THE PSYCOLOGICAL, ECONOMIC AND SOCIAL EFFECTS OF LEPROSY ON AFFECTED WOMEN IN ADDIS ABABA CITY ADMINISTRATION

By

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DECLARATION

I hereby declare that the dissertation entitled: THE PSYCHOLOGICAL, ECONOMIC AND SOCIAL EFFECTS OF LEPROSY ON AFFECTED WOMEN IN ADDIS ABABA submitted by me for the partial fulfilment of the MSW to Indira Gandhi National Open University, (IGNOU) New Delhi is my own original work and has not been submitted earlier, either to IGNOU or to any other institution for the fulfilment of the requirement for any other programme of study. I also declare that no chapter of this manuscript in whole or in part is lifted and incorporated in this report from any earlier work done by me or others.

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Which she is submitting, is her genuine and original work

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ACRONYMS

ALERT---------	All Africa TB Leprosy Rehabilitation and Training Center
CSSP-----------	Civic Society Support Program
ENAPAL-------	Ethiopian National Association of People Affected by Leprosy
GLRA-----------	German Leprosy and TB Relief Association
KII--------------	Key Informant Interview
MDG-------------	Millennium Development Goal
MDT-------	Multi Drug Treatment
MEDaC-------	Ministry of Economic development and Cooperation
MOH--------	Ministry of Health
NCDR--------	New Case Detection Rate
PALS ----------	People Affected by Leprosy
PWD----------	People With Disability
SNNPRS-----------	Southern, Nations, Nationalities and Peoples Regional State
WHO-----	World Health Organization

ABSTRACT

Leprosy is a public health problem that strongly affects the whole aspects of life of the victims due to the wrong conceptions about its causes. It is known that the common misconception that a society holds about leprosy include: that it is a hereditary health problem, it’s untreatable and it’s a curse from God. These societal beliefs have usually resulted in stigma and discrimination of the victims. The psychological, economic and social effects of leprosy on affected women along with the roles and responsibilities assigned to them made the problem severe.

The main objective of this study is to investigate the psychological, economic and social effects of leprosy on affected women and identify areas for social work intervention strategies to improve the life of women leprosy patients in woreda 1 of Kolfe Keranio sub city of Addis Ababa.

The study was conducted in a purposely selected woreda to collect qualitative information on the root causes, and the effects of leprosy on women. The data was collected through structured interview to assess the situation, challenges and experiences of the people living with leprosy. In-depth interview, key informant interview, document analysis and FGD were also held to gather detailed information that help to investigate the root causes and consequences of leprosy.

Findings of the study reveal that leprosy is one of the public diseases that prevail in the area where treatment is given. That is why victims dwell around the institution, ALERT, for years even after treatment and cure. The whole issue of social exclusion emanates from the misconception on the root causes of leprosy. The finding of the study identified loneliness as a major psychological problem which people with leprosy usually encounter. This feeling arises from the separation of the leprosy patients from their families and beloved ones. The other finding of the study is the lack of equal opportunity on the job market for persons with disabilities in general and leprosy patients in particular. The respondents have revealed that they often face unjust treatment when applying for a job. With regard to the stigma and societal segregation caused by the disease, the finding of the study shows that, almost all leprosy affected persons are forced to hide themselves from their relatives, so as not to be stigmatized and not to disgrace their families in their communities, and migrate to areas very far from their birth places preferably to leprosy colony settlements.

The study concludes that leprosy and the consequent social, economic and psychological effects causes a double burden on particularly the affected women. To overcome the situation, the findings of the study call for a strong campaign to enhance awareness creation of the victims and the society at large.

CHAPTER ONE

INTRODUCTION

1.1 Background of the Study

“Leprosy” or Hansen’s disease is named after Armauer Hansen, the Norwegian doctor who first detected the bacteria of the disease in 1870’s. It is a chronic infectious disease, caused by mycobacterium leprous. It mainly spreads via droplets from nose to mouth. Its transmission is high during close and frequent contacts with untreated, infected individuals (Naafis,).

Leprosy is one of the oldest diseases that affected millions of people around the world mainly Asia, South America and Africa. According to WHO report, every year, between 500,000 and 750,000 new leprosy cases are detected throughout the world. In the year 2005, for instance, over 500,000 new cases were identified, that is over 1400 every day or close to 60 people every hour (WHO, 2007). Leprosy is one of the critical public health problems in developing countries. It affects the social and economic status of the patient (Menberu et al. (2001).

Leprosy has a long history in Ethiopia. Historical evidence indicates that the disease was in Ethiopia before 16th century (Duff, 2005; Mesele 2005). According to Mesele (2005) the Portuguese diplomatic missionary, Chaplain Franciso Alvaes, had rendered the first information about the disease in the country in 1520. Mesele believed that the disease might have occurred in Ethiopia through the long distant trade and other cultural relationships.

However, medical treatment began in the country in 1950 (ENAPAL, 2000). But this does not mean the disease had not received any attention before this period. It had received much consideration during the period of Menilk and Hailesilase when different colonies and settlement areas were established in different parts of the country from 1900 to the beginning of 1960’s (Mesele, 2005). The Multi Drug Treatment (MDT) which is currently being used and relatively effective type of medical treatment was also introduced in the country in 1983. Consequentially, tremendous decreases have been registered regarding the prevalence rate of the disease in the country (MOH, 2005)

Although the prevalence rate of the disease has been decreased after the introduction of MDT in the country, the number of new identified leprosy cases in the country has remained similar over past decades. For instance, the Ministry of Health report shows that new cases reported in the year 2004 were 5,277 and this has not shown remarkable change when compared with 5,585 cases that were identified before ten years in 1994 (ENAPAL,2006). This statistics does not signify the prevalence of the problems in the country as it only represents those who were diagnosed in health centers. There might be many cases that were not detected particularly in rural areas where there is limited basic health care service. On the other hand, because of low level of awareness on the causes, transmission and treatment of the disease, people might not go to the health centers even if the health services are accessible to the community.

The Ethiopian National Association of Persons Affected by Leprosy (ENAPAL) was established in 1997 in the name of Ethiopian National Association of Ex-Leprosy affected people (ENAPAL, 2009). The organization was founded by leprosy patients who were angry at the discontinuance of free medical service of Alert hospital (Duff, 2005).

