

**ON FACTORS CONTRIBUTING TO DIFFERENCES IN NEW
LEPROSY CASES DETECTED IN ADAMAWA STATE, NIGERIA**

Focus on Koma and Za districts

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Public Health

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ABSTRACT

Nigeria achieved the WHO elimination target for leprosy in 1998, however, pockets of high endemic areas exist. Adamawa State leprosy statistics showed that Jada, one of its 21 LGAs, has persistently been detecting high numbers of new leprosy cases from 2002 – 2006; Koma, one of the 11 districts of Jada LGA, contributed 70% of the new leprosy cases detected in Jada LGA during this period, despite continuous leprosy control interventions by the programme. The need to investigate factors contributing to the high case detection in Koma district is the focus of a research conducted in 2007 in Koma and Za districts on which this thesis is based.

Piot model was adopted and used to describe factors influencing leprosy case detection. In order to appreciate these factors in Koma district of Jada LGA, a comparison is made with Za district of Michika LGA which shares similar demographic and geographic features with Koma but detects lower numbers of leprosy cases from 2002 - 2006. A cross sectional study was done comparing the 2 districts; 18 leprosy patients were interviewed, 4 FGDs were held and 11 GHCWs were assessed on leprosy in the 2 districts. Records of 132 leprosy patients who were treated from 2002 – 2006 in the 2 districts was analyzed.

Findings include poor knowledge of GHCWs and irregular health education of leprosy patients on leprosy by GHCWs in both districts, worse in Koma in comparison to Za district; poor knowledge and awareness on leprosy among leprosy patients from both districts; misconceptions about leprosy and stigma towards patients, worse in Koma in comparison to Za; poor accessibility of leprosy services in Koma compared to Za and high influence of traditional healers in Koma district.

Recommendations includes the need to review the leprosy programmes' health education messages and create more awareness, produce a curriculum to train GHCWs on counseling of leprosy patients and training of GHCWs and volunteers from the.

Key words: Leprosy, case detection, knowledge, awareness, stigma, misconceptions, alternative treatment.

LIST OF ABBREVIATIONS

ATBLCP	Adamawa State Tuberculosis and Leprosy Control Programme.
CHEW	Community Health Extension Workers
CHO	Community Health Officers
DC	Disease Control
EHO	Environmental Health Officers
FGD	Focus Group Discussion
FMOH	Federal Ministry of Health
GDP	Gross Domestic Product
GHCW	General Health Care Workers
GHS	General Health Services
ILEP	International Federation of Anti-Leprosy Associations
LEC	Leprosy Elimination Campaign
LGA	Local Government Area
LGTBLS	Local Government Tuberculosis and Leprosy Supervisor
MB	Multi-Bacillary
MDT	Multi Drug Therapy
MLGA & C	Ministry of Local Government and Chieftaincy Affairs
NCD	New Case Detection
NPC	National Population Commission
NTBLCP	National Tuberculosis and Leprosy Control Programme
PB	Pauci-Bacillary
PHC	Primary Health Care
RA	Research Assistant
SMOH	State Ministry of Health
STBLCO	State Tuberculosis and Leprosy Control Officer
TB	Tuberculosis
TBL	Tuberculosis and Leprosy
WHO	World Health Organization

INTRODUCTION

In 2003, I joined the State Ministry of Health and was posted to Numan General Hospital as a medical officer. After six months, I was transferred to the Adamawa State Tuberculosis and Leprosy Control Programme (ATBLCP) as the Programme Manager where I worked until my admission to the International Course in Health Development at KIT.

The State's leprosy programme started in 1991 with the creation of Adamawa State from the former Gongola State. The Tuberculosis (TB) component was added in 2002 and the programme was renamed to ATBLCP which provides TB and leprosy control services in the state. It receives technical, financial and logistic support from the Netherlands Leprosy Relief (NLR). Although ATBLCP achieved the elimination target for leprosy (prevalence of $<1/10,000$ population) since 2001, some of its 21 Local Government Areas (LGAs) still detect high numbers of new leprosy cases. Persistent high numbers of new leprosy cases are being reported from Jada LGA and one of its 11 districts (Koma) contributes 70% of the new leprosy cases detected in the LGA.

The ability of leprosy to cause permanent disability, making its sufferers become burden to their families and the stigma incurred by those affected makes leprosy an important public health problem. In an attempt to investigate factors influencing the high leprosy case detection in Koma, an earlier research was conducted in Koma district in 2004. Getting admitted into the ICHD programme provided me an opportunity to improve on the earlier research. A study comparing factors contributing to the high leprosy case detection observed in Koma district of Jada LGA and the low leprosy case detection observed in Za district of Michika LGA was conducted in 2007. The research tools used in 2004 were reviewed and used to collect data from Koma and Za districts in 2007.

The focus of the 2007 research was to investigate factors that influence the high leprosy case detection observed in Koma while comparing it with Za, a district with low leprosy case detection. As part of my study (thesis) in KIT, I decided to conduct a literature review of the factors that influence leprosy case detection, analyze the collected data from Koma and Za districts, critically analyze the methodology and findings of the 2007 study and come up with recommendations on how to improve leprosy control in the study districts, Adamawa and other NLR supported states.

1 BACKGROUND

1.1 Nigeria

Nigeria is located in the West African sub-region and occupies a land mass of over 900,000 square kilometers with a population of 140 million (NPC census, 2006) and an annual growth rate of 2.7 % (Population Reference Bureau, 2007). The population is relatively young with 51% aged 0-14, 46% aged 15-64 while 3% are over 64 years. Life expectancy at birth is 46 and 47 years for males and females respectively. 53% of the population resides in the rural areas while 47% reside in the urban areas. 68% of the adult population is literate with more males (74%) than females (59%) being literate (Nigeria country report, 2006).

The country is diversified culturally with 370 ethnic groups. 60% of the population is made up of the 3 major tribes; Hausa, Yoruba and Igbo (Nigeria country report, 2006). Nigeria is abundant in natural resources (oil, tin, uranium, lead etc); while most of these resources are untapped, the country over-dependes on the oil sector. Agricultural sector has declined over the years, but still accounts for 33% of GDP. Despite the economic potentials, 70% of Nigerian lives below the poverty line (Nigeria, 2003).

Nigeria is divided into 36 semi-autonomous states with the Federal Capital Territory (FCT) and each state further divided into semi-autonomous Local Government Areas (LGAs). There are 774 LGAs in the country.

Adamawa State

Adamawa State is one of the 36 states of Nigeria and is located in its North-Eastern part (annex 1), occupying a land mass of over 42,000 sq. Km and has a population of 3.17 million people (NPC, 2006). It is administratively divided into 21 LGAs with Yola being the state capital. Adamawa state is multi-ethnic in composition with Hausa and Fulani languages widely spoken. Subsistent farming, fishing and cattle rearing are the main occupation of the people (Adamawa State Tuberculosis and Leprosy Control Programme Annual Reports, 2003 and 2006).

Jada LGA and Koma district

Jada LGA is located in South Eastern Adamawa State. It has a population of over 182,000 (NPC, 2006) and is divided into 11 districts one of which is Koma.

Koma is a mountainous district which borders the Republic of Cameroon (annex 1) and has a population of 32,000. Literacy level of Koma people is probably the lowest in Adamawa State because they were discovered in the 80s following centuries of limited contact with

the outside world (Ethnologue, 2005). They belong to 3 main religions: Traditionalists, Christianity and Islam; and speak 3 main dialects (Gomme, Gomnome and Ndera) with several sub-dialects; Gomme and Hausa are widely spoken and understood across other dialects (Ethnologue, 2005). Farming and hunting are their main occupations. There are 6 clinics in Koma district (1/5,300 population) which are unevenly distributed, mostly located in its less mountainous parts which is less populated. The clinics are overseen by the Primary Health Care (PHC) department of Jada LGA. Seven General Health Care Workers (GHCW) manage and provide basic primary care in the 6 clinics, with 1 GHCW each in 5 clinics and 1 in the 6th. With support from the ATBLCP through training, supervision, drugs, consumables and logistic supply, these health facilities provide leprosy and TB services in Koma district.

Michika LGA and Za district

Michika LGA is located in the North Eastern part of Adamawa State has a population of 149,875 (NPC, 2006). It is divided into 11 districts one of which is Za which stretches up to the Cameroon border.

Za is a mountainous district with a population of 13,447 (NPC, 2006) and is home to the Kamwe tribe who widely speak Hausa. They mainly practice 2 religions: Traditional and Christianity. Their main occupations are farming and hunting. There are 2 health facilities in the district (1/6,723 population) which are evenly distributed. The facilities are managed by 4 GHCWs, 2 in each health facility, who provide basic primary care. The facilities are overseen by the PHC department of Michika LGA. With support from the ATBLCP through training, supervision, drugs, consumables and logistic supply, they provide leprosy and TB services in the district.

1.2 Health Care System

The Federal, State and Local Governments are jointly responsible for the provision of health services in Nigeria as stated in the National Health Policy of 1988 (Annex 2).

The **Federal** Ministry of Health (FMOH) is the planning and policy co-ordination body at the Federal level. It also runs most of the tertiary health facilities in the country including military health facilities and university teaching hospitals.

The **State** Ministry of Health (SMOH) also formulate policies, implements the national health programmes and runs the state health institutions while offering support to all its LGAs on the management of their Primary Health Care (PHC) system.

The **LGAs** serve as the operational level of the health system and delivers service through a network of public health centres (dispensaries, health posts, maternities) which are under its control.

GHCWs of various cadres (nurses, midwives, Community Health Officers (CHO), Community Health Extension Workers (CHEW) and Health Assistants) provide the work force for health facilities at this level. Although not formally recognised, the traditional health institutions (mainly traditional healers) also operate at this level.

Under the Directorate of PHC and Disease Control in the FMOH is the National Tuberculosis and Leprosy Control Programme (NTBLCP) which is headed by a National Coordinator from the Office of the Director Disease Control. Each State has a State Tuberculosis and Leprosy Control Officer (STBLCO) under the Directorate of disease control in the SMOH (annex 3). At the LGA, under the directorate of PHC, there is a Local Government Tuberculosis and Leprosy Supervisor (LGTBLS). Using this structure and through donor agency support, leprosy control activities are planned, implemented, supervised, monitored and evaluated in Nigeria.

1.3 Leprosy situation in the world

Global prevalence of leprosy has continued to decline over the years following the introduction of the WHO recommended Multi Drug Therapy (MDT) ¹ which guaranteed cure following decades of uncertainty on the curability of leprosy. Based on data from 115 countries, 298,626 new leprosy cases were detected in 2005 while the registered prevalence of leprosy in the world was 222,427 in 2006 (WHO, 2006).

Table 1: Prevalence rates and new case detection in the WHO regions, 2005.

WHO Region	Registered prevalence (Rate per 10,000 population)	New cases in 2005 (rate per 100,000 cases)
Africa	43,425 (0.63)	44,769 (6.48)
Americas	32,910 (0.39)	41,952 (5.00)
South East Asia	133,422 (0.79)	201,635 (11.99)
Eastern Mediterranean	4,024 (0.08)	3,133 (0.61)
Western Pacific	8,646 (0.05)	7,137 (0.42)
Global Total	222,427	298,626

WHO, 2006. The leprosy burden at the end of 2005.

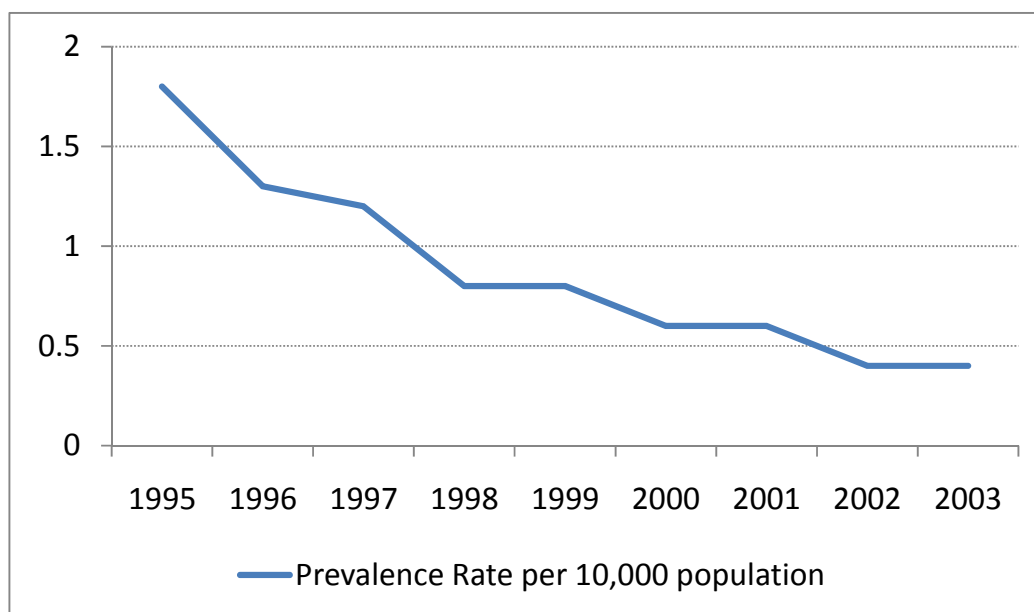
¹ A combination drug containing Rifampicin, Dapsone and Clofazimine used for treatment of leprosy.

Table 1 shows the breakdown of the world's leprosy prevalence and New Case Detection (NCD) in the WHO regions. The highest burden is in South-East Asia followed by Africa.

1.4 Leprosy situation in Nigeria

The NTBLCP was launched in 1989 and it is responsible for coordinating leprosy control activities in Nigeria. MDT was introduced in 1991 and by 1995, a 100% MDT coverage has been achieved with a leprosy control programme established in all 36 states of the Federation and the FCT. The last leprosy survey (1990) found the prevalence rate to be 30 per 10,000. By the end of 1998, leprosy data collated from all states showed that the WHO elimination target of prevalence of less than 1 case per 10,000 population (Meima A et al, 2004) has been achieved at the National level. However, at the state level, 3 of the 36 states of Nigeria had leprosy prevalence above the target, 14 states had prevalence between 0.5 and 1 per 10,000 population and WHO identified Adamawa with 4 other states as still having high leprosy prevalence (WHO, 2007). A leprosy prevalence above 1/10,000 population was recorded by some LGAs (Osahon IO, 2005) despite reaching the leprosy elimination target at the state level.

