ ]     N [ ]
If yes, how many?
Suggest ways on how community awareness about leprosy can be improved
........................................................................................................
Suggest ways on how passive leprosy case finding can be improved?

Attitude and practice:
25 Do you examine contact of MB patient?     Y [ ]     N [ ]
26 How do you feel examining a leprosy patient? --------------------------------------------

27 Do you examine leprosy patient with other patients?   Y [ ]   N [ ]

If no why? -----------------------------------------------

<table>
<thead>
<tr>
<th>Quality check</th>
<th>Name</th>
<th>Signature and Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Questionnaire administered by</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Completeness and consistency checked by</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Categorization/ coding done by</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Entered in data master sheet by</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Countersigned by team leader</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Interview guide for Focus Group Discussion**

1. Community Belief about leprosy
2. Knowledge of the community on leprosy and for other common illness - What do they know about leprosy
3. Community health seeking behaviour. Do you think there is delay in reporting for if there is discoloration or of skin or loss of feeling, willingness to be treated in nearest clinic to home
4. Attitude of the community members on leprosy patients
5. Availability of alternative treatment of leprosy in the community
6. Major source of information in the community?
7. How leprosy services can be improved?