The major objective of the association is to fight against leprosy and leprosy related problems. According to quarterly bi-lingual newsletter published in May 2007 by ENAPAL, advocating for equal opportunity, ensuring full participation, creating awareness among the communities about the disease, rehabilitating PALS(persons affected by leprosy) and tackling cultural, social and economic shocks is the basic mission of the organization.(ENAPAL,2007)

There appears to be regional gender disparity among leprosy patients being diagnosed and treated. In Asian countries, more men than women are registered whilst in Africa female patients outnumber males. The Netherlands Leprosy Relief (NLR) therefore initiated research into factors underlying these regional gender differences. Between 1997 and 1999, leprosy control teams in Indonesia, Nigeria, Nepal and Brazil supported by social/public health scientists, conducted comparative exploratory research. They looked at three groups of potential explanatory factors: biological, socio-cultural/economic and service-related. The studies were partially quantitative (analysis of the records of patients who according to prescription could have completed treatment) and partially qualitative (interviews/focus group discussions with patients, their relatives, community members and health staff on perceptions of leprosy, its socio-economic consequences, treatment and cure). Biological factors appeared similar in the four countries: irrespective of the male to female ratio, more men than women were registered with Multi Bacillary (MB) leprosy. Strong traditions, the low status of women, their limited mobility, illiteracy and poor knowledge of leprosy appeared to be important socio-cultural factors explaining women’s under reporting.

Yet, accessible, well reputed services augmented female participation and helped to diminish stigma, which in three out of the four societies seemed greater for women than for men. These positive effects could still be higher if the services would enhance community and patient education with active participation of patients and ex-patients themselves.

The psychological, economic and social problems of women affected by leprosy is interwoven with the misconception of the large community about the cause of leprosy and the socio cultural factors related to gender roles and responsibilities that inhibit women from accessing and controlling resources including decision on their personal health care and services.

The misconception around the causes of leprosy: that it is hereditary or is a curse of God exposed victims of leprosy including women to stigma and discrimination. The low status of women, lack of access to information and education about leprosy, the household chores of women or work load has its own negative bearing on women affected by leprosy. Therefore, women affected by leprosy do not give time and due attention for medical checkup and timely treatment. If women do not go to health facilities and get diagnosed, they would be susceptible to disabilities. Disability has a strong psychological effect on women affected by leprosy as it leads to lack self-confidence and respect of their identity as women and mothers. Women affected by leprosy also face a challenge to get employment; and even if they get employed they do not get equal opportunity and are discriminated. Moreover, socially a woman affected by leprosy lacks self-esteem to get involved in different social affairs such as Idir, wedding and different social gatherings with the other community members freely.

This particular research on the psychological, economic and social effects of leprosy on women has its own contribution for the victims. Due to the additional responsibility they have at the family and community level and the negative or low attitude given to them, the influence of the disease is severe on women. Hence, the research focuses on the social exclusion and the effects of women affected by leprosy in Addis Ababa, with particular emphasis on Woreda 1 communities of Kolfe Keranio sub city.

1.2 Statement of the problem

A baseline needs assessment study on persons affected by leprosy and their family members in Addis Ababa was conducted in 2001. It focused on disability, socio-economic situation, attitude, self-esteem. The study is one of its kind and can be considered as a baseline assessment and a pioneer for it has extensively raised many critical issues of the victims. It has specifically focused on the area around All Africa TB Leprosy Rehabilitation and Training Center (ALERT) where ex-leprosy patients dominantly live. As the study involved leprosy patients, their families and those people living in their surroundings who are not affected by leprosy, it is very comprehensive in describing the issue and the situation of the victims (Menberu et al., 2001).

According to annual magazine, ‘Truth”, published by ENAPAL the aim of GLRA is the medical and social healing of the individual and victims of leprosy. There is TB and Leprosy Control program in all regions including the two Administrative cities. There are also a socio-economic rehabilitation projects in Tigray, Oromia, Amhara, SNNPRS, Harari, Dire Dawa and Addis Ababa. As a result, PAL are excluded from the family and the other community and led their own lives (ENAPAL, 2015).

If the woman affected by leprosy is not treated or delayed to get proper treatment, she will be exposed to disability or physical impairment. This is the common incidence for women affected by leprosy. In most cases, the physical impairment due to the disease provoked the stigmatized attitude at the society level and affects the psychological, economic and social well-being of the victims. The stigmatized attitude strongly breaks the social bond and results in isolation and discrimination of PAL from family, friends, relatives and the community at large (ENAPAL, 2004). Not only for the disabled women in leprosy but also the women who are treated and cured from the disease do not escape from the social exclusion due to the deep rooted misconception of leprosy.

The issue of leprosy is serious for the women victims of leprosy due to lack of adequate information and education on a disease. Besides, if they are not treated and cured timely, they are exposed to disabilities. Different studies show that men in leprosy outnumber those of women for women do not go to the health facilities and do not know the conditions they are in. This fact is also supported by the annual magazine of ENAPAL, “Truth”, issued on January 2016. However, for the women who are illiterate, dwell in the traditional and socio-cultural setting of the community and are not diagnosed and do not go to health facilities, the manual may not benefit them.

The whole system of social marginalization is often understood by a powerful centuries old ideology. It affects everyone and shapes the prejudice of mainstream group but may also generate low esteem to people who experience discrimination. In particular, it captures the experience of certain groups and categories in a society of being somehow ‘set apart’ from others, of being ‘locked-out’ or ‘left behind’ in a way that the existing frameworks for poverty analysis had failed to capture. It also allows a bridge between the concept of poverty, which focuses on absolute levels of deprivation, and that of inequality, which is concerned with distributional issues (CSSP, 2014)

The communities in general and women in particular are seriously affected by leprosy and are deprived of socio-economic benefits for they are enclosed in their own surrounding, the participation and benefits acquired from different infra-structure are not accessible. Hence, this particular research helps to shift the balance of attention towards the most excluded people particularly women and will ensure that the strength and asset of poor people and their culture are recognized.

Hence, this particular research tries to address the situation of women in leprosy and fill the gap on the information, education and communication of women affected by leprosy. It reveal the severe psychological, economic and social effect women’s in leprosy face as a result of social stigma and discrimination.

Research questions

- What does the life of women affected by leprosy look like?
- How does leprosy affect the psychological, social, economic well-being of women?
- What is the perceptions of people (both affected and non-affected) about the causes of leprosy as a disease?
- What are the major causes of social exclusion of women affected by leprosy?
- What social wok interventions could be put in place to improve the conditions of women with leprosy?

1.3 Objectives of the study

1.3.1 General objectives

The overall objective of the study is to investigate the psychological, social and economic effects of leprosy on affected women in Addis Ababa and identify possible areas for social work intervention strategies to improve the life of the patients.

1.3.2 Specific objectives of the study

a) To assess the psychological, social and economic effects of leprosy on women patients
b) To identify the root causes of social exclusion of women affected by leprosy
c) To assess the ways in which the social exclusion is manifested in the life of victims
d) To pin point contributing factors and actors that influence change
e) To analyze the issue of leprosy from gender perspective
f) To draw recommendations per the discussion and analysis of the study

1.4 Scope of the Study

This paper deals with the psychological, social and economic problems of women affected by leprosy due to the social exclusion. It also tries to pinpoint the factors and actors for the perpetuation of the social exclusion of people affected by leprosy so as to get the underlying and immediate causes.