Figure 1: Trends of leprosy prevalence rate, Nigeria. 1995 – 2003.



NTBLCP. A presentation at Leprosy Elimination Programme Managers meeting, June 2004. Harare.

Figure 1 shows the gradual decrease in leprosy prevalence rates after the introduction of MDT. Despite the fall in prevalence, Nigeria

currently ranks 16th among the 24 highly endemic countries for leprosy in the world (NTBLCP, 2004).

There were 4,830 registered leprosy cases of which 3,544 were newly detected in Nigeria at the end of 2006 (WHO, 2007).

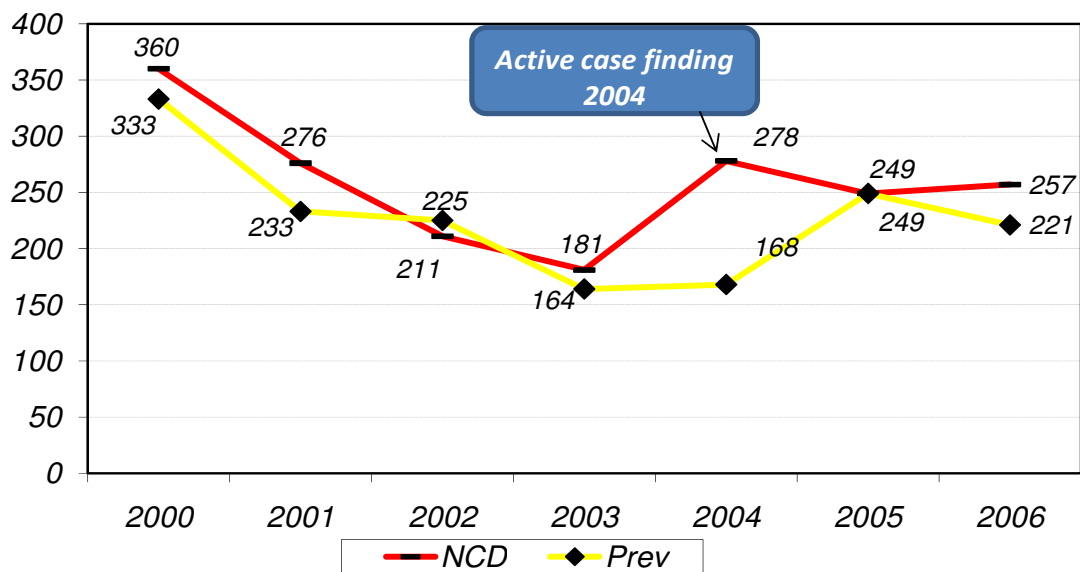
1.5 Leprosy situation in Adamawa State

In 1950, there were 16,648 leprosy patients registered by Garkida leprosarium, in the then North Eastern Region of Nigeria from which Gongola State and later Adamawa State was carved. With the creation of Gongola State in 1976, the leprosy control programme had 19,215 registered patients in 241 MDT clinics² across the state. By 1991, this number had fallen to 10,398 leprosy patients on register and following the creation of Adamawa State in the same year, the new Adamawa State Leprosy Control Programme became responsible for 5,687 leprosy patients in 130 MDT clinics with a state prevalence of 2/10,000 population (ATBLCP Annual Report, 2003).

MDT was recommended by WHO in 1981 (ILEP, 2001) but it was introduced in the Adamawa State in 1991. A 100% MDT coverage of all facilities offering leprosy services in the state was soon achieved and this was followed by a gradual reduction in the number of leprosy cases in the state as cured patients were discharged from the register. At the end of 1999, there were 278 cases of leprosy in the state with a leprosy prevalence rate of 1/10,000 population. In 2001, with a prevalence of 0.8/10,000 population, the Adamawa State Leprosy Control Programme achieved the WHO elimination target for leprosy (prevalence of less than 1/10,000 population). The control of tuberculosis (TB) was combined with that of leprosy in 2002 and the Programme was renamed to Adamawa State Tuberculosis and Leprosy Control Programme (ATBLCP) (ATBLCP Annual Report, 2003, 2004).

² Clinic offering leprosy control services.

Figure 2: Trends of leprosy prevalence and new case detection in Adamawa State: 2000 – 2006.



ATBLCP presentation at North East Zonal Quarterly Meeting, 2nd Quarter 2007.

The state prevalence and new case detection from 2000 to 2006 kept fluctuating with the highest case detection of 360 registered in 2000 and the lowest case detection of 181 registered in 2003. The intensification of active case finding activities in high endemic areas of the state by ATBLCP in 2004 led to an increase in leprosy New Case Detection (NCD) and prevalence in Adamawa State (figure 2).

1.6 ATBLCP: Organization, Objectives and Activities

At the state level, a medical officer [State Tuberculosis and Leprosy Control Officer (STBLCO)] assisted by 4 State Tuberculosis and Leprosy Supervisors (STBLS) manage activities of the ATBLCP while at the LGA level, the Local Government Area Tuberculosis and Leprosy Supervisor (LGTBLS), who is a staff of the PHC department manages the programme. As a team, the STBLCO, STBLS and the LGTBLS ensure the smooth running of ATBLCP activities in Adamawa State.

NLR assists ATBLCP through provision of technical, financial and logistics support including training, planning, monitoring and evaluation. ATBLCP operates in accordance with the NTBLCP guidelines (ATBLCP Annual Report, 2006).

See annex 1 (b) for objectives and activities of leprosy control of the ATBLCP.

1.7 Human Resource for Health in Adamawa State

There were approximately 1,300 public and private health clinics, dispensaries, health posts and maternities in Adamawa state; 127 of these are clinics where leprosy control services are offered (also called MDT clinics). Leprosy control services are delivered in these facilities by a mixture of Community Health Officers (CHO), Environmental Health Officers (EHO), Community Health Extension Workers (CHEW) and sometimes nurses and midwives. These GHCWs, some of which are trained on leprosy control, are supervised by LGTBLS who are in turn supervised by the ATBLCP to deliver leprosy and TB services in the MDT clinics (ATBLCP Annual Report, 2006).

1.8 Integration of leprosy services into general health services in Adamawa State

A survey carried out by ATBLCP in 2005 showed that there were 145 GHCWs working in the 127 MDT clinics (average of 1 GHCW per MDT clinic); 96 (66%) were trained on leprosy control out of which 75 (78% of 96) could diagnose and manage leprosy cases and are doing so as part of their routine PHC job description (ATBLCP Annual Report, 2006). The state has 17 doctors (1/190,000 population) and 886 nurses (1/3600 population), they are unequally distributed even within same type of hospitals in the state (MLGA & C, 2004).

2 STATEMENT OF THE PROBLEM AND OBJECTIVES

2.1 Justification

Despite having leprosy prevalence below WHO elimination target, Nigeria is one of the countries with uneven distribution of leprosy, concealing high endemic areas at its local level (ILEP, 2001). Of the 21 LGAs of Adamawa State, Jada is one of the most endemic for leprosy. Koma is one of the 11 districts of Jada LGA and it contributes 70% of all cases detected in the LGA (table 2) (ATBLCP statistics, 2002 – 2006).

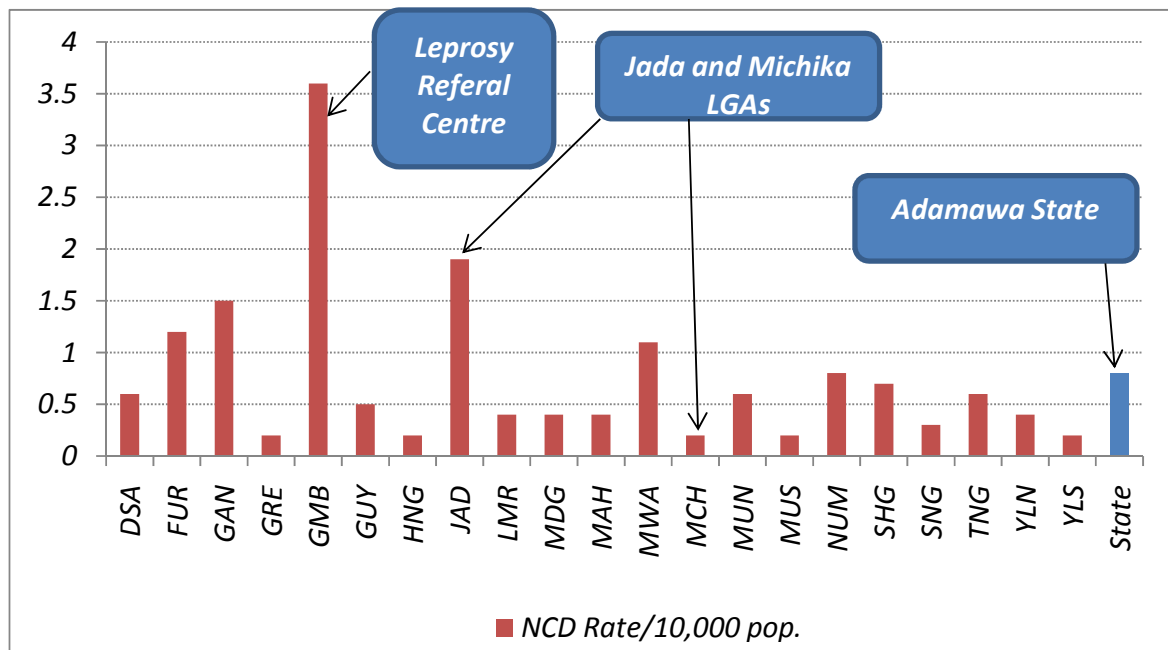
The disability associated with leprosy, which is preventable by early treatment with MDT, mostly affects individuals in their most productive stage of life leading to loss of physical and economic independence thereby imposing a significant economic and social burden on those affected and their families (Niera, 2001).

2.2 High and Low Case Detection of leprosy in LGAs of Adamawa State

ATBLCP statistics shows that from 2002 to 2006, Gombi and Jada have the highest leprosy NCD rates compared to all other LGAs in Adamawa State. The average leprosy NCD rates for Gombi and Jada during this period was 3.6 and 1.9/10,000 population respectively while it varies from 0.2 to 1.5/10,000 population for the remaining 19 LGAs (figure 3).

While all cases of leprosy detected in Jada LGA arise from its own communities, those detected in Gombi LGA are mostly from the Adamawa State Dermatological Hospital (formerly called Adamawa State Leprosy Hospital) in Garkida which serves as a referral centre for Adamawa State and beyond; most of the leprosy patients registered in Gombi LGA were referred cases to the referral centre (ATBLCP statistics, 2002 – 2006).

Figure 3: Average NCD rates of leprosy in 21 LGAs of Adamawa State: 2002 – 2006.



ATBLCP Leprosy Statistics, 2002 – 2006.

2.3 High leprosy NCD rate in Jada versus low leprosy NCD rate in Michika LGAs

Jada and Michika LGAs represent high and low endemic areas for leprosy in Adamawa State. While the average NCD rate of Jada (1.9/10,000) doubles that of Adamawa (0.8/10,000) from 2002 to 2006, the average NCD of Michika (0.2/10,000) is a fraction of the state average in the same period (figure 3). This trend of leprosy NCD have persisted for over 5 years despite continuous implementation of leprosy control interventions (ATBLCP Statistics, 2002 – 2006).

2.4 Koma district in Jada LGA and Za district in Michika LGA

Koma is one of the 11 districts of Jada LGA, and most of the new leprosy cases recorded in the LGA from 2002 to 2006 were from this district as shown below.

Table 2: A comparison of the number/proportion of new leprosy cases detected in Koma to 10 other districts of Jada LGA: 2002 – 2006.

Jada LGA	2002	2003	2004	2005	2006
Koma District	25 (74%)	20 (63%)	29 (64%)	27 (82%)	25 (71%)
10 Other districts	9 (26%)	12 (37%)	16 (36%)	6 (18%)	10 (29%)
Total	34	32	45	33	35

Za is one of 11 districts of Michika LGA. Like other districts in the LGA, low leprosy NCD was reported from 2002 to 2006.

Table 3: A comparison of the number/proportion of new leprosy cases detected in Za to 10 other districts of Michika LGA: 2002 – 2006.

Michika LGA	2002	2003	2004	2005	2006
Za District	0	1	1	3	1
10 Other districts	2	1	2	6	4
Total	2	2	3	9	5

2.5 The choice of Za for comparison

Koma and Za districts are similar in the following ways:

- Topography: Mountainous with difficult terrain (Atlantika and Mandara mountains)
- Poor terrain
- Location {bordering Cameroon (annex 1a)}

Due to their poor terrain, it is difficult for ATBLCP staff to supervise and monitor activities especially at the peak of rainy season and this leaves gaps in implementation. Za district was selected for comparison with Koma district because of its demographical and geographical similarity to Koma (see 1.1) and because of its low leprosy NCD although there are districts in Michika LGA with a lower leprosy NCD.

2.6 Objectives of the thesis.

Overall Objective:

To describe general factors influencing case detection of leprosy and conclude on how far they apply to Koma district of Jada LGA and Za district of Michika LGA in order to make recommendations for improvement of leprosy control in Adamawa State.

Specific Objectives:

1. To carry out a literature review on factors influencing leprosy case detection.
2. To describe and compare findings from the study in Koma and Za districts in 2007 with those identified from literature.
3. To critically analyze the research methodology and findings of the study conducted in Koma and Za districts in 2007.
4. To formulate recommendations based on the findings of this thesis as a pre-condition to improve leprosy control services in Koma and Za districts and Adamawa State.
5. To propose further research based on findings from this thesis.

Study Questions:

1. What are the factors found in literature that influences leprosy NCD?
2. What are the factors that influence leprosy NCD in Koma and Za districts of Adamawa State?
3. How does the influence of the identified factors from this study differ in Koma and Za districts?
4. What are the strengths and weaknesses of the study design and methodology applied in Koma and Za districts in 2007?
5. How can ATBLCP adapt to address the findings of this study?