The study area of the paper is Addis Ababa, Kolfe Keranio sub city around ALERT and Saint Gebre Kiristos Church where the majority of ex-leprosy people dwell. Because of financial and time constraints, the scope of the study is delimited to Woreda one of Kolfe Keranio sub city.

1.5 Significance of the Study

This study is significant in terms of identifying the problems that women in leprosy face due to the stigma, discrimination and social exclusion. It is also significant as it pinpoints the special needs of women affected by leprosy due to the negative attitude of the society towards the leprosy as disease and the double marginalization that women encounter due to their gender roles and responsibilities in the community.

Hence, the study primarily helps the women victims suffering from leprosy by showing the situation they are in and indicating action points that would help to improve their situation. The findings of the study will benefit policy makers and planners serving as an indicator of the gap that has to be worked on. Besides, it is beneficial for implementing partners both government and non-government organizations for it reveals the actual life of women in leprosy face and address the problems accordingly. The fact that the study highlights the importance of including the needs of this section of the society in all development endeavors and the importance of hearing their voices are additional significance of the study. It can also attract and direct the attention of different governmental and non-governmental organizations to this particular issue.

1.6 Definitions of Basic terms

Conceptual Definitions of Basic Terms

Leprosy: - a chronic, mildly infectious disease caused by *Mycobacterium leprae,* affecting the peripheral nervous system, skin, and nasal mucosa and variously characterized by ulcerations, tubercular nodules, and loss of sensation that sometimes leads to traumatic amputation of the anesthetized part.

Social exclusion: -refers to tendency of vulnerability of people to be excluded socially and economically due to the inability of a society to treat all groups with equality

Social Marginalization:-is discrimination based on the basis of caste, gender, age, HIV status, occupation, ethnicity , religion, sexual orientation color leading to stigma, discrimination, sustained exclusion and something violence, overlooked development challenges or themes such as chat addiction and mental health problems.

Stigma-is an attitude of identifying and labeling people, based on presumed thought through out to be unacceptable qualities or deviant.

Prejudice: a rigid and usually unfavorable judgment about an out group that does not change in the face of contradictory evidence and that applies to anyone who shares the distinguishing characteristics of the group.

Discrimination: intentional or unintentional unequal treatment of individual or groups on the basis of attributes unrelated to merit, ability, or past performance.

Operational definitions of Basic terms

Leprosy prevalence: - is the total number of leprosy cases registered for MDT at the end of the reporting year. The **prevalence rate** is the total number of leprosy cases registered for MDT at the end of the reporting year divided by the total population of the area; usually expressed as a rate per 10,000 population. WHO defines the ‘elimination’ of leprosy as the achievement of a prevalence rate below one case per 10,000 population?

Leprosy case detection: - is the total number of new leprosy cases detected during the reporting year. **New Case Detection Rate (NCDR)** is defined as the total number of new leprosy cases detected during the reporting year divided by the total population of the area; expressed as a rate per 100,000 population.

The conceptual and operational definitions are given regarding the major concepts and terms that are employed in this study and it is in the light of these explanations that the paper tries to analyze them.

CHAPTER TWO

REVIEW OF RELATED LITERATURE

2.1 An overview of Leprosy in international and regional context

Different speculations as to the birthplace of leprosy as a disease have been made. Some writers consider upper Nile and others believe river Indus and Israel as the cradle of leprosy. In fact, the absolute evidence for the occurrence of the disease is seen in the skeleton of Egyptians in the 2nd century BC and mummified bodies of the 5th A.D. (Menberu et al., 2001).

According to Mesele (2005) historical literature of leprosy came in the 2nd half of the 20th century particularly on speculating the birth place or origin of leprosy as a disease. After different historical episodes the first objective evidence for the prevalence of leprosy in Egypt came only from archaeological findings, which uncovered four leprous skulls buried in the Egyptian oasis of Dakhleh,in 200 B.C. The second indubitable archaeological evidence, with clear pockmarks of mutilating leprosy was discovered from the burial ground of Coptic Christians at El-Bigha, in Upper Egypt dated 500A.D. India and the Indus river valley have also been ascribed by others as birth place of leprosy. Moreover, the Persians who had developed strong socio-economic relations with Indians and had recruited them in their armies had such experience too.

In general, more than single historical episodes such as wars, trade and pilgrimages are given for other long term factors for the dissemination of leprosy among different regions and peoples. (Mesele, 2005)

Leprosy presently occurs markedly in territories of Asia, Africa, and central and South America. However, the disease is observed to be severe and widely spread in Africa. As the baseline need assessment study carried out in 2001 revealed, the distribution and prevalence of leprosy is neither uniform nor random. The distribution and prevalence of leprosy are observed to be higher in males than females apart from certain African countries, where higher rates have been reported among females. However, it is the female who suffer more from the effects of leprosy than men due to the low natural immunity, resulting from pregnancy and their low social status. ((Menberu et al., 2001).

2.2 Leprosy in the Ethiopian context

Historical records and researches reveal that leprosy is ages old in Ethiopia and it is believed to have originally spread from neighboring countries-Nubia, Egypt and countries around the Red Sea because of Ethiopia's strong trade relations with these areas. (Baseline, 2001) A book on historical studies of selected sites 1901-2001"Leprosy, Leprosaria and society in Ethiopia" by Mesele (2005) also revealed that by virtue of its long standing trade and other cultural relations with the leprosy ridden regions of the world i.e. Egypt, the Orient, the Greco-Roman world and the Arabian peninsula, leprosy might have been one of the most ancient diseases in Ethiopia.

At the moment, more than ten thousands of leprosy affected citizens including their families and relatives live in leprosy settlements. Thousands are adding up every year with 7-14% of disability rate among newly diagnosed cases alone which reach up to 5000 annually. The number of new cases in the twenty years seems to show no significant change. As a result, thousands have become disabled and are forced to live in Stigma and the resulting socio-economic complications. (ENAPAL, 2014,). The book entitled 'The pleasing unspoken voices' written by Desalegn (2014) also acknowledges that before MDT the treatment was taken for long and people interrupt taking the medicine and engaged in labor works that aggravated disability profoundly.

Leprosy is considered as hereditary and a curse of God. Even marriage with leprosy affected people was prohibited legally in the former Ethiopian family law. There were also poems written to depict the social disparity of the victims from others. In this particular book, the misconception about the disease inhibited the victims from going to hospital but rather resort to traditional medicine. (Desalegn, 2014)

The landmark contribution for contemporary leprosy work in Ethiopia started in 1955 when a German reporter Graf Von Magnis and a theology student Mr. Recke had travelled through Ethiopia. On their way, they met Dr. Jean Feron, the pioneer of modern medication for leprosy patients in Ethiopia. The French Doctor came to Harar in 1930 and used to work and facilitate the leprosy medical service together with the Catholic Church that was granted a plot of land from the then governor of Harar, Ras Mekonnin, in the beginning of the 20th century for looking after leprosy patients. (GLRI, 2012)

2.3 Prevalence and Distribution of Leprosy

According to the Ethiopia Leprosy Mapping project-phase one, conducted at national level by involving concerned bodies based on the subsequent six years data from 2000-2005 E.C, among the 837 Woredas found in the country 768 (92%) have submitted the complete data on leprosy based on the questionnaire. Of the 768 Woredas that have submitted leprosy mapping data; 93, 121 and 324 Woredas respectively were categorized as high, medium and low leprosy burden Woredas based on the nationally developed operational definition. (Ethiopia Leprosy Mapping Project Phase 1Results, March 2015 Addis Ababa, Ethiopia)

These 93 high leprosy burden Woredas were reported to accommodate 54% of all leprosy cases. Those 121 and 324 Woredas who are categorized as medium and low leprosy burden Woredas were reported 28% and 19% leprosy cases respectively. This result is clear indication that more than half of leprosy cases were reported to the national level only from few Woredas (93). Among regions, 2,046 leprosy cases (49%) were reported from Oromia followed by Amhara region with 1,409 cases (34%) and SNNPR region 348 cases (8%).These three main regions in Ethiopia constituted 91% of all the cases reported. Addis Ababa is found in the 4th place by registering 100 cases. Reports of all leprosy cases recorded in the six year period under study were analyzed. Leprosy cases between 3,669 and 4,539 were recorded annually in Ethiopia, giving six year average of 4, 143 leprosy cases registered annually. Of all cases reported in the study period, 93.4% are new cases. The remaining 6.6% represent cases that are categorized either as defaulters or relapses. This brings into question the management of almost 300 cases per year: why did the default? Was it truly a case of relapse?

The prevalence of leprosy has sharply declined from 19.8 per 10,000 populations in 1983 to 0.5 per 10,000 populations in 2012 following the introduction of Multi Drug Therapy (MDT) since 1983. According to Ministry of Health data sources, after introduction of MDT a total of 126,592 new cases were detected and 149,592 patients were released from treatment. However, notifications of new leprosy cases have been consistent over the last ten years starting from 2001(ENAPAL, 2014).

According to the five years data (2008-2012) shown below in Table 1, there is a wide variation in the leprosy prevalence among regions from 0.1 per 10,000 in Somali region to 2.2 per 10,000 in Gambella. Even between years there can be a large variation in leprosy prevalence in each region.

Table 1: Regional leprosy prevalence per 10,000 population over 2008 - 2013

Region	2000 E.C/ (2007/08)	2001 E.C (2008/9)	2002 E.C (2009/10)	2003 E.C (2010/11)	2004 E.C (2011/12)	Five year average
Tigray	0.3	0.2	0.2	0.0	0.1	0.2
Afar	0.1	0.2	0.5	0.0	0.6	0.3
Amhara	1.0	0.9	0.9	0.0	0.5	0.6
Oromia	0.9	0.9	0.9	1.1	0.7	0.9
Somali	0.0	0.0	0.1	0.0	0.2	0.1
B/Gumuz	0.6	0.8	1.0	0.6	1.0	0.8
SNNPR	0.2	0.2	0.2	0.1	0.2	0.2
Gambella	2.8	1.2	3.1	2.0	2.1	2.2
Hareri	1.6	0.5	0.3	0.2	0.4	0.6
Addis Ababa	0.4	0.3	0.2	0.1	0.1	0.2
Dire Dawa	0.6	0.5	0.5	0.0	0.5	0.4
National	**0.7**	**0.6**	**0.7**	**0.4**	**0.5**	**0.6**

The most relevant epidemiological measure of the burden of leprosy is the incidence of the disease, which represents the number of people developing leprosy during a set period of time (usually one year), in a specific population. Since incidence of disease is difficult to measure directly, the "New Case Detection Rate" (NCDR) is used as a proxy for incidence rate. It seems likely, however, that some new cases never come for diagnosis and treatment, so the number of cases detected is lower than the number of incident cases.

Table 2: Number of new leprosy cases notified from 2008-2012 by regions

Region	2000 E.C/ (2007/08)	2001 E.C (2008/9)	2002 E.C (2009/10)	2003 E.C (2010/11)	2004 E.C (2011/12)	5 year Average	Average %
Tigray	115	66	78	19	63	68	1.7
Afar	19	29	83	0	112	49	1.2
Amhara	1556	1393	1330	0	1007	1057	26.1
Oromia	2152	2201	2285	3063	1873	2315	57.1
Somali	8	15	16	0	80	24	0.6
B/Gumuz	37	58	71	47	72	57	1.4
SNNPR	272	280	222	163	261	240	5.9
Gambella	67	31	107	37	80	64	1.6
Hareri	29	9	6	5	9	12	0.3
Addis Ababa	84	85	42	13	44	54	1.3
Dire Dawa	19	16	17	0	18	14	0.3
Fed.Hospitals*	58	119	170	0	157	101	2.5
National	**4,416**	**4,302**	**4,427**	**3,347**	**3,776**	**4054**	**100**

Nearly 7% of new cases were children under 15 years of age but it was as high 61% for Benishangul Gumuz. The proportion of new cases with Grade II disabilities at the time of diagnosis was 11% in average and it was high in some regions like Benishangul Gumuz, Gambella, Amhara and SNNPR regions. The male-to-female ratio at national level was 2.2 with some regions like Afar reaching a ratio of 3.7 (Table 3).

Table 3: New leprosy cases versus grade II disability, child cases and male-to-female ratio from the leprosy mapping data

Region	New case	No. Grade 2 disability	Perc.	No. child case	Perc.	Male cases	Female case	Proportion(Male to Female)
Tigray	60	4	7%	2	3%	40	20	2.0
Afar	14	0	0%	0	0%	11	3	3.7
Amhara	1277	183	14%	123	10%	750	354	2.1
Oromia	1920	144	8%	103	5%	1342	579	2.3
B/Gumuz	56	18	32%	34	61%	5	7	0.7
SNNPR	327	45	14%	9	3%	164	63	2.6
Gambella	71	17	24%	0	0%	37	32	1.2
Harar	18	0	0%	1	6%	13	5	2.6
Addis Ababa	88	5	6%	6	7%	47	31	1.5
D/ Dawa	20	1	5%	2	10%	13	7	1.9
National	**3,841**	**417**	**11%**	**280**	**7%**	**2,419**	**1,099**	**2.2**

Looking at the regional data for new leprosy cases over the last six years, although the average national proportion of male to females is 2.2, showing that twice as many men are diagnosed compared to women. This proportion is as high as 3.7 in Afar. Traditionally leprosy cases seem to be higher in men than women, but such large difference may be reflecting a social issue such as gender equality and access to healthcare services.