These study questions will be answered through:

- Literature review on factors influencing leprosy NCD
- Descriptive analysis of data collected from Koma and Za districts in 2007
- Analysis of the study methodology and findings

3 FACTORS INFLUENCING NEW LEPROSY CASE DETECTION

This section of the thesis will adapt and apply Piot model to describe factors that influence leprosy NCD. The influence of factors relating to the stages in the model with respect to leprosy NCD will be discussed.

Literature search strategy

Relevant literature was accessed from WHO, ILEP and TLMI web sites. Search engines and data bases used include pubmed, scielo, science direct and Google scholar.

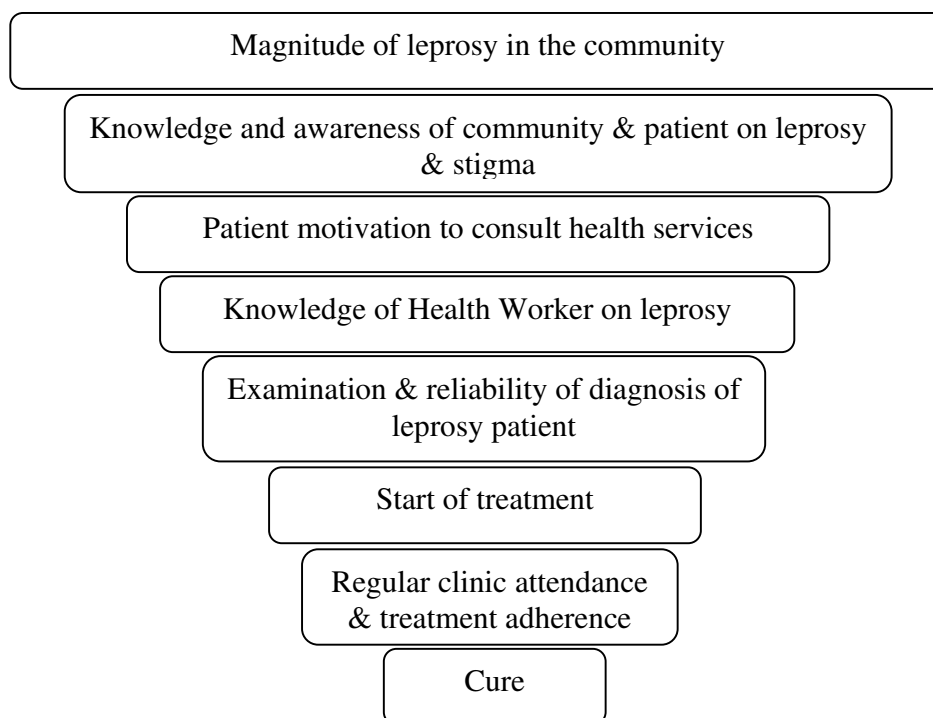
My lecture notes and other resources from NLR and KIT libraries, annual reports and quarterly leprosy statistics of ATBLCP, and publications from KIT and NTBLCP were also used.

My experience as the ATBLCP programme manager for more than 4 years was also helpful.

3.1 The Piot Model

This model was introduced by Piot in 1967. It is based on a passive case detection strategy of smear positive TB cases starting from the different steps individuals in the community go through between becoming ill with active TB and getting cured under the programme (Dujardin et al, 1997). The steps will be used to describe factors influencing leprosy NCD as patients pass from their community to diagnosis and finally completion of treatment and how they are lost at each stage.

Figure 4: Diagrammatic representation of adapted Piot model in leprosy.



(ICHD lecture notes, 2008)

3.2 Literature Review

The steps in the adapted Piot model will be discussed in this section highlighting factors influencing leprosy NCD.

3.2.1 *Magnitude of leprosy in the community*

It is expected that a decrease in leprosy prevalence will lead to a decrease in incidence; however, little evidence exists to support this expectation. A decrease in prevalence is usually due to discharge after cure or default and decreased treatment duration, not due to decrease in transmission of leprosy (Rinaldi, 2005). Lockwood and Suneetha (2005) observed in India that although leprosy prevalence has fallen, incidence remained constant over the years and new leprosy cases are being detected.

Trends in leprosy NCD rates reflect trends in incidence rates (and hence the endemicity of the leprosy problem) provided no significant changes occur in case detection efforts, self reporting behavior, and diagnostic criteria and procedure (Meima et al, 1997). In a community where high numbers of new leprosy cases are persistently detected, it is likely that the incidence of leprosy is high. Persistent high numbers of new leprosy cases are being detected in Koma district (table 2).

3.2.2 *Knowledge and awareness of community and patients on leprosy and stigma*

The community and stigma

Knowledge and awareness on leprosy in a community could influence stigma and leprosy NCD. Barkataki et al (2006) in a study done in India showed that much of the stigma associated with leprosy is due to inadequate or wrong knowledge about the disease. Rafferty (2005) also associated stigma with poor knowledge on leprosy in communities.

Cultural beliefs and misconceptions are common in communities and may be partly responsible for the stigma leprosy patients and their families suffer and this could contribute to delay in presentation at the health facility and low leprosy NCD. Leprosy is viewed as punishments from God for sins committed especially in India (Browne, 1975; Richards, 1977; Muthankar, 1979): as due to Immoral conduct e.g. sex with prostitutes especially in China (Skinsnes, 1964): as due to bad or unclean blood, evil spirits, local charms, witch craft or breaking a taboo and thus called "ngara" or "lepero" in Botswana (Kumaresan

and Maganu, 1994). The belief that leprosy is hereditary is common in Africa, India, China, and Malaysia (Chen, 1986; Gussow, 1989).

A study conducted in Nepal showed that 64% of the respondents believed leprosy was contagious, 9% believe it was a curse from God, while 18% believe it was due to both (De Stigter, 2000). A study carried out by Alubo et al (2003) in Nigeria revealed how community members avoid exchanging greetings and even asking for anything from known leprosy patients for fear of getting infected. Carefully tailored health education messages around misconceptions, cultural and religious beliefs in a community will contribute to stigma reduction and the challenge for health educators is to get the "right mix" of these and integrate into current knowledge on leprosy (Wong, 2004; Rafferty, 2005).

Knowledge of leprosy patients and stigma

Poor knowledge among leprosy patient is an important cause of delay in seeking health services among new leprosy patients. Leprosy patients in northern Nigeria often guess ring worm, rashes, eczema or any common skin condition at first presentation to the health facility while others present with fever (due to leprosy reaction) thinking its malaria (Alubo et al, 2003).

The signs and symptoms of leprosy include painless non itching skin patches (except in complications) with loss of feeling, painless/painful nerve enlargement, loss of power in affected areas, and sometimes swellings and visible deformity. These signs and symptoms require the awareness and knowledge of the patient or the community in order to suspect leprosy. Poor knowledge is common among leprosy patients in northern Nigeria (Awofeso, 1995).

In Ethiopia, stigma has been found to be a major factor that leads to delays in seeking treatment by leprosy patients (Bekri et al, 1998). The deformities and disabilities associated with leprosy which steadily gets worse and becomes visible to the communities is related to the stigma generated from the communities (Rafferty, 2005). According to Bainson and Van Den Borne (1998) the residual effects after full treatment of those detected late, which usually limits or prevent them from fulfilling their normal roles in society leads to loss of economic independence through loss of their jobs, loss of physical independence because of the disabilities and loss of self esteem as a result of social isolation leading to a lower quality of life. Other factors responsible for stigmatizing attitudes towards leprosy patients are low level of education, female gender, rural residence and religion (van den Broek et al, 1998).

Studies from India and Myanmar have showed that leprosy patients experience unsympathetic reactions, insults, hate and rejection from society (Kant, 1984; Myint et al, 1992; Ulrich et al, 1993).

Stigmatization is also extended to families of leprosy patients with visible deformities who faced 10 times higher societal problems than those having leprosy patients with no deformities (Kopparty, 1995). Although MDT appears to have blunted out the sharpest edge of stigma (Burathoki et al, 2004) it still influences the health seeking behavior of leprosy patients leading to delays in presentation thereby influencing leprosy NCD.

Alternative treatment (traditional healers)

Traditional healers are persons within the communities who are recognised as competent providers of health care by using vegetables, mineral substances, and methods based on socio-cultural and religious backgrounds as well as on the knowledge, attitudes and beliefs prevalent in the community regarding physical, mental and social well being and the causation of disease and disability (Stekelenburg et al, 2005). More than 80% of Africans use traditional healers and such alternative treatment is found to actively compete with modern health services (Ibid). Reddy (1984) found in Northern Nigeria that 47% of leprosy patients were detected late because they went to traditional healers first before coming to the health facilities.

Due to misconceptions, the community's faith in its perceived efficacy may be high and this makes leprosy patients go for traditional medicine. According to Van de weg et al (1998) in a study carried out in Adamawa State, over-the-counter drugs from chemists and traditional medicine were the reasons given to explain the delay in seeking treatment at the health facilities by most leprosy patients.

In areas where awareness of leprosy is low, the influence of alternative treatment on new leprosy case detection may be high leading to low leprosy NCD and vice versa. Leprosy patients from such communities in Botswana are known often try traditional healers before eventually presenting to the health facilities for treatment (Kumaresan and Maganu, 1994).

3.2.3 Patient motivation to consult health services

Factors motivating patients to consult health services could be viewed from the patients' and the health service perspectives.

Factors influencing leprosy patient motivation from the patients' perspective include:

Attitude of community towards leprosy patients

The attitude of communities towards leprosy patients could influence patients' motivation to consult health services. Despite medical advances in the treatment of leprosy, stigma, misconceptions and negative attitudes towards leprosy patients are common in most

communities (see 3.2.2). Such misconceptions contribute to stigmatization of leprosy patients in communities (Wong, 2004) and the fear of stigma de-motivates leprosy patients from accessing health services. In Nepal, women fear being accused to have contaminated the family because leprosy is known to stay in families for generation thereby making marriage for descendants difficult, this is the reason why women are being isolated or divorced (Burathoki et al, 2004). Therefore misconceptions in communities could lead to stigmatization against leprosy patients and fear of stigma de-motivates them from accessing health facilities thereby influencing leprosy NCD

Gender

Although males suffer more from MB leprosy and deformities than females (Meima et al, 1999), females are known to report in equal numbers or even more than males in Northern Nigeria; further more, females are motivated to access health services earlier than males (despite being less mobile and having less resources) in order to prevent the appearance of deformities which is associated with irreversible stigma in the communities (Alubo, et al, 2003). A study conducted in Zimbabwe also showed that males suffer more from MB leprosy and delay in presenting to health facilities compared to females (3.1 years versus 2.1 years). However, Meima et al (1999) showed that the mean registration delay among females compared to males in Ethiopia was identical (2.4 years versus 2.3 years).

In Southern Nigeria, Peter and Eshiet (2002) found a leprosy male female ratio of 2:1, with women presenting late to the health facilities and also having more visible deformities than male leprosy patients.

Other studies have shown that female leprosy patients are more vulnerable to abuse compared to men; the disability associated with leprosy makes women more reluctant to expose themselves to health facilities for fear of stigmatization (Le Grand, 1997; Vlassof, et al, 1996). A study done in India revealed that women suffer more isolation, loss of touch, and rejection and are more restricted compared to men with the same level of disease. A woman with leprosy is seen as a threat to the well being of the entire family. Fear of transmitting the disease can prevent bonding and emotional closeness with her children. 49% of breast-feeding mothers with leprosy in Nagpur, India, stopped breast-feeding their children (Vlassof, et al, 1996). Therefore, depending on the influence of the community, female leprosy patients could either be motivated or de-motivated to consult health services and this influences leprosy NCD.

Health seeking behavior of leprosy patients

Wong and Subramaniam (2002) defined health seeking behavior as what people do and where they go on suspicion of illness. This is

influenced by patients' and societal beliefs and perceptions about leprosy; the availability, accessibility, acceptability and affordability of health services; quality of the health services, provider-patient relationship and the patient's socio-demographic characteristics (Bakirtzief, 1996; Bijleveld, 1977; Wong and Subramaniam, 2002). In a society where leprosy patients face discrimination, the tendency could be to conceal their condition, refuse to seek or adhere to treatment due to fear of social rejection.

Even after the diagnosis of leprosy by lay men in the communities, most leprosy patients delay before presentation to health facilities in Adamawa State (Van de Weg et al, 1998); home based care with over the counter drugs and traditional medication were responsible for the delays in seeking modern treatment (Ibid). This substantiates the earlier findings of Mull et al (1989) and Kumaresan and Maganu (1994) in Pakistan and Botswana which showed that the health seeking behavior of leprosy patients follows a pattern of home based care with over-the-counter drugs, followed by traditional healer consultations and finally approaching the local health facility. Therefore, health seeking behavior of leprosy patients could influence their presentation at the health facility and leprosy NCD.

Perceived quality of leprosy services by leprosy patients

The satisfaction of leprosy patients' with leprosy services has been considered as an indicator of the quality of care from the patients' perspective (Kampirap, 2005). In Nepal and Brazil, leprosy patient satisfaction is important with respect to the motivation of leprosy patients to access health facilities (van Dijk et al, 2003). As leprosy cases continue to be detected in high endemic areas, it is important to sustain a good quality of leprosy services which requires regular feed backs from leprosy patients and their communities; information generated from the clients on their experiences and opinions are important in understanding their motivation which gives an insight into knowing if leprosy services satisfy their perceptions and ideas. Such information could enhance leprosy NCD (Ibid).

Accessibility in terms of cost and waiting time, community and patient health education, examination procedures, state of the health facility (e.g. cleanliness), attitude of GHCWs, contact tracing and examination by GHCWs, availability of drugs and recording and reporting materials at the health facilities, advice on stigma, Prevention of Disability (POD) and socioeconomic consequences by GHCWs are some important issues that shed light on quality of leprosy services from the clients perception (Ibid).

A good perception of quality by leprosy patients could motivate them to consult health services.

Acceptability of leprosy services

Burathoki et al (2004) found in Nepal that acceptability of health services by leprosy patients is poorest in remote areas where discrepancies between staff and patients in terms of gender, education, language and culture are common. The study further revealed that GHCWs confessed that opposite gender makes their relationship with patients difficult and hence the diagnoses of leprosy as patients are not comfortable undressing for a GHCW of opposite gender to examine them. This becomes difficult especially in health facilities with only one GHCW; in such situations, GHCWs are known to call in a community health worker of appropriate gender to help them examine patients (Ibid).