As it was expressed from different sources, the number of men affected by leprosy outnumber the number of women. The issue of leprosy on the one hand is the discrimination ofthe victims from the community and when it is seen from gender perspective, it has double effect on women to go out to the front and get diagnosis due to the sociocultural, economic and low attitude given to them.

Analyzing the leprosy mapping data by zones shows uneven leprosy prevalence within the regions of Ethiopia with some zones carrying a larger leprosy burden than others. For example, in Tigray, 75% of leprosy cases were reported from Southern zone. Kolfe Keraneyo and Nefas Silk Lafto reported relatively high leprosy cases from Addis Ababa city Administration. Of the 10 sub-cities in Addis Ababa, reported cases of leprosy with the highest numbers being Kolfe Keraneyo (29.5% of Addis Ababa's cases) and Nefas Silk Lafto (11.8%).

As it has been observed from the data (Desalegn, 2014) leprosy is an issue of the country and at the moment there are about 40 settlements for leprosy victims. The major ones are Gebre Kiristos in Addis Ababa, Addis Hiwot, Tesfa Hiwot and Kuyera Settlements in Oromiya regions. According to German leprosy and TB Relief Association (GLRI Ethiopia) bulletin of 2012 the number of leprosy cases / prevalence in 1982 was 80,927 and in 2012 it become 534,587. Number of leprosy cases released from treatment in 1982 was 4813 in 2012 in total new cases detected from 1983-2012 were 156,500. Number of leprosy cases that have been released from treatment as cured since 1982 are 156, 500(GLRI, 2012).

The leprosy is a public health and it is found in all nine regions and the two city administration though the prevalence varies. The Annual bulletin by Ethiopian National Association People Affected by Leprosy (ENAPAL) published in 2014 revealed that regarding the number of newly detected leprosy cases at national level in 2012 was 3776 people, additional 171 new cases were also reported from the federal referral hospitals. The largest new cases were reported from Oromia and Amhara regions that account 1873 and 1007 respectively. New cases in Addis Ababa in this particular year was 44 and the least new cases is in Harari, 9 people (ENAPAL, 2014).

As it can be observed from the detailed information of the prevalence and distribution of leprosy mentioned above, the issue is very alarming that needs the collaboration of partners and stakeholders. It is particularly serious to give due attention to children that are affected to leprosy. As one of the KII respondents and one respondent from women affected by leprosy revealed the level /extent of being exposed to leprosy exacerbated due to poverty.

2.4 Causes of leprosy

The causes of the disease are closely interwoven with myths, superstitions and false conceptions of people. Hence, leprosy is mostly considered to have natural and super natural cause. As a result, the majority think that leprosy is a punishment to something evil that the victims have done. More and more, it is recognized to be related with witchcraft visitation of sins of past life, eating certain kinds of food and hereditary. etc. (Baseline, 2001)

Although misconceptions exist even today, Dr. Armaur Hansen, a Norwegian physician, scientifically identified the cause of leprosy as mycobacterium laprea in 1873. Thus, leprosy is identified "as a chronic infectious disease of man caused by Mycobacterium laprea leprosy is essentially a disease of peripheral nerves but it also affects the skin and sometimes certain other tissues, notably the eye, the mucus of the upper respiratory tract, muscle, bone and testes"(Bryce son A.,1990)

Leprosy or Hansen's disease named after Armauer Hansen, the Norwegian doctor who first detected the bacteria of the disease is a chronic infectious disease, caused by Mycobacterium leprea. It mainly spreads via droplets from nose to mouth. Its transmission is high during close and frequent contacts with untreated, infected individuals. Furthermore, there are 3 major forms of leprosy such as lepromatrous, tubercluoid and borderline leprosy. The first type mainly targets skin, eyes, nerves, tastes and upper respiratory tract. Tuberculiod mainly damages legs, arms, face and buttocks. The last type combines the characters of both lepromatous and tubercluloid and attacks various parts of human body (MOH, 2002:141).

There are theories that developed in relation to the causes of leprosy. The first one is hereditary theory high among the caste of India. The 2nd one is 'chicken and Squash eaten' well known among Philippines. Moreover, leprosy is also cited in different literature including the Holy Bible.

Leprosy is a communicable disease that could be transmitted from an infectious person to healthy one. However, the mode of transmission is not clear. The authorities in the field, specified three possible ways in which the germ could enter into the body of a healthy person. These possible roots are the skin, the gastro intestinal tract, and respiratory tract (Crochrane, 1964). However, all leprosy sufferers could not transmit the germ because only a certain proportion of patients could communicate the disease in this ways. The proportion of victims that can be considered as potentially infectious will not exceed 60% of leprosy patients (Jopling, 1978). Furthermore, the closed cases bacteriologically negative cases cannot pass the disease to the healthy individual. There is also a consensus among leprologists that children are more susceptible to leprosy than adults. Accompanying this, Jopling (1978) cited that though the child is born healthy, he/she can easily contracts the disease from his mother. The societal stigmatization and the psychological and social stress that follows have grave consequences to the victims as well as the family in social relations such as marriage, schooling work and entertainment (Alemu, 2002).

According to WHO (1980), the term “Disabled Person” means any person unable to ensure by him/herself; wholly or partly, the necessities of normal individual and/or social life, as a result of a deficiency, either congenital or not, in his/her physical or mental capabilities. Considering this definition one can imagine that disability has been associated with humanity ever since man started to work for his living. Stories and age-old written scriptures also confirm this. The worldwide concept of the causes of disability, which include polio, leprosy, trachoma, measles, and others, is differently understood in many societies from the scientific explanation. Many societies look at the disabilities as heredity or being caused from curses and sin. (Alemu, 2002)

2.5 Social Exclusion and Consequences on People Affected by Leprosy/PAL

Social exclusion is a concept focusing on whole person who is cut off from different angle of the social bond that attached to the society. It is reflected in a combination of - a lack of normative integration and low degree of social participation, material deprivation, and insufficient access to social rights (Gijisberg and Vrooman, 2007). Thus, the leprosy affected persons are the marginalized and stigmatized group that have multidimensional exclusion. (Yonas, 2014)

The belief that leprosy is hereditary is deep rooted. Except for few people who had the chance to understand the nature of the diseases from various sources, whatever the educational level of the individual, the belief that leprosy hereditary is still widespread. Because of such deep-rooted concepts about leprosy, persons living with leprosy are stigmatized and isolated from all interactions in society. The leprosy disabled individual, however, faces still another problem. The society believes that: the disease is contagious and hereditary. Although the family members of persons disabled by any other cause feel ashamed of and tend to hide, this problem is exasperated for persons disabled by leprosy. (ENAP, 2000, Alemu, 2002).

Leprosy has deep rooted stigma in the society, it is absolutely feared and caused migration of thousands of Ethiopian leaving behind their beloved ones and birth places. The society holds misconception that it is hereditary, calamity of God, curse, etc. This exposed persons affected by leprosy to loss social dignity. Begging has been accepted by the leprosy affected people themselves and the society for years. (Desalegn, 2014)

Among communicable diseases, leprosy is the leading cause of permanent physical disability. High disability grade in a newly diagnosed leprosy patient represents a delay in diagnosis which may be due to the patient presenting himself at the health facility late in the course of the disease or due to misdiagnosis at the health facility as a result of poor competence of health workers in recognizing the signs and symptoms of leprosy.

In Ethiopia, the national data shows that rates of disability grade II among newly diagnosed cases of leprosy have remarkably decreased (70% in 1986/7 to 6.9% in 2012). But the regional breakdown data shows that the average five years disability grade II in newly diagnosed cases is greater than 10% in most of the regions except Afar, Oromia and Amhara regions (Table 4).

Table 4: Proportion of disability grade II among new cases of leprosy from 2008 - 2012 during the last five years, regional and national.

Regions	2000 E.C/ (2007/08)	2001 E.C (2008/9)	2002 E.C (2009/10)	2003 E.C (2010/11)	2004 E.C (2011/12)	5 year Average
Tigray	6.1	22.7	9.0	21.1	17.5	12.9
Afar	0.0	10.3	7.2	0.0	2.7	4.9
Amhara	9.3	6.5	12.0	0.0	6.8	8.7
Oromia	8.2	4.8	5.2	2.9	4.8	5.0
Somali	12.5	20.0	50.0	0.0	3.8	12.6
B/Gumuz	5.4	13.8	8.5	17.0	11.1	11.2
SNNPR	11.4	11.8	10.4	7.4	12.6	11.0
Gambella	6.0	16.1	13.1	59.5	15.0	17.7
Hareri	0.0	11.1	0.0	80.0	11.1	10.3
Addis Ababa	7.1	15.3	14.3	7.7	18.2	12.7
Dire Dawa	10.5	0.0	35.3	0.0	0.0	11.4
Fed. hospitals	58.6	21.0	17.1	0.0	15.9	22.4
National	**9.2**	**7.0**	**8.7**	**4.2**	**6.9**	**7.4**

Among those Woredas reported for mapping, 29 and 16 Woredas from Amhara and Oromia region reported leprosy disability grade II > 10%, respectively. Similarly 6 Woredas from SNNPR and 2 Woredas from Benshangul Gumuz regions and one sub city from Addis Ababa were reported disability grade II > 10%(table 12).

Similar to disability grade II, high number of 30 Woreda from Amhara and 23 from Oromia were reported > 5% childhood leprosy case amongst those Woredas reported at least six new leprosy cases per year in average. Four sub cities from Addis Ababa and two Woredas each from SNNPR and Benshangul Gumuz also reported Childhood leprosy >5% and (table 13).

Delay in diagnosis and treatment can have adverse physical, psychological, economic and social effects. The occurrence of deformity is the most important concern, since the social response to those suffering of leprosy related deformity and their families are often tragic, hash, and unsympathetic accompanied with insult, ostracism and even the deliberate killing of those affected. This leads to stigma with a negative effect on the dignity and behavior of those affected by leprosy. Consequently, those affected will develop anger, distress, dread, aggression and show a preference for living somewhere where no one knows of their history (kaur and Brakel, 2002).

Stigma can leave people marginalized and excluded from their own community. It can stop people with ability getting the jobs that are qualified to do leaving them dependent on state benefits (McKeever, 2006). Stigma against people with disabilities often includes stereotyping based on misperceptions. A stereotype is a form of social typing, which has the potential to be misleading, as it does not acknowledge variability (Nolan et al, 2006).

Stigmatization has internal and external consequences. Its effects on peoples' quality of life and social and psychological well-being is huge. It causes stress, anxiety and further stigma. It causes reduced acceptance, discrimination, rejection and social exclusion. It causes label avoidance and makes it difficult to pursue employment or access to services. It can result in a lowering of self-esteem and self-efficacy (Nolan et al, 2006). People who perceive themselves as stigmatized may internalize stigmatizing ideas (Graham et al, 2003 cited by Nolan et al, 2006).

Although there is international and national legal provisions for the full participation of all disabled people including leprosy victims, the deep rooted attitudes prohibited the victims from the realization of all of the social and economic benefits.

2.6 The effects of leprosy on women

The case of women affected by leprosy is not different from other people affected by leprosy. However, the effect has severely affected women due to the low status given to them in the community. The burden of women affected by leprosy is doubled due the gender or power relationship between male and female in the community made the women subordinate, and discriminate them from access and control of resources. Lack of money to go to health facilities or get treatment is part of the influence of gender. Besides, for leprosy women it is difficult to fully engage in the household chores due to the severe physical attach of the disease.

In developing countries, woman hold subjugated and dependent status. When she becomes disabled she loses the little positive status she may have all together. Thus, she becomes totally isolated, immobile and confined to the house. It is much more difficult for her than it is for a male with disability to participate in public activities or meetings, unless special efforts are made to help her do so. For her, there is no disability allowance, no environmental adjustment, practically no access to education or training and therefore to employment, and no opportunity to become involved in self-help movements. (Alemu, 2002)

As far as marriage problem is concerned, the situation of disabled women including women in leprosy cases in developing countries is much more difficult, as marriages are mostly arranged. Stereotyped concepts, prejudices and negative attitude about disability are so deep-rooted that they greatly influence these arrangements. (Boylan, 1998). The marital opportunities of females with disability are limited. For example, the blind women are downward to in marriage than blind men. This happens due to people’s perception of persons with disability and gender relations, particularly as they are manifested in the roles of a housewife. (Ingstand et al., 1995)

2.7. Conceptual framework

A simple Model for understanding Social Exclusion

What is Social Marginalization? How does it operate?

Prejudice

(Dislike, hostility, or unjust behavior towards an individual or group of people, driven by preconceived and unfounded opinions about them)

+

Power to discriminate

(The capacity or Ability to treat unfairly different categories of people-e.g. in allocation of, or access to, resources)

+

“**Outsider**”

Those on the Outside often internalize the ideology of **inferiority.** They believe they deserve less, that it may be their fault.