Some male leprosy patients find it difficult to use health facilities within their communities for fear of being exposed as leprosy patients in their community; such patients prefer to travel over long distances to consult far away clinics (Alubo et al, 2003). These could draw down heavily on their income and could contribute to treatment interruption. Therefore, if health services are not acceptable, patients may not be motivated to consult and this could affect leprosy NCD.

Factors influencing leprosy patient motivation from the health service perspective include:

Availability of leprosy services

The availability of leprosy services is an important aspect of leprosy control (see perceived quality of leprosy services by leprosy patients). As observed in India, the integration of leprosy services into GHS has improved the availability of services through primary health centres and sub-centres and this has led to tremendous achievements in accessibility and leprosy service delivery (Arif, 2005).

The availability of leprosy services in communities motivates leprosy patients to utilize and this may influence leprosy NCD.

Accessibility of leprosy services

Health facilities are not equally accessible to all leprosy patients. While some reside within a walking distance (5km) from the clinic, others travel over longer distances that may take over a day to access health facility. The cost of travel and the opportunity cost could constitute a burden to leprosy patients. Poverty is common among leprosy patients and it is viewed as both a "cause" and "result" of leprosy: A "cause" because of increased susceptibility of the poor to disease, due to poor housing (overcrowding, poor ventilation), poor nutrition and weaker immune system; a "result" because it is one of the leading cause of permanent disability which often afflicts individuals in their most productive stage of life, thereby preventing them from generating

income and imposing a significant economic and social burden on their families (Niera (2001). Kampirapap et al (2005) in a client satisfaction study in Thailand identified travel cost as a barrier to accessing health services especially among the poor and the aged leprosy patients who needed to be accompanied.

Long home-clinic distance constitutes problems to leprosy patients and GHCWs with respect to leprosy services. Greater than 5km home-clinic distance affects patients' regular attendance and affects case detection efforts of GHCWs who can no longer conduct effective contact tracing and examination, community education and other activities which influences the detection of new leprosy cases (Alubo et al, 2003).

In my experience, long waiting times after reaching the health facilities, especially in rural areas which may not be frequently supervised by the LGAs or leprosy control programmes de-motivates leprosy patients from going to health facilities.

Therefore, as observed by Feenstra and Pannikar (2005), it is important to provide accessible leprosy services in communities so that new leprosy cases would continue to be detected which would further lead to a reduction in the burden of the disease.

Effectiveness of leprosy services

See 3.2.5 and 3.2.6.

3.2.4 Knowledge of Health Worker on leprosy

The knowledge of GHCWs on leprosy, especially on its signs, symptoms and diagnosis, could influence leprosy NCD. A GHCW that is not knowledgeable on these aspects of leprosy could continue to misdiagnose leprosy which may lead to low leprosy NCD. GHCW motivation, skills, training, workload and supervision could also influence leprosy NCD.

Poor knowledge and misconceptions are known to be prevalent among GHCWs. A study conducted in Nigeria showed that 65% of final year nursing students said leprosy was highly infectious and deformities was inevitable (Awofeso, 1992). Another study conducted in the Philippines showed that while 88.4% of GHCWs agreed with the germ theory of disease, 70% believe leprosy to be highly contagious and 11.6% believe it was caused by bad "unclean blood" and witchcraft (Valencia,1983). According to Wong (2004), low level of knowledge on leprosy was observed among GHCWs in Guyana: 50% did not know that leprosy is curable and 15% thought it could be spread by touch. In a study among GHCWs in Botswana, more than one-third believed that leprosy patients should be isolated and treated (Ibid). Poor knowledge and misconceptions are associated and are partly responsible for the stigmatization of leprosy patients (Ibid) which could influence leprosy NCD.

3.2.5 **Examination process and reliability of diagnosis of leprosy**

The diagnosis of leprosy is based on clinical examination; three cardinal signs form the basis for diagnosis; anesthetic skin lesions, enlarged peripheral nerves and acid-fast bacilli in the skin smear (WHO, 1997; Chen et al, 2006). These cardinal signs are easy to observe and elicit by GHCWs after a short training; once one of the three signs is elicited, a diagnosis of leprosy is made (WHO, 2008). However, Saunderson and Groenen (2000) earlier showed how difficult it was for GHCWs to diagnose leprosy; their study showed that anesthetic skin patch which is the earliest and most important sign of leprosy was absent in 49% of new leprosy cases with positive skin smears (n=268). Enlargement of peripheral nerves (ulnar) is also valuable in leprosy diagnosis (Ibid); however, constant practice is required to perfect and maintain the skill by GHCWs. Chen et al, (2006) further emphasized the importance of assessment of anesthetic lesions and peripheral nerve enlargement for the diagnosis of paucibacillary (PB) and neuritic leprosy because skin smear examination is often negative in these cases.

Examination requires adequate exposure of leprosy patients in a well lighted private room in order to examine all parts of the skin for lesions. Cotton wool, ball point and a screen are required. Simple as it seems, errors still occur because the clinical diagnosis of leprosy depends on the examiner's knowledge and skills in identification of anesthetic skin lesions and peripheral nerve enlargement.

Factors influencing the knowledge of GHCWs (3.2.4) could also influence the examination and reliability of diagnosis of leprosy patients

3.2.6 **Patient Management**

The influence of start of treatment, regularity of treatment and treatment adherence on leprosy NCD will be discussed here.

Start of Treatment

No literature was found showing that starting treatment by leprosy patients influence leprosy NCD. Leprosy patients are known to draw consolation from reassurances and health education given by GHCWs on leprosy after diagnosis (Alubo et al, 2003).

In my experience, patient and leprosy service related factors influence starting treatment. On the patient side, accessibility, affordability, acceptability of leprosy services and the presence of alternative treatment and stigma in the community influences the start of treatment. On the part of leprosy services, knowledge, attitude, motivation, skills, workload and training of GHCWs as well as the availability of MDT at the health facility is important.

Due to stigma associated with leprosy, adequate counseling of leprosy patients may be crucial at this stage else the patient could be lost soon after diagnosis. Starting treatment by leprosy patients is an important step towards getting a cure in leprosy and hence interrupting the cycle of leprosy transmission in the community.

Regularity of MDT clinic attendance and treatment adherence

No literature was found showing that regular MDT clinic attendance and treatment adherence by leprosy patients influences leprosy NCD. However, regular clinic attendance brings the leprosy patients and GHCWs in contact frequently and patient counseling and health education on leprosy takes place during such contacts; health education of patients on leprosy (cause, curability, duration of treatment, side effects of drugs) is known to motivate other patients to seek treatment earlier (Alubo et al, 2003).

In my experience, factors that influence regularity of attendance and adherence to treatment from the patients' perspective include home – clinic distance, awareness, cost of clinic visits, duration of treatment, changing weather conditions, poor terrain, perceived quality of MDT clinics, alternative treatment, stigma and opportunity cost of the clinic visits. On the aspect of the GHCWs, knowledge, skills, and attitude towards leprosy patients, motivation, workload and availability of MDT at health facilities influences regularity and adherence.

Therefore, regular clinic attendance contributes to better treatment adherence which leads to cure and decreased transmission, magnitude and NCD of leprosy in the community.

Cure

MDT cures leprosy (WHO, 2000) and by doing so, the cycle of transmission of leprosy is interrupted and this reduces the magnitude of leprosy in the community. Cured leprosy patients are involved in providing health education and creation of awareness on leprosy in communities and through electronic media (ATBLCP annual report, 2006); communities may listen more to health education messages from their own member than from outsiders (Wong, 2004).

Therefore, curing leprosy patients reduces the magnitude of leprosy in communities and cured patients could influence leprosy NCD through involvement in health education activities.

Summary

Factors influencing leprosy NCD were discussed in this chapter. It was difficult to get literature on the influence of start of treatment, cure, regular clinic attendance and treatment adherence on leprosy NCD probably because their influence on leprosy NCD is indirect.

The following chapter will focus on describing the study done in Koma and Za districts (2007); the influence of these factors on leprosy NCD will be seen in the findings and interpretation section.

4 DESCRIPTION OF THE FIELD STUDY, FINDINGS AND INTERPRETATION

The aim of this chapter is to give an insight into how this study was conducted in Koma and Za districts (2007) and to identify factors influencing leprosy NCD from the 2 districts.

Data collection, processing and analysis will be discussed. Results of the study will be analyzed in order to identify factors that influence leprosy NCD. Where necessary, reference will be made to findings from the Koma study of 2004 (annex 7).

4.1 Methodology of the study

A comparative cross-sectional study of two districts, one reporting high numbers of new leprosy cases (Koma) and the other reporting low numbers of new leprosy cases (Za) detected persistently from 2002 to 2006 was done on factors that influence leprosy NCD. Research tools used in Koma study of 2004 were modified and applied.

Study Variables

The study variables (annex 5) included socio-cultural (stigma, family clustering, awareness among leprosy patients and the communities, misconceptions, alternative treatment), socio-economical (poverty, occupation), health service related (home-clinic distance, waiting time, knowledge of GHCWs).

Sampling

The study population consisted of all leprosy patients on treatment register in Koma and Za districts, all GHCWs in health facilities in Koma and Za districts and 20 community members per district, forming 2 FGD groups of 10 males and 10 females in each district.

Four (4) of the 5 patients registered in Za district and 14 of the 17 patients registered in Koma district were interviewed. Of the 3 leprosy patients in Koma district that could not be reached, 2 travelled after receiving their drugs while 1 defaulted. The leprosy patient that could not be reached in Za travelled after receiving his drugs.

The research team selected members of the FGD groups randomly. A bottle at the end of a rope was spun at the center of the community, the pointed direction was followed and house-hold heads were picked in the same direction until 10 members were selected. Same method was used for women from houses in the community.

The treatment records of patients registered for MDT from 1st January 2002 to 31st December 2006 was reviewed. Questions on awareness and treatment of leprosy and attitude towards leprosy patients were explored (annex 9).

We planned to sample 2 GHCWs each from the 6 MDT clinics in Koma and 2 MDT clinics in Za. There were 2 GHCWs each in the 2 clinics in Za district while one of the 6 clinics in Koma had 2 GHCWs, the remaining 5 clinics had 1 GHCW each. All 4 GHCWs from Za and 7 GHCWs from Koma participated in the study.

Data collection

- Approval to conduct this study was obtained from the Adamawa SMOH, Jada and Michika LGA authorities and community leaders in both districts
- Six Research Assistants (RAs) were trained for 2 days on the research tools (questionnaires, test questions for GHCWs and FGD guide) and data collection lasted 2 months.
- The research tools were not pre-tested
- The questionnaires consisted of both closed and open ended questions and administered by the RAs to all leprosy patients on treatment; some were administered at the health facilities while other patients were followed to their homes
- Standard test questions on leprosy were administered to GHCWs by research team members in their clinics
- The FGDs in Koma took place under a tree in the premises of the clinic on the preference of the group members.
- LGA leprosy central registers and patient record cards in clinics were also reviewed (1st January 2002 to 31st December 2006)

See table of data collection in annex 6.

Data processing and analysis

- Questionnaires were checked for completeness and internal consistency by a member of the research team daily
- Questionnaires were sorted out according to study districts: one group representing Koma while the other group represented Za districts
- Open ended questions including FGDs were categorized according to questions asked
- Data were finally entered into an excel sheet where questions have already been categorized

Quality Assurance

- RAs were trained by the team leader and 2 STBLS for 2 days at the ATBLCP office to ensure standardization of research technique
- The research questionnaires were not pretested before use to collect data.

- Data was checked for completeness and consistency during processing. Inconsistencies discovered were cross-checked with the interviewer or respondent
- In order to maintain the originality of the questions, research tools were translated into the local language (Hausa) by 2 contracted experts, it was translated back to English by 2 different persons. The FGD transcripts were similarly translated
- FGD was recorded on tapes to ensure original words of informants could be maintained and reproduced.

Ethical consideration

- Informed consent was obtained from all respondents
- Respondents were assured of the protection of their privacy and confidentiality with respect to this study
- Recorded tapes of interviews was not used for anything other than the study

Avoiding bias

- RAs were recruited from districts bordering Koma and Za in the study LGAs. This was to ensure a good understanding of the culture and norms
- Standard guidelines were used by RAs while asking questions
- Adequate information on the purpose of the study was given to respondents in order to build trust between them and the research team
- Findings from FGDs, leprosy patient interviews and standard test question for GHCWs were integrated

4.2 Findings and interpretation

The sample size in this study is small; 18 leprosy patients (14 from Koma and 4 from Za) and 11 GHCWs (7 from Koma and 4 from Za); therefore, a descriptive method is used and the data should be interpreted with caution. Findings from FGDs are integrated into other findings in this section.

This section will be discussed under 5 main headings:

- General Information
- Knowledge and awareness of GHCWs, patients and community on leprosy
- Health seeking behavior of leprosy patients
- Social, cultural and economic factors
- Quality of leprosy services

4.2.1 *General Information*

Background variables of leprosy patients considered in this study are presented in table 4.

The age of the 14 leprosy cases on treatment in Koma district ranged from 12 to 60 with a median age of 30 years; 3 were children (less than 15 years) while 11 were adults (15 years and above). The age of 4 leprosy patients on treatment in Za district ranged from 7 to 70 with a median age of 35 years; 1 was a child while 3 were adults. Eight of the leprosy patients in Koma are married, 3 were single while another 3 were divorced. Two leprosy patients in Za were married while 2 were single. Divorce of the 3 leprosy patients in Koma was not related to leprosy.

Table 4: Composition of the registered leprosy population for Koma and Za districts

Variables	Koma District	Za District	Total
AGE (yrs)			
Child (<15)	3	1	4
Adult (15 +)	11	3	14
SEX			
Male	4	2	6
Female	10	2	12
Marital Status			
Married	8	2	10
Single	3	2	5
Divorced	3	0	3
Widow	0	0	0
Widower	0	0	0
Occupation			
Farmer	9	2	11
Trader	2	0	2
Civil Servant	1	0	1
Beggar	0	0	0
Student	1	1	2
Others	1	1	2
Classification			
MB leprosy	13	4	17
PB leprosy	1	0	1

Subsistent farming is the main occupation among leprosy patients in both districts (9 of 14 in Koma and 2 of 4 in Za). Almost all cases detected in both district had MB leprosy type (13 of 14 in Koma and all 4 in Za). Overall, there are more leprosy cases detected in Koma

district (14) compared to Za district (4). Female leprosy patients outnumber the males in Koma (10:4) while this is balanced in Za district (2:2).

4.2.2 **Knowledge and awareness of GHCWs, patients and community on leprosy**

Health Workers

A standard test question was administered to 11 GHCWs in Koma and Za district. Result of the assessment is presented in Table 5.

All 11 GHCWs from clinics in both districts know the cause of leprosy, and all 4 GHCWs in Za district know the transmission of leprosy.

Table 5: Knowledge of GHCWs on Leprosy in Koma and Za health centres

	Cause		Signs		Transmission		Diagnoses		Treatment Duration	
	Koma	Za	Koma	Za	Koma	Za	Koma	Za	Koma	Za
Knows	7	4	5	2	4	4	5	1	5	1
Don't Know	0	0	2	2	3	0	2	3	2	3
Total	7	4	7	4	7	4	7	4	7	4

However, 2 of the 7 GHCWs in Koma did not know the signs, diagnosis and treatment of leprosy and 3 of the 7 GHCWs in the same district did not know how leprosy was transmitted. On the other hand, 3 of the 4 GHCWs in Za did not know how to diagnose and treat leprosy patients and 2 of the 4 GHCWs in the same district did not know the signs of leprosy. Similar gaps in knowledge of GHCWs were identified in the Koma study of 2004 (annex 7).

Therefore, findings from this study indicate that there are gaps in the knowledge of GHCWs on signs, transmission, diagnosis and treatment of leprosy in both districts which is more pronounced in Za district.

Patients

Leprosy patients were asked how frequent they received health education on leprosy from GHCWs when they come to the clinics (annex 11, table 2).

Three of the 4 leprosy patients from Za district were educated by GHCWs monthly on treatment of leprosy, drug compliance, side effects and leprosy reactions and 2 of the 4 leprosy patients in the same district were educated monthly on the cause of leprosy.

Seven of the 14 leprosy patients in Koma district were educated by GHCWs monthly on cause of leprosy and leprosy reactions and 9 of the 14 leprosy patients in the same district were educated on treatment of leprosy, drug compliance and side effects.

The remaining leprosy patients were either educated irregularly or not educated at all when they come to the clinic to collect MDT. This indicates that health education of leprosy patients is not regularly done in both Koma and Za districts; however, it is more irregular in Koma district.

The knowledge of leprosy patients on aspects of leprosy on which GHCWs educate them was assessed in Koma and Za districts (table 6).

Table 6: Knowledge of registered leprosy patients in Koma and Za districts on leprosy

	Knows their disease		Cause of leprosy		Signs & Symptoms		Transmission	
	Koma	Za	Koma	Za	Koma	Za	Koma	Za
Knows	11	3	2	1	13	4	5	2
Don't Know	3	1	12	3	1	0	9	2
Total	14	4	14	4	14	4	14	4

Most leprosy patients from both districts know that they are suffering from leprosy (11 of 14 in Koma and 3 of 4 in Za) and know its signs and symptoms (13 of 14 in Koma and all 4 in Za), however, majority do not know the cause of leprosy (12 of 14 in Koma and 3 of 4 in Za). The FGDs in Koma showed a similar deficiency in awareness on the cause and transmission of leprosy. The opinion on the cause of leprosy was divided between heredity and eating certain foods (goat meat and fresh fish) with most of the opinions in support of eating goat meat and fresh fish as a cause of leprosy. An elderly member of the Koma FGD group said:

"We breed goats in our community to sell, not to eat. Only those who do not know that it causes leprosy eat goat meat. Those that have the disease get worse when they eat goat meat"

On the transmission of leprosy, only one member of the male FGD and 3 members of the female FGD in Koma stated that it was airborne. Most members of both FGDs were still of the opinion that it is transmitted through eating goat meat and fresh fish.

Most of the opinion in Za district FGDs agreed that leprosy is caused by a germ that is airborne, except two members who said it was hereditary.

4.2.3 **Health seeking behavior of leprosy patients**

After noticing their first symptoms, 10 of the 14 patients in Koma consulted traditional healers because of their belief in its ability solve their problem (table 7); in 7 of the 10 that took this action, the symptoms worsened while in 3, there was no change.

Table 7: First action taken by leprosy patients following symptoms in Koma and Za districts

Actions Taken	Koma Patients	Za Patients	Total
Health Centre	2	4	6
Traditional Healer	10	0	10
Nothing	2	0	2
Total	14	4	18

The 2004 study in Koma (annex 7) showed that 70% of leprosy patients visited the clinics first and 16% went to the traditional healers (n=30); this could be because GHCWs in Koma MDT clinics served as RAs. This could intimidate leprosy patients leading to denials of having receiving treatment from the traditional healers.

The opinion of most members of the male FGD group in Koma agreed that traditional healers are better for leprosy patients. This differs from the general opinion of the female FGD group which agreed with going to the health centres as the best action to take. The opinion of the male FGD group corroborates with the health seeking behavior of most leprosy patients in Koma who took traditional medication.

On the other hand, the opinion of the female FGD group shows that women in Koma community prefer the health facilities to the traditional healers. This could be why 10 of the 14 leprosy patients in Koma are females.

Both FGD groups in Za district agreed that it is better for patients to go to the clinics; all 4 leprosy patients in Za went to the clinics when they noticed their signs/symptoms. Members of the FGD group in Za went on to link traditional medicine to failure in treatment and appearance of deformities in leprosy patients. One member said:

"Traditional medicine makes leprosy progress fast in patients and ends up bringing out the disease physically on the patients skin, fingers and toes."

This statement indicates fear of traditional medicine by Za community.

Delay in presentation:

Time lost between noticing of leprosy symptoms and presentation at the health facilities ranges from 5 months to 10 years for the 14 leprosy patients in Koma (median is 2.5 years) and 1 to 5 years for the 4 leprosy patients in Za (median is 3.5 years). An average delay of 2 to 3 years was observed from literature (3.2.3).

4.2.4 Social, cultural and economic factors

Family setting and history of leprosy, attitude of community towards leprosy patients and poverty are discussed below.

Family setting and history of leprosy

While all 4 leprosy patients in Za district and 9 leprosy patients in Koma district stay in single family homes (annex 11, table 3), 5 of the leprosy patients in Koma stay in multiple family setting (2 or more family in the same compound). Most of the members of both FGDs in Koma agreed that it is common in Koma society to find multiple families staying in same compound. One member of the male group stated that:

"It is common in Koma to see a son, father and grand parents, all with their respective families living in one compound."

Similarly, most members of the Za FGD also agreed with this, despite the fact that all 4 patients from Za stay in single family homes.

A member of the Za FGD went on to point out the effects of multiple families staying in one compound. One member stated that;

"It is sad that some fathers allow their children to marry and still stay with them in the same house, sometimes with inadequate rooms. This is why when a disease comes, like leprosy or TB; it infects everybody; because they are too crowded in the house"

This could mean that some members of the FGD group in Za were not happy with multiple family setting in their community. Such expression was not elicited from the Koma FGDs.

On the family history of leprosy (annex 11, table 3), 11 of the 18 patients in both districts have a family history of leprosy (9 of 14 in Koma and 2 of 4 in Za) and more often, it was the mother (4 of 14 in Koma and 2 of 4 in Za). According to the 2004 study in Koma, 50% of leprosy patients (n=30) had a family history of leprosy (annex 7) and in most cases, it was the mother.

Attitude of community and spouses towards leprosy patients

All 4 leprosy patients in Za district and 11 of 14 patients in Koma agreed that their spouses remained caring and supportive towards them. Among leprosy patients registered in Koma, one was divorced, one was isolated and another one said his spouse was not concerned (annex 11, table 4).

All 4 patents in Za district and 12 of 14 patients in Koma agreed that their community remained caring and supportive. However, the opinions from the FGDs were different. While the Za FGD opinion agreed that they freely interact with leprosy patients that are receiving treatment at the health centre, they made it clear that they avoided those that are not on treatment.

One member of the Za FGD went on to say;

"How can we be safe from leprosy if we continue to interact with patients that are not taking treatment? They will infect us."

On the other hand, the opinion of most members of the male FGD in Koma was that leprosy patients are avoided and denied certain foods (goat meat and fresh fish) because these foods are believed to cause or aggravate leprosy and making the disease more contagious. In the female FGD group of Koma, majority of the opinions was that leprosy patients should not be avoided; they however agreed that these foods should not be given to leprosy patients.

The views from both districts indicate stigma contrary to views of the leprosy patients interviewed.

Poverty and leprosy

From this study, 14 of the 18 leprosy patients in the 2 districts are adults, 11 of them are subsistent farmers (table 4).

The effect of leprosy on their occupation is shown in annex 11 (table 5). 6 of the 18 leprosy patients from the 2 districts (4 from Koma and 2 from Za) said leprosy had affected their occupation; their ages were 13, 22, 30, 41, 48 and 70. Note that children above the age of 6 help their parents with farm work in Koma and Za communities.

Table 8 shows the amount reported to be spent by leprosy patients in Koma and Za districts per visit to the clinic. 7 of the 14 patients in Koma spend an equivalent of \$1 or less on transportation per visit to the clinic while 6 spend between \$1 and \$2 equivalent with one patient spending approximately \$7 (N 800) per visit.

Table 8: Cost of transportation (in Naira) to clinic by leprosy patients in Koma and Za districts

Naira	Koma	Za	Total
0 – 120	7	3	10
120 – 240	6	1	7
>240	1	0	1
Total	14	4	18

Note: \$1 is equivalent to N120.

In comparison, 3 leprosy patients in Za spend \$1 or less per visit while 1 patient spends between \$1 and \$2. Only 2 patients (who are in Koma) spent nothing per visit.

When asked on why leprosy patients interrupt treatment in their communities, most members of Za FGD agreed that home – clinic distance and poverty are the causes of treatment interruption while in Koma, patients’ attitude and alternative treatment was mostly mentioned as the cause of treatment interruption.

4.2.5 **Quality of leprosy services**

Review of leprosy patient record cards (2002 – 2006)

132 Leprosy Patient Record Cards (PRCs) from 6 MDT clinics in Koma and 2 MDT clinics in Za districts were reviewed.

PRCs from Koma district (n=126) indicates that the MDT completion rates for MB and PB leprosy cases was 85% and 95%³ respectively with a child proportion of 10% and grade 2 disability rate of 11%. The proportion of children among leprosy cases detected indicates recent infection while grade 2 disability rate indicates delayed case detection from Koma. This shows that transmission of leprosy is ongoing and leprosy cases are still being detected late from Koma communities.

In comparison, PRCs from Za (n=6) showed the MB and PB completion rates to be 83% (5/6) and 100% respectively. No children⁴ or visibly disabled leprosy patients were detected in the period. Treatment completion was satisfactory for both districts.

Home – clinic distance:

All 4 leprosy patients in Za district reside within 5km of the MDT clinics while only 5 of the 14 leprosy patients in Koma stay within 5km, the remaining 9 patients are 6 to 10 km away from the health centres (annex 11, table 6).

This indicates that access to MDT clinics is poor in Koma in comparison to Za district.

³ A completion rate of 85% and above is satisfactory (ILEP, 2001).

⁴ Less than 15 years

Waiting time:

Regarding waiting time of leprosy patients at the health facilities (annex 11, table 7), 6 of the 14 patients in Koma waited for 40 min to 1 hr to be attended to by GHCWs while 3 of the 4 patients in Za wait as long. Only 7 patients in Koma and 1 patient in Za wait for 30 min or less.

When asked what aspect of leprosy services needed to be improved at the end of the study, 7 of the 14 patients in Koma asked for more clinics to be provided closer to or in their communities while all patients in Za were satisfied with leprosy services at their clinics. The 2004 study in Koma also showed that 55% of leprosy patients (n=30) asked for more clinics.

Most members of the FGDs in Koma agreed that more clinics needed to be set up in their communities. The need for increased community awareness on leprosy was also mentioned by a few members of the Koma female FGD while three members of the Koma male FGD mentioned that the availability of drugs at all times is more important than setting more clinics.

Most of the members of the FGDs in Za are satisfied with leprosy services, but a few stated that there was a need for the programme to increase awareness on leprosy within the community.

Summary

In this chapter, an insight was given on how the field study was conducted in Koma and Za districts of Adamawa State and the findings, including those from the FGDs, were presented and interpreted.

The next chapter will summarize important findings from this chapter and discuss them accordingly. The research methodology and the study findings would also be critically analyzed.

5 SUMMARY OF FINDINGS, DISCUSSION AND ANALYSIS OF FINDINGS AND RESEARCH METHODOLOGY

The aim of this chapter is to summarize, discuss and analyze findings and the methodology of the study done in Koma and Za district in 2007. Differences in the influence of factors contributing to leprosy NCD in the 2 districts and the strengths and weaknesses of the study design and methodology will be discussed.

5.1 Summary of findings

Findings from this study indicate the following:

1. Knowledge of GHCWs on leprosy especially its cardinal signs, diagnosis and treatment is poor in both districts; however, this gap is more pronounced in Za compared to Koma districts.
2. Health education of leprosy patients by GHCWs is not regularly given in both districts; it is more irregular in Koma compared to Za district.
3. Leprosy patients in Koma and Za districts have inadequate knowledge of their disease, especially on the cause (12/14 in Koma and 3/4 in Za did not know) and transmission (9/14 in Koma and 2/4 in Za did not know) of leprosy.
4. There are misconceptions about leprosy among leprosy patients and the community in both districts; this is higher in Koma compared to Za district.
5. Most leprosy patients in Koma district (10/14) went to traditional healers after noticing their first signs/symptoms while all 4 leprosy patients in Za district went to the health facilities after noticing their first signs/symptoms.
6. The median delay between acquiring leprosy symptoms and presentation at the health facilities was 2.5 years among leprosy patients in Koma in comparison to 3.5 years among leprosy patients in Za district.
7. Multiple family setting is common in Koma and Za communities, however, only 5 of the 14 patients from Koma and none of the 4 patients from Za live in multiple family settings.
8. Family history of leprosy is common among leprosy patients from Koma and Za districts.
9. Stigmatization of leprosy patients by community members occurs in both Koma and Za districts.
10. Treatment completion rates from both districts is satisfactory, however, there is more evidence of late diagnosis, recent and active infection in Koma district.
11. Health facilities are more accessible to leprosy patients in Za in comparison to leprosy patients in Koma district.