Ideology of superiority and inferiority (A set of ideas and beliefs, belonging to a particular group of people, which determines who is ‘inside’ the system and who is ‘outside’ the system)

“**Insiders**”

Those on the inside often internalize the ideology of **superiority.** They believe they are better and deserve them.

=

Social Marginalization

A system which seeks to exclude people from a full set of relationships in society, and full access to the benefits available in that society, so that the dominant group retains its position in the society

It is about ‘**insiders’ and ‘outsiders’**, which means that it **affects everyone. Everyone shares responsibility** for removing the barriers between ‘outsider’ and ‘insiders’

Source: -Adopted from Inspire Training Civic Society Support Program (CSSP, 2014)

Every research activity is conceptualized and will be carried out within some contextual frame work. This contextual framework is in part conceptual, in part valuation, and in part practical or operational and all of these factors must typically be considered. The framework is a research tool intended to assist a researcher to develop awareness and understanding of the situation under analysis and to communicate this.

The above diagram depicts the situation of leprosy victims and the social exclusion or marginalization due to the deep rooted prejudice towards the issue. It is founded on unjust attitude or misconception about the root causes of the leprosy and it being accepted from generation to generation. The social exclusion has a strong effect on psychological, economic, social wellbeing of the victims. One thing that has to be understood is the victims of leprosy also exclude themselves from others and would prefer to be with people having similar identity to be more comfortable.

CHAPTER THREE

RESEARCH DESIGN AND METHODOLOGY

3.1 Research design

Descriptive survey is the method that is employed in this research. This is because; facts, conditions and attitudes were described and discussed. The research approach employed in the study is qualitative since the data gathered and the method used to analyze appeared to be qualitative. Qualitative research is mostly associated with words, language, feelings and experiences. Consequently, this research used qualitative method because the focus is on the assessment of the psychological, social and economic aspects of leprosy victims in general and women in particular.

As many scholars explained, qualitative researchers study problems in their natural settings, attempting to make sense of interpret and phenomena in terms of the meanings people bring to them (Denzin et al., 2005). Similarly, Berg added that qualitative techniques allow researchers to share in the understandings and perceptions of others and to explore how people structure and give meaning to their daily lives. Researchers using qualitative techniques examine how people learn about and make sense of themselves and others (Berg, 2001). Qualitative study is best when the issue of concern at hand needs exploration, comprehensive understanding of the context and the phenomenon (Creswell, 2007).Besides a qualitative approach enables the researcher to get an in-depth understanding of the issue and allow research participants to express their views broadly so that the researcher employed a qualitative design since the issue at hand needs a comprehensive understanding.

Case Study Approach

In this study the researcher believes that, case study is appropriate study approach for that it gives a wide opportunity to explore the distinctive and multifaceted experience of the targeted population of this study. As Yin (2003) point out that, case study allows investigator to retain the holistic and meaningful characteristics of contemporary phenomena and real life event desire to understand complex social phenomenon (Yin, 2003, P. 88). In addition, case study can provide important information about the issue by using various information sources (Padgett, 2003) Therefore, the study aimed at obtaining rich information about the psycho-social and economic aspects of leprosy patients in Woreda 1 of Kolfe Keranio sub-city of Addis Ababa..

3.2 Study area and participants

As Creswell (2007) puts, in case of qualitative research, for the purpose of deep understanding of the subject matter under study or research question, it is up to the researcher to make a decision on the research participants, sites and even the materials to use. The study area of the research was Woreda 1 of Kolfe Keranio Sub-city around Saint Gebre Kirsots church in Addis Ababa.
This sub city is one of the ten sub cities in Addis Ababa. It is located to the west of the city. The population of the sub city was estimated to be ____according to the census report of 2007.
The rationale for selecting this research site is that it is the typical place where dominantly the leprosy victims dwell. The study was done with leprosy affected people considering the study site, with relatively high concentration of leprosy patients or leprosy affected people on the basis of preliminary assessment. It was, thus, before the onset of the data collection that the location was visited and potential site was identified. In many cases, site characteristics and availability of leprosy victims were appeared to be the basis for selection of the site.

This site was selected purposively based on the preliminary assessment. During the preliminary assessment the researcher observed that many leprosy patients and leprosy affected people were there in this particular Woreda one and many more lead their life in the slum near the Saint G/Kiristos Church. Besides, there are NGO's and local associations in the surrounding of the center. For example, Rai'y Ex-leprosy women's association, Social Medihin Center, Birhan and ENALPA can be mentioned. Since these NGO's and associations are working for long in issues related to leprosy, the researcher found out that it could be an asset for the success of the study. Above all, the presence of ALERT, the lonely federal referral hospital which has been working on leprosy made the site more relevant. Moreover, the site was selected to easily access participants who are illegible for the study.

The participants of this study were initially proposed to be women leprosy victims, key informants from concerned bodies of the government sectors and NGO's including FGD with women's affected by leprosy and women of non-PAL. The primary rationally for selecting few number of participants was as the issue is very sensitive and difficult to get as many willingness to participate, resource and time availability.

3.3 Sampling method

According to Merriam (1988), sampling in qualitative study tends to be small number of people nested in their context and studies in-depth unlike quantitative studies, which aim for large number of context of stripped cases and seek statistical significance. Purposive sampling was employed to select the research participants from all population units. In order to make sure that research participants were drawn from different social strata, the researcher employed those who were embraced in one of the local women's associations and women in slums area.

3.4 Data Collection Procedure

The first step was to go to one of the women's ex-leprosy association and informed them informally as I know them before. I had a letter of support that I submitted to Woreda one so as the concerned bodies may facilitate the Key Informant Interview/ KII with different sectors and the FGD. I had established a good rapport and clearly communicated the purpose of the study with my participants. Then, the date for data collection was arranged after the potential participant fulfilled the inclusion criteria and the participants decided to go through the interview. I made an appointment with each participant at a time. Place which suited them and a quiet place conducive to conversation were arranged with the participants. In addition I prepared a note book and other necessary materials for the interview.

Before each interviewing, I thanked the participant for the time and willingness to be part of the study, reminded the participants about the agreement, and explained that the interview will be unstructured with probing questions. During the interview, efforts were exerted to make the discussion open, free, no domination and unreserved. As the initiator of the interview, the researcher played an active role in making certain decision about the progress of the interview. The researcher showed sensitivity to the uniqueness of each participant and approached with empathetic understanding. I tried to be a good listener, friendly and non-judgmental throughout the interview process.