5.2 Discussion and analysis of study findings

5.2.1 Magnitude of leprosy

Review of leprosy PRCs for 5 years from Koma and Za districts indicated that the magnitude of leprosy is higher in Koma in comparison to Za district; leprosy cases are being diagnosed late (DG2=11%), active and recent transmission (Child proportion=10%) is ongoing in Koma unlike in Za district. Such information is used by ATBLCP and other NLR supported states to identify populations that need active screening for leprosy.

A satisfactory treatment completion is important in relation to the magnitude of leprosy as it reduces the source of infection in the communities. It also indicates ATBLCPs ability to keep leprosy patients on treatment till completion. This is achieved through regular GHCWs training, supervision and monitoring of MDT clinics.

5.2.2 Knowledge of GHCWs on leprosy

Knowledge of GHCWs in health facilities on leprosy must be sound in order to ensure leprosy cases are detected among suspects presenting to the clinics. This is why ATBLCP trains all GHCWs from both MDT and non-MDT clinics formally and on-the-job (during supervision), regularly. This study indicates inadequate knowledge of GHCWs on cardinal signs, diagnosis and treatment. This could mean that leprosy cases are being missed especially in Koma district where the gap in knowledge is wider in comparison to Za districts. Already registered cases could also be lost due to the inability of GHCWs to properly educate leprosy patients on their disease. Patients are known to default because of leprosy reaction or side effects of drugs (Alubo et al, 2003).

GHCWs also carry out community health education and poor knowledge of GHCWs could lead to inadequate education of the communities on leprosy which makes case detection and case management of leprosy difficult. Lay men in the community are known to diagnose leprosy in Adamawa State (Van de weg et al, 1998) among peers groups. They can only do so if they are educated on leprosy.

However, factors like motivation, skill, attitude, workload (Awofeso, 1992), supervision, on-the-job training, date of last training on leprosy, availability of workers manual in MDT clinics and qualification of GHCWs which could influence knowledge on leprosy control were not explored in this study. This could have shed more light on why the knowledge of GHCWs was found to be poor which would be helpful for intervention.

5.2.3 ***Knowledge and awareness of leprosy patient and community on leprosy***

Knowledge and awareness of leprosy patients and community is important and has been found to influence early reporting of new leprosy cases to clinics (Burathoki et al, 2004).

ATBLCP uses prepared media jingles and programmes on leprosy which are aired regularly throughout the state; it also carries out community seminars and distributes posters to all health facilities.

Findings from this study indicate poor knowledge and awareness of leprosy patients on cause and transmission of leprosy and misconceptions in both districts which were worse in Koma compared to Za district.

Poor knowledge and misconceptions on leprosy influences stigma. Most opinion from Koma community indicates stigmatization of leprosy patients which could prevent undetected leprosy patients from coming to the health clinics. Community health education has been shown to result into improved knowledge of the patients and the community and a reduction in the level of stigma (Croft and Croft, 1997) and education and media campaigns are known to counteract false beliefs about leprosy and raise awareness about the disease (Rafferty, 2005).

Lack of involvement of communities in producing materials for health education on leprosy could be the reason why poor knowledge, awareness and misconceptions are prevalent in the districts. It is important to work round traditional beliefs and integrate relevant ones into current knowledge of leprosy when producing health education materials in order to achieve the desired impact (Wong, 2004; Rafferty, 2005). Furthermore, the use of community members (cured leprosy patients) in health education could be more effective as they will be believed easily compared to an outsider (Ibid).

Leprosy patients in this study are at different levels in their treatment and their frequency of contact with the health facilities differs and hence their exposure to health education by GHCWs. In addition, their knowledge may not be a reflection of the knowledge of undetected leprosy patients in the communities.

The educational status of leprosy patients was not explored in the study. This is important because it could influence knowledge. Furthermore, most of the leprosy patients are females and studies have shown that their level of knowledge and awareness is lower than that of male leprosy patients (Awofeso, 1995).

5.2.4 Health seeking behavior of leprosy patients in Koma and Za districts

This study indicated that most leprosy patients in Koma accessed traditional medicine before coming to the health facilities unlike patients in Za district. The opinions of Koma community members (unlike that of Za community members) showed that traditional healers are relevant in the treatment of leprosy. This could be why most patients in Koma went to the traditional healers the moment they noticed their signs/symptoms which may be responsible for the delay observed among leprosy patients registered in Koma; this corroborates with the findings of Van de weg, et al (1998) which showed the role of traditional healers and road side chemists in delay by leprosy patients' to access health facilities in Adamawa State. The behavior of leprosy patients in Koma community is also similar to what Mull et al (1989), Reddy et al (1984), and Kumaresan and Maganu (1994) described as reasons for delay in accessing health facilities.

All 4 leprosy patients interviewed in Za said they went to the clinics first, however, it is difficult to draw conclusions due to the small sample (n=4). Unlike Koma, Za communities associated traditional medications with deterioration in health of leprosy patients and this may have influenced the health seeking behavior of leprosy patients in Za district.

Traditional healers are known to be influential in their communities and have a wide coverage. This is why WHO at the Alma Ata declaration recommended collaboration between traditional healers and health system (Stekelenburg et al, 2005). Traditional healers in Koma community could help by referring leprosy patients to the health facilities for treatment with MDT. Collaboration with traditional healers was in the 2005 ATBLCP work plan, however, this could not be achieved (ATBLCP annual report, 2005).

5.2.5 Family setting and family history of leprosy

The transmission of leprosy is favored by prolonged close contact which is possible when people live in multiple-family⁵ settings. 5 of the 14 leprosy patients in Koma and none of the 4 patients in Za stayed in multiple family homes. Opinions of both districts indicated that multiple-family setting is common; however, the opinion of Za community members did not support that.

More than half of the leprosy patients interviewed had a family history of leprosy and most frequently, it was the mother and mothers have a close contact with their family. Multiple-family settings offer an opportunity for prolonged contact between leprosy patients (especially

⁵ Two or more families staying in the same compound.

undetected cases) and members of their families. Being a communicable disease, this favors the transmission of leprosy which adds to the magnitude of leprosy in the community. Leprosy is known to cluster in families and in communities spreading in concentric circles around patients (Chen et al, 2003; Wallace et al 2003).

Although ATBLCP produce and use materials for health education of leprosy patients and communities throughout the state on leprosy, such materials do not capture the hazards of overcrowding and poor ventilation which are common in multiple-family settings and this could contribute to reducing the risk of transmission of leprosy in communities.

5.2.6 *Attitude of spouses of leprosy patients and community towards leprosy patients*

Leprosy patients from Koma and Za communities affirmed that their spouses and communities remained caring and supportive towards them. However, Koma communities avoid and deny leprosy patients goat meat and fresh fish which they believe causes or aggravates leprosy. Although community and patient education has been associated with a positive change of attitude towards leprosy patients, Rafferty (2005), Croft and Croft (1997) found that community members in Bangladesh refuse to eat with leprosy patients despite 90% of them knowing that leprosy is curable.

Findings from this study indicate that patients known not to be on treatment at the health facilities are avoided for fear of transmission of leprosy in Za district. How community members know which leprosy patient is on treatment is not clear. The attitude of community towards leprosy patients in Koma is conflicting. The patients are avoided and denied certain foods by their communities, yet they agreed that the community cares and supported them. Being a sensitive issue, expertise is required by interviewers in order to adequately explore issues related to leprosy stigma. Interviewers in this study only had a brief training and are not experienced in the field of research. This could have affected the way interviews were conducted.

Due to its complex nature, more studies are needed to identify the determinants of stigma in order to identify interventions that work (Wong, 2004). Apart from health education activities carried out by ATBLCP, counseling of leprosy patients is important and helps reduce stigma and restore dignity of leprosy patients (Rafferty, 2005), however, GHCWs in ATBLCP and other NLR supported states have not been trained on counseling of leprosy patients. This leaves a gap in leprosy care which could continue to compromise early case detection, an important strategy of leprosy control.

5.2.7 **Quality of leprosy services**

This study indicated that MDT clinics are less accessible to communities in Koma compared to Za. This could be due to the location of the 6 health facilities in Koma in less mountainous areas making leprosy patients resident in more mountainous areas to walk longer distances. For those with deformities in their feet, long home – clinic distance could result to ulcers even while wearing protective footwear. Long home – clinic distances also affects GHCWs who must conduct contact tracing and examination, community health education and active screening of suspects. These are activities that lead to an increase in leprosy NCD. ATBLCP trained 6 volunteers in 2005 in Koma district to provide leprosy control services; this improved access to MDT services but there are still more distant communities without MDT services.

6 of 14 leprosy patients in Koma reported spending between \$1 and \$2 per clinic visit. Considering how rural Koma district is, where subsistent farming and hunting is the main occupation, this amount is too expensive for leprosy patients.

7 of 14 leprosy patients wait for more that 40 minutes to be attended by GHCWs at the facilities, not to mention the opportunity cost of waiting. This implies that the access of leprosy services in Koma district is poor. Availability, accessibility and affordability of leprosy service are important for case detection and case management of leprosy (3.2.3).

5.2.8 **Gender**

Gender plays an important role with respect to acceptability of services by leprosy patients in their communities (Alubo et al, 2003; Burathoki et al, 2004). All GHCWs from clinics in Koma and Za districts are males. Proper examination of leprosy patients requires adequate exposure, privacy and comfort for the patients in order to diagnose leprosy. Where all GHCWs are male, it could be difficult to deal with female leprosy patients. Health facilities with only male GHCWs could be a barrier for female leprosy patients (Ibid).

Most of the leprosy patients in Koma are women (10 of 14) and most of them have tried traditional medicine before coming to the health facility; this action could have been due to the influence of their husbands who support traditional medication as indicated by the male FGD in Koma. After taking traditional medication without improvement, they presented at the health facilities, which was what they preferred according to the female FGD. This could mean that even if women are aware that it is better for leprosy patients to go to the health facilities, their opinions may be overshadowed by that of their husbands. It is important to consider this while preparing community education

messages for Koma and other similar districts. On the other hand, the stronger belief of Koma men in traditional medication could be the reason why only few are found receiving MDT.

ATBLCP has no intervention targeted at gender issues and this could improve leprosy NCD and minimize the delay in diagnosing leprosy in Koma and Za districts.

5.3 Critical analysis of research methodology

This will be discussed in 2 parts:

1. The relationship between Piot model, the study objectives and the research issues
2. The study methodology in relation to the objectives

5.3.1 *Piot model in relation to the study objectives and research issues*

The objective of this study is to describe general factors influencing case detection of leprosy and conclude on how far they apply to Koma district of Jada LGA and Za district of Michika LGA in order to make recommendations for improvement of leprosy control in Adamawa State.

The adopted Piot model has 8 stages; this study only looked at 5 stages:

1. Magnitude of leprosy in the community
2. Knowledge and awareness of community and patients on leprosy
3. Knowledge of GHCWs on leprosy
4. Patient motivation to consult health services
5. Regularity of clinic attendance and treatment adherence

These aspects that were investigated in this study were not exhaustively dealt with and they were mostly studied from the patients' perspective.

The 3 stages in the Piot model that were not explored in this study are:

1. Examination of leprosy patients and reliability of diagnosis
2. Start of treatment
3. Cure

These are health service related aspects and are important to this study because they also contribute to leprosy NCD (see 3.2.5 and 3.2.6).

Study type

This study described and compared factors that influenced leprosy NCD in 2 rural districts: one with persistent low case detection (Za) and the other with persistent high detection (Koma). A cross-sectional comparative study was used. Considering the sample size of this study, an exploratory study would have been more appropriate.

Sampling and respondents

The total number of leprosy patients on register at the time of this study was small; therefore, all leprosy patients on treatment were interviewed. Being drawn from the MDT clinics, findings from leprosy patients interviewed may not be truly representative of all leprosy patients in Koma and Za districts.

Members of the FGDs in the 2 districts were randomly selected. This was not appropriate because when using a qualitative research method, representativeness of the sample is not of primary concern; study units that could generate the richest possible information are of primary concern (Varkevisser et al, 2003). The FGD groups would have been purposefully selected such that the groups would be homogenous in terms of age, social status, education level etc. This would have given more opportunity for freer discussion during the FGD.

All GHCWs working in all clinics in the 2 districts were administered standard leprosy test questions in order to have an insight into their knowledge on leprosy. An in-depth interview would have generated more valuable information regarding their knowledge. Issues that influence their knowledge like motivation, workload, qualification and level of training on leprosy would have been explored.

Interview of key informants from the communities was not done. We did not know the term "key informers" at that time. They would have been purposefully selected from the communities and could be teachers, community or religious leaders.

Interview with already cured leprosy patients from the community would have contributed a lot to this study, especially on the status of stigma in their community. This would have given us an insight into the level of stigmatization after treatment of leprosy in comparison to stigmatization during treatment.

An interview with traditional healers within the communities was another opportunity missed. This would have given an insight into their opinion about their knowledge on leprosy, whether they refer leprosy patients to health facilities and whether they are willing to collaborate with GHCWs in leprosy NCD.

Over all, information from the potential respondents that were missed out would have allowed for more triangulation of information generated in this study thereby improving its validity.

Study variables and research instrument

Variables used in this study were on knowledge and awareness of patients, community and GHCWs on leprosy, aspects of quality leprosy service such as recording and reporting, accessibility of service (home-clinic distance, waiting time), socio-cultural issues like family setting, alternative medicine and cost of accessing health facilities (annex 5). Acceptability of leprosy services and aspects of quality leprosy services from health service perspective like patient examination, treatment, and community health education were not explored; findings from these aspects could have given more useful information on factors contributing to leprosy NCD.

The leprosy patient questionnaires had mostly closed and a few open ended questions which were not probed during interviews. In addition, some of the questions were not clear (section A; 6, 7, 8: Section B; 26: Section C; 6: Section D, 3). These may have led to loss of valuable information during the interview.

Standard test questions extracted from GHCWs leprosy training manual was used to assess the knowledge of GHCWs. It would have been more appropriate if in-depth interviews were conducted with GHCWs covering additional issues on examination, diagnosis, patient education, community education, treatment, training and supervision. Furthermore, the research tools were not pretested before conducting this study; this would have given us opportunity to identify areas that need clarifications.

Data collection

RAs were not selected from Koma and Za districts, but from other districts of the LGAs. It would have been more appropriate to select RAs from Koma and Za districts so that they will be more conversant with the culture, norms and language in the study areas.

3 leprosy patients in Koma had a poor understanding of Hausa language in which the interviews were conducted and a local interpreter had to be used. Information from these leprosy patients could have been misinterpreted and lost during the interviews.

All leprosy patients' questionnaires had names, dates and signatures of interviewer and person who crosschecked the data for consistency; this made it easier to make clarifications where necessary.

Quality and analysis of data

Data were crosschecked daily by the STBLCO and STBLS and there were no cases of incomplete entries. However, minor inconsistencies were noted and verified with respective interviewers and respondents where necessary.

Translation of research tools including recorded FGD from English to Hausa language and back was done by different persons to ensure the original meanings of questions were retained. Windows Excel was used to analyze the data.

6 CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

One of the ways to improve progress towards complete elimination of leprosy is through improved case finding. Most countries have achieved the WHO elimination target of leprosy; however, some still conceal high endemic areas in their communities. Such is the case with Nigeria, Adamawa and other NLR supported states.

Standard strategies of intervention based on the NTBLCP workers manual has been used in all 36 states of Nigeria since 1995. Now that the national and state prevalence is reduced and the trend shows areas like Koma still being endemic for leprosy, there is need to reshape our strategies. This thesis reveals factors that influence leprosy NCD from available literature and the field study conducted. These factors should be used to improve leprosy control strategies in Koma, Za districts of Adamawa State and other NLR supported states with similar condition.

The need for an intervention to address high endemic areas for leprosy is almost urgent and such interventions should be community specific because of the diversity between communities. Therefore, such a research is the starting point, identifying what factors influence leprosy NCD so that interventions would be well targeted towards them. Further research will build on the weaknesses observed in this research.

With this study, we have taken the first step. I remain optimistic that despite the pitfalls in this study, the findings from this study will be useful in improving leprosy control services in Koma and Za districts of Adamawa State, and other NLR supported states.

6.2 Recommendations

The following are recommendations based on the findings from this study:

To NLR:

Proper counseling of leprosy patients will help in coping with stigma associated with the disease. There is need for NLR to develop a curriculum for training GHCWs on counseling of leprosy patients.

An epidemiological study of existing data should be conducted by NLR in order to identify states with local areas that are highly endemic for leprosy. Another study which builds on the pitfalls in this study should be conducted in such states in order to improve leprosy NCD.

To Jada and Michika LGA:

In order to improve the effectiveness of GHCWs, there is need for the LGAs to transfer female GHCWs to MDT clinics in Koma and Za districts.

To ATBLCP:

There is an urgent need for ATBLCP to review its health education materials in order to include the right mix of traditional beliefs and knowledge on leprosy and create more awareness in Koma and Za communities on leprosy.

The ATBLCP should re-train all GHCWs in both Koma and Za districts. This would improve their knowledge and skills so that they would adequately educate leprosy patients and their communities which will lead to improvement in leprosy case detection.

The ATBLCP should ensure that GHCWs educate leprosy patients monthly and carry out community health education on leprosy quarterly in Koma and Za districts. This will improve the knowledge of leprosy patients and the community and will lead to improvements in leprosy NCD.

The ATBLCP should plan and embark on active case finding (mini-LEC) in Koma and Za communities. This will improve leprosy NCD in the districts.

In order to improve access to MDT services, ATBLCP should identify and train volunteers from Koma district on leprosy case detection and treatment in order to provide leprosy services within each community.

ATBLCP should identify and collaborate with traditional healers from Koma district on suspecting and referring leprosy patients to health facilities. This will reduce delay in diagnosing and improve leprosy NCD in the district.

There is need for the ATBLCP to advocate to the PHC department of Jada LGA in order to solicit for the transfer of female GHCWs to Koma and Za districts.

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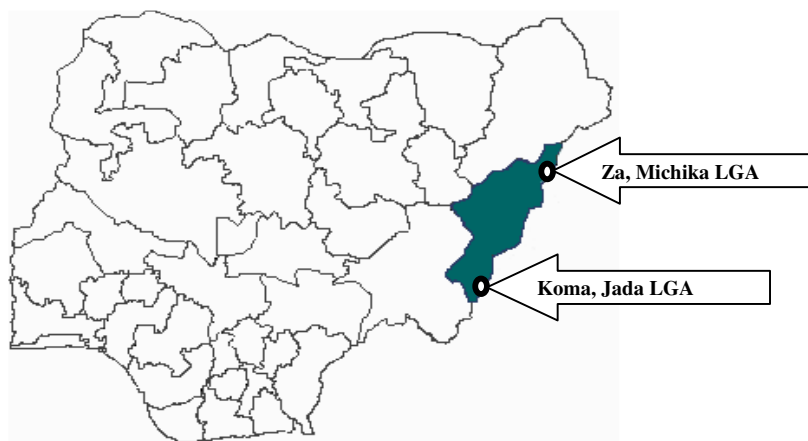
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8 ANNEXES

Annex 1 (a). Map of Nigeria showing Adamawa State, Jada and Michika LGAs.



Annex 1 (b). Objectives and Activities of ATBLCP

The general objectives of the ATBLCP are:

- To reduce the prevalence of leprosy to an extent that it no longer constitutes public health problems by using MDT
- To prevent physical impairments, disabilities, and deformities in all newly detected cases

Specific objectives are:

- To further reduce the prevalence of leprosy
- To detect as early as possible all hidden cases and treat with MDT
- To prevent disabilities among leprosy patient on treatment by using prednisolone in the field

Source: NTBLCP workers manual

1. Case detection of leprosy:

- Public awareness on leprosy through patient and community health education, media and electronic jingles.
- Training of GHCWs on leprosy case detection and management.

- Active case finding in carefully selected communities through organization of mini-Leprosy Elimination Campaigns (mini-LEC).
 - Suspecting, diagnosing and treating leprosy cases in MDT clinics including recording and reporting.
2. Drug and supply management:
 - Planning and maintaining an effective drug, recording and reporting materials and logistic supply management system.
 - Ensuring all STBLS and LGTBLS are trained at the National Tuberculosis and Leprosy Training Centre (NTBLTC) Zaria, Nigeria.
 3. Supervision and monitoring of leprosy control activities:
 - Planning and implementing regular supervision of LGTBLS (including on-the-job training) and all MDT clinics across Adamawa State.
 - Planning and conducting advocacy to relevant authorities.
 4. Other activities include:
 - Collaboration with Governmental and non-Governmental agencies.
 - Production of quarterly work plan, reports of all activities conducted and distribution to LGA PHC departments, SMOH, NLR, NTBLCP and WHO.
 - Production and distribution of annual reports.
 - Continuous monitoring of all activities.

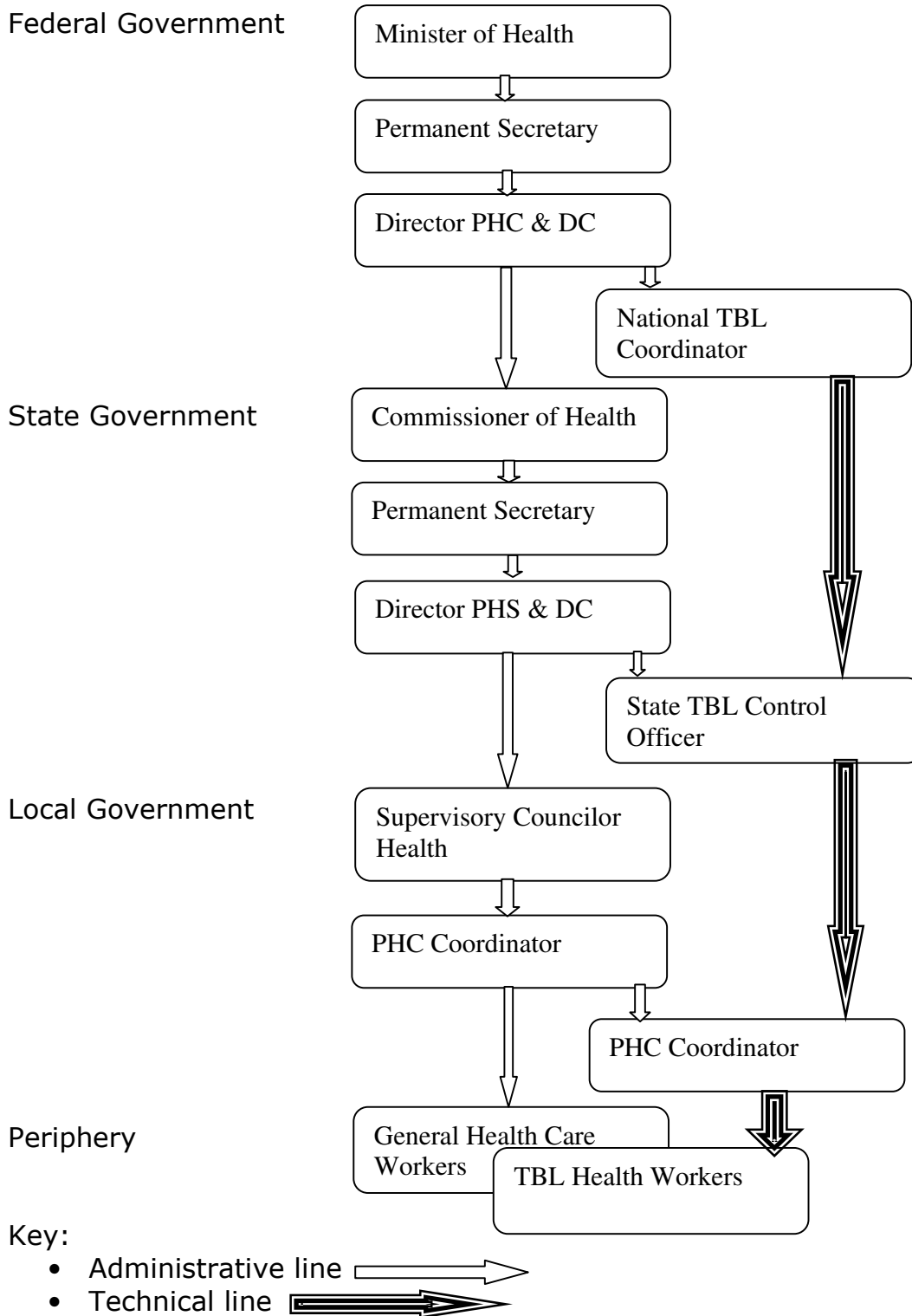
Source: ATBLCP Annual Report, 2006

Annex 2. Government structure and responsibilities in health care delivery in Nigeria.

Tier of Government	Population Covered	Responsibilities
Federal Government	Approximately 100 million	<ul style="list-style-type: none"> • Policy formulation • Information dissemination on public health matters • Technical supervision and support to states • Procurement of special items • Curriculum development and guidelines for training institutions • Training of doctors and specialists • Running and funding of tertiary health facilities
State Government	Approx. 3.6 million	<ul style="list-style-type: none"> • Redefining policies according to local needs • Running and funding of secondary health facilities • Coordination of health activities between LGAs • Supervision of LGA health activities • Training of paramedical staff
Local Government	Approx. 200,000	<ul style="list-style-type: none"> • Funding and implementation of PHC (curative and preventive)

Source: Alubo O et al, 2003.

Annex 3. Organogram of NTBLCP



Source: NTBLCP Workers Manual.

Annex 4. Problem tree

Annex 5: Table of study variables

	Factors	Variables	Indicators
Dependent	High number of new Leprosy cases.	New Leprosy case detection	CDR/10,000 population
			% of Children amongst leprosy cases.
Independent	Living in large family cluster settings	Family clustering	% of registered leprosy patients that reside in cluster type family setting.
			% of registered leprosy cases who had previous or current incident leprosy cases in their immediate family
			Family size (No. of contacts susceptible /family)
	Inadequate Treatment of leprosy cases.	Treatment compliance.	% of new PB and MB leprosy cases completing 6 or 12 doses of MDT respectively within the specified period.
		Alternative treatment for leprosy	Proportion of registered patients that used non-MDT treatment before.
	Poor accessibility.	Travel time to clinic	Average hours
Travel cost		Average cost in Naira	

	Factors	Variables	Indicators
		Poor terrain	Proportion of patients living in hard to reach areas (top of mountains).
	Low level of community awareness about leprosy.	Level of awareness about leprosy.	Proportion of patients aware of early signs/symptoms of leprosy
	Inadequate screening of contacts of leprosy patients.	Examination of household contacts of new leprosy cases	Prop. of registered leprosy cases detected through contact examination.
	Poor socio-economic status	Income status of patient families.	Prop. of patients whose family income lies below the average for the community (to be determined by rapid assessment).
	High trans-border transmission of infection.	Trans – border infection.	Proportion of diagnosed patients who migrated from across the border.

Annex 6: Table of data collection

Variables	Indicators for the measurable Variables.	Definition (if applicable)	Data collection technique	Sources of data	Comments
New Leprosy case detection	% of Children amongst Leprosy cases.	Age 0-14 yrs	Review of clinic records	Patient record cards	What is the influence of health care seeking behaviour on this? Patient record card
Inadequate Treatment of leprosy cases.	Treatment completion rate.	Proportion of new PB and MB leprosy cases completing 6 or 12 doses of MDT respectively within the specified period.	Review of existing records.	Patient record cards and leprosy central register.	Patient record card
	Alternative treatment for leprosy	Proportion of registered patients that used non-MDT treatment before.	Patient interview through questionnaire FGD with community members	Interview and FGD	Question 8 and 9 of patient quest.

Variables	Indicators for the measurable Variables.	Definition (if applicable)	Data collection technique	Sources of data	Comments
Living in large family cluster settings	Family clustering	<p>Proportion of registered leprosy patients that reside in cluster type family setting.</p> <p>Proportion of registered leprosy cases who had previous or current incident leprosy cases in their immediate family</p>	<p>Patient interview using questionnaire</p> <p>FGD with community members</p>	<p>Interview data</p> <p>FGD report</p>	<p>Clinic-based and very little inference can be made as no room for comparison either in that community or neighbouring communities without high case detection rates</p> <p>Modified objective 2. Patient questionnaire C 5, 6, 7.</p>
	Use of non-MDT treatment.	% of registered patients who ever used non-MDT treatment as remedy for leprosy.	In-depth interview with patient using questionnaire/ Focus Group Discussions with community members	<p>Interview data</p> <p>FGD report</p>	Objective 3, Patient questionnaire B 8 ,9, 10

Variables	Indicators for the measurable Variables.	Definition (if applicable)	Data collection technique	Sources of data	Comments
Accessibility	High travel time	Proportion of patients that travel more than 1 hr to health facility	Interview	Interview data	Service-related factor – objective 5 Patient questionnaire D 1, 2, 3,4, 5, 6,7
	High travel cost	Proportion of patients spending more than 50/day to attend clinic	Questionnaire	Interview data	
Poor terrain	Proportion of patients living in hard to reach areas.	Mountain top areas	Questionnaire	Interview data	D 6
Level of awareness about leprosy./practice	Proportion of patients aware of early signs/symptoms of leprosy its treatment.	Knowledge of cause of leprosy, transmission, availability of treatment.	Questionnaire interview	Interview data	Patient questionnaire Section B 1 - 13

Variables	Indicators for the measurable Variables.	Definition (if applicable)	Data collection technique	Sources of data	Comments
	Awareness about leprosy among community members	Knowledge of cause of leprosy, transmission, availability of treatment.	Focus group discussions (FGD) with community members	FGD data	FGD, 1-4
Examination of household contacts of new leprosy cases	Prop. of new cases whose contacts were actually examined by a health worker for signs of leprosy.	Contacts being persons living in same compound as leprosy case.	Questionnaire interview	Interview data/clinic records	Find relevant objective or create one
Trans – border infection.	Proportion of diagnosed patients who migrated from across the border.	Person not originally resident of Koma area that migrated from across the Nigerian border.	Patient questionnaire		Patient questionnaire B, 16 - 21

Annex 7: Summary of findings from 2004 study in Koma district

- From this study, the essential Control indicators for transmission of Leprosy in Koma community are: Child proportion, 24.5%, MB Completion Rate, 82%, PB Completion Rate, 95%, MB proportion, 62% and Proportion of Grade 2 Disability, 1% (3% amongst the patients on register, n = 30).
- These indicators show that there are high numbers of patients recently infected with Leprosy (Child 24.4%) despite having a high treatment completion rate (MB: 85%, PB: 95%) with a low grade 2 disability proportion (DGr 2: 1%), meaning most patients are detected early (DGr 2:1%) and most complete their treatment. 62% of the patients had the more infective type of Leprosy (MB).
- The study also shows that the knowledge of GHCWs in the area under study ranges from 57-100%. More so, the GHCWs working in the area are inadequate in numbers.
- 80% of registered patients received health education at the facilities, and 70% reported first to the Health Facility when they took ill, however, 16.7% went to the herbalists first before reporting to the Health Facilities.
- 50% of leprosy patients had a family history of leprosy; 34% had their mothers as the index case.
- 90% of the patients on register trek to the Health Facilities out of which 23% waited for over 30 minutes to be attended to by the GHCWs.
- 56.7% of the patients on register take an hour or more to reach the nearest health facility; 46.7% of the respondents interrupted treatment. However, some of the reasons given for the interruption were, attitude of the GHCWs (36%), "fed up" (14%), 14% were "too busy with their work"(14%) and "travelled out"(14%).
- 55% of the respondents suggested the need for more clinics, while 35% were satisfied.

Annex 8. Leprosy patient questionnaire.

A. Patient administrative data

1. Name
(optional) _____
 2. Age _____ (Years) Sex M [] F []
 3. Address- _____
-

4. Date of registration. / / 200....

5. Marital status:
- Married []
 - Single []
 - Divorced []
 - Widow []
 - Widower []

6. Occupation:
- Farmer []
 - Trader []
 - Civil servant []
 - Beggar []
 - Others,

Specify _____

7. Disease classification: MB [] PB []
8. WHO disability grade (Eyes): 0 [] 1 [] 2 []
9. WHO disability grade (Hands): 0 [] 1 [] 2 []
10. WHO disability grade (Feet): 0 [] 1 [] 2 []

B. Patient's awareness on disease and treatment

1. Do you know the disease you are suffering from? Yes [] No []
2. If yes to Q1, can you say what it is?

3. What do you think is the cause of the disease?

 - Evil spirits []
 - Germs []
 - Curse by God []

- Eating bad food
- Hereditary
- Others

specify _____

4. How can a person contract leprosy?

- Eating contaminated food
- Inhaling of germ
- Drinking of bad water
- Others,

specify _____

5. What are the signs and symptoms of leprosy?

- Skin patch with loss of sensation
- Headache
- Nerve enlargement/pain
- Abdominal pain
- Tingling sensation
- Others,

specify _____

6. How long have you had this illness (leprosy)? _____
Months/Years

7. When you first developed the illness, how did it affect your daily life?

- Affected the performance of my daily work only partially
- Cannot perform my daily work
- No effect on my daily work
- Others,

Specify _____

8. What action did you take when you first developed the problem:

- Took local traditional medications
- Sought spiritual treatment
- Went to a clinic/hospital
- Did nothing
- Others, (Specify) _____

9. What was the reason for your action in Q8?

- I believe in its ability to solve my problem
- I didn't know of any alternative
- That was the one I could afford
- That was the one closer to me
- Others, specify _____

10. What happened after you took the action in Q8?
- I got some relief []
 - My problem worsened []
 - There was no effect []
 - Others, Specify _____
11. Have you ever known about leprosy before you had it yourself? Yes [] No []
12. If yes to Q11, How long ago before your own case? _____ Years
13. Where did you get the information from?

14. Was there any member of your family who had leprosy before you? Yes [] No []
15. If yes to Q14, what was your relationship with him/her? _____
16. Have you ever stayed on the Cameroonian side of Koma? Yes [] No []
17. If yes, how long did you stay there? _____
Months _____ Years
18. Did you have leprosy before your stay in Cameroon? Yes [] No []
19. Were there leprosy cases where you stayed? Yes [] No []
20. If yes to Q19, did you share same compound? Yes [] No []
21. If yes to Q19, for how long did you share same compound?
_____ Months, _____ Years
22. How long ago did you start your present treatment?
_____ Months
23. How long are you supposed to take your present treatment?
_____ Months
24. Have you had any break in your treatment so far? Yes [] No []

25. If yes to Q24, for how long? _____ Months

26. If yes, to Q24, what was the reason for the break in treatment?

- I thought the treatment was complete []
 - I was too busy with my work []
 - I had no idea of the duration of my treatment []
 - I became fed up with the medicines []
 - I felt my problem had gone []
 - I was discouraged by the health worker's attitude []
 - I was discouraged by my relations []
 - I was discouraged by my friends []
 - I became sicker while taking the medicines []
 - Others, Specify _____
-

C. Socio-cultural and economic factors

1. Where do you reside presently?

- In my personal house []
 - In a rented house []
 - I am accommodated by a relation/friend []
 - I am homeless []
 - Others, Specify _____
-

2. How many other families are staying with yours?

3. How many people in total do you have in your own family?

4. If, more than one family living together, what is the total number in the larger family _____

5. How do you take care of your daily needs?

- From my work I am able to provide for myself and family []
- From begging []
- My Children provide for me []
- My relations provide for me []
- Others,

Specify _____

6. What is the attitude of your spouse(s) towards your illness?

- Caring and supportive []
- Not concerned about it []
- Not caring []

- Isolates me []
- Divorced me []
- Others, specify _____

7. What is the attitude of other members of the community towards your illness?

- Caring and supportive []
- Not concerned about it []
- Not caring []
- Isolates me []
- Others, specify _____

8. Do you suffer any form of discrimination due to your illness?

- I cannot attend important community functions []
- I cannot be a community leader []
- I cannot marry in the community []
- People isolate me []
- Others, specify _____

9. What were you ever taught about leprosy in your clinic?

- Cause of leprosy Yes [] No []
- Treatment of leprosy Yes [] No []
- Importance of regularity of treatment Yes [] No []
- Drug side effects Yes [] No []
- Leprosy reaction Yes [] No []
- Other, _____

10. How frequently were you taught about your illness?

- Monthly [] Once in 3 months [] Can't remember []

D. Accessibility to health services

1. Which part of Koma do you reside in? Mountain Top []
Bottom of Mountain []

2. How far is your home from your treatment centre?
_____Km

3. How long does it take you to reach the clinic from your home? _____Hours

4. How motor able is the road from your home to the clinic?

- Motor able throughout the year []
- Motor able only during dry season []
- Not motor able throughout the year []

- Others
 (Specify) _____

5. How long do you wait for the health worker to attend to you? _____ Min

6. How much does it cost you in Naira to attend your clinic?
 N _____

7. Do you pay for the treatment you are receiving? Yes
 [] No []

8. If yes to Q6, How much did you pay?
 N _____

9. What do you think should be done to improve this service?

Quality check:

	Name	Signature and Date
Questionnaire administered by		
Completeness and consistency checked by		
Categorization/ coding done by		
Entered in data master sheet by		
Countersigned by team leader		

Annex 9. Guide for focus group discussion

Purpose:

The purpose of the FGD will be explained to the participating members of the community. The aim is to discuss with them as representatives of their community concerning leprosy as it relates to their social and cultural beliefs and practices. That the result of the discussions will provide useful information that will enable the State and National TBL control programme assist in containing the situation.

Introduction:

We are health-workers dealing specifically with leprosy patients. This discussion will help us as health-workers to be able to provide adequate care for people with leprosy. Your assistance and co-operation will be highly appreciated (Personal introduction by names of research team). Dr. John Stephen will be the Moderator while Mr. Samuel Saidu and Joel Kaigama will be the note taker and recorder respectively.

Awareness:

What have you heard about leprosy?

What is the cause of leprosy?

What action(s) do you take when someone is suspected of having leprosy?

What is the mode of transmission of leprosy?

Treatment:

How do you think leprosy can be cured?

If traditional treatment is available, is it combined?/ Is one given after the other?/ or in what sequence are they given?/ and for what duration?

If modern treatment is available- try to explore.

Do you believe that leprosy can be cured in your health clinics?

How long a time can someone afford to be treated for leprosy in the clinics?

What will happen if a leprosy patient on treatment decides to discontinue treatment?

What are usually the causes of discontinuation of treatment by leprosy patients?

Attitude:

How do people view leprosy in this community?

How do they relate to patients with leprosy?

If somebody has leprosy what would you advice him to do?

What kind of family setting is common in this community?

Remarks / Suggestions:

Suggest ways in which the existing leprosy control services can be improved upon to meet your local needs.

What role do you as community feel you can play in ensuring that the increase in numbers of leprosy patients arising from Koma community is reduced?

Conclusion:

Thank the community for the co-operation and end with discussions on health education.

Annex 10. Standard test questions on leprosy

General health care workers

1. What is the cause of Leprosy?.....
2. List the cardinal signs of Leprosy:
 - a) _____
 - b) _____
 - c) _____
3. How does one contract Leprosy?.....
4. How _____ is _____ Leprosy diagnosed?.....
5. How is Leprosy treated?.....
6. What are the drugs used in the treatment of Leprosy?
 - a) _____
 - b) _____
 - c) _____
 - d) _____
7. Mention _____ the _____ types _____ of _____ Leprosy _____ you know.....
8. Distinguish _____ between _____ the _____ types _____ of _____ Leprosy _____ stated above.....
9. How _____ long _____ does _____ it _____ take _____ to _____ treat leprosy?
10. What are the parts of body commonly affected by Leprosy?
 - a) _____
 - b) _____
 - c) _____
 - d) _____

Annex 11. Tables

Table 1: Age and sex distribution of registered patients in Koma and Za districts.

Age (yrs)	Number of new cases detected				Total
	Koma		Za		
	Male	Female	Male	Female	
Child (<15)	1	2	1	0	4
Adult (15 or more)	3	8	1	2	14
Total	4	10	2	2	18

Table 2: Health education of leprosy patients by HWs at clinics in Koma and Za districts

	Cause		Treatment		Compliance		Drug side effects		Leprosy reactions	
	Koma	Za	Koma	Za	Koma	Za	Koma	Za	Koma	Za
Yes	7	2	9	3	9	3	9	3	7	3
No	7	2	5	1	5	1	5	1	7	1
Total	14	4	14	4	14	4	14	4	14	4

Table 3: Family settings by family history of leprosy in Koma and Za districts

Family History of leprosy	One family		Two or more families		Total
	Koma	Za	Koma	Za	
Yes	6	2	3	0	11
No	3	2	2	0	7
Total	9	4	5	0	18

Table 4: Attitude of spouses and community towards leprosy patients in Koma and Za districts

Attitude	Spouse		Community	
	Koma	Za	Koma	Za
Caring and supportive	11	4	12	4
Not concerned	1	0	2	0
Not caring	0	0	0	0
Isolates Me	1	0	0	0
Divorced me	1	0	0	0
Others	0	0	0	0
Total	14	4	14	4

Table 5: Effect of leprosy on daily work

	Koma	Za	Total
Affected Work	4	2	6
No Effect on Work	10	2	12
Total	14	4	18

Table 6: Home – Clinic distance of leprosy patients in Koma and Za districts

Kilometer	Koma	Za	Total
0.5 - 5	5	4	9
6 - 10	9	0	9
Total	14	4	18

Table 7: Waiting time of leprosy patients at the clinics in Koma and Za districts

Waiting time	Koma	Za	Total
0 - 30 min	7	1	8
40 min - 1 hr	6	3	9
>1hr	1	0	1
Total	14	4	18