3.5. Data collection Tools

Both primary and secondary source of information were used in order to undertake the study. Primary data was collected through in-depth interview with women leprosy victims, KII with social workers, Women’s affair and other key informants and through observation. Focus group discussion was also conducted. While, secondary data was obtained from published and unpublished materials including books, magazines, journal articles, and electronic materials.

The tools that were used for primary data collection were In-depth interview, Key Informant Interview (KII), Focus Group Discussion (FGD) and personal observation. The researcher tried to capture the beliefs and attitudes of the target communities in its locality, assess the root causes of the social exclusion particularly the case of leprosy, factors and actors influencing the change of attitudes and suggest entry points on how to transform the existing challenges of social exclusion so that the problems will be addressed per the needs and priorities of the leprosy communities in general and women in particular. Before applying the instrument to the main study, a pilot study was conducted in few similar women groups affected by leprosy so as to improve the reliability and validity of the instrument.

3.5.1 In-depth Interview

To asses about the psychological, social and economic situation of women leprosy victims, the researcher developed an open ended interview guiding items. The interview guide allow the researcher to maintain a certain level of control over the process while enabling the researcher to gather the most relevant data in relation to the phenomenon of interest (Burns & Grove, 2003). The researcher choose open-ended interviews as it allows participants to discuss their opinions, views and experiences fully in detail whereas perhaps a set interview with closed ended questions may inhibit them to express their full opinions and feelings. Open ended questions allow participants to respond in their own words.

Efforts made to include probing questions from the main stem items. These interview guiding items are developed in line with concepts assessed in literature section and research questions. These questions are attempted to assess the psychological, social and economic situation of women leprosy victims in Kolfe Keranio, of Woreda1 Addis Ababa.

3.5.2 Key informant interview

The researcher made the interview with seven key informants, among whom two from women's affair, two from social affairs, one from MSE one from Addis Ababa and one from the national leprosy association. The Associations and the NGO are still closely working with leprosy affected people. Unstructured questions were used as a tool of data collection to assess the psycho-social and economic situation of leprosy patients and about how social work intervention could be put in place to overcome those challenges. This help the researcher to triangulate data obtained through in-depth interview with leprosy patients.

3.5.3 Focus group discussions

Two FGDs was conducted with leprosy patients and non-leprosy. The FGD was made in two groups. One of the two groups consists of female participants with leprosy cases/victims and the other group consists of women of non-PAL. The groups were purposively selected to incorporate and understand the extent of social exclusion from both angles. The women in leprosy and non-leprosy that could have different experiences to see the psycho, social and economic situations of leprosy affected people. That is also aimed at obtaining some information as to how people see the psycho social and economic effect of the disease and what possible measures could be suggested to at least minimize the adverse effect of the disease. In addition, the gender difference is helpful to see the issue from the perspective of both sexes. Literatures suggest that the number of FGD participants can be from six to ten; but due to time constraints the researcher simply chose the smaller one. I had six participants in each FGD.

3.5.4 Personal Observation

Observation will be one of the data collecting instruments in such study. Since leprosy is a sensitive issue respondents may not tell us everything. At this point, the researcher will observe their feeling, gesture, facial expression and the match between their internal feeling and external expression. Besides, the researcher also tries to see their interaction with each other and their care provider. The researcher has tried to analyze the nonlinguistic data using a check list.

3.6. Data Analysis Technique

Data analysis is a mechanism for reducing and organizing data to produce findings that require interpretation by the researcher (Burns et al., 2003). Data analysis consists of preparing and organizing the data for analysis, reducing the data into themes through a process of coding and condensing the codes, and finally representing the data in figures, tables, or a discussion (Creswell, 2007, P. 164). Accordingly, the steps in the data analysis process of this study are the following.

The first step in data analysis is pre-coding the raw data. I conducted the entire interview in Amharic language. After data collection I transcribed the data from field notes in to English language every day. Then, I read and re-read the transcripts closely until understanding of the main points are achieved. According to Boyatzis (1998) pre-coding is done by circling, highlighting, bolding, underlining, or coloring rich or significant participant quotes or passages that strike the researcher (as cited in Saldana 2008, p. 16). Accordingly, I underlined significant participant quotes that impressed me.

After the pre-coding process coding followed. Coding is reducing the data into meaningful segments and assigning names for the segments (Creswell, 2007, p. 165). Saldana (2008, p. 10) added that, to codify is to arrange things in a systematic order, to make something part of a system or classification, to categorize. In this study the codes after the interview were transcribed; both specific topics or words and recurrent issues in the text were coded and then codes were emerged.

The codes transformed in to categorical labels. Categorizing in qualitative research means, searching for patterns or grouping exactly alike, very much alike data or data which have something in common within coded data (Saldana, 2008, p.6).Categorizing transcribed data helps to sort out texts into various segments, which make the data to be manageable. A category contains related codes explored from the analysis of the data. In this study the coded data were categorized depending on the similarity and relationship of codes under different headings and condensed into categories.

According to Saldana (2008, p.13), ―A theme is an outcome of coding, categorization, and analytic reflection, not something that is, in itself, coded. In this study, themes will be created from the categories by extracting common and significant linkages. Padgett (2008, p.199) stated that, ―Writing up a qualitative study takes a good deal of effort-it is a craft to be learned and honed over time.‖ She added that, ―writing is not merely reporting; it requires systematic thought and creativity‖ (p.199). After the pre-coding, coding, categorizing and theme development processes, I exhaustively examine those themes that could be merged into a single super-ordinate theme.

After refining themes, interpretation followed to look for meanings. Interpretation deals with less obvious and more abstract dimensions of the data, the act of ―reading in to‖ and ―extracting meaning from‖ (Padgett, 2008, p. 171). After all the processes the final report was prepared. I employed pseudonyms instead of code numbers while presenting participant‗s story to maintain their anonymity.

3.7. Ethical Considerations

The researcher considered it very important to establish mutual trust and respect (Burns et al., 2003, P.65). The ethical measures in this study included consent, confidentiality and anonymity, privacy, and the right to withdraw from the study.

The support letter obtained for informed consent was the first vital ethical pre-requisite**.** All participants freely decided to participate in this study. They were informed about all necessary information regarding the research. The participants were informed that they can withdraw from the study at any time if they wish to. Their rights were explained to them prior to engagement in the study before the interview (see appendix A). The researcher has to be sensitive to the participants ‗emotions when probing questions that could psychologically harm the participants and gave enough time for the participants until they became stable.

Qualitative Data quality

Quality in qualitative research is one of the key concern to be seen. Quality in qualitative data is maintained through treating both comprehensive data and deviant case analysis. Comprehensive data treatment is nothing but inspect and compare all data till ones generalization is able to apply to every single gobbet of relevant data collected. Whereas deviant-case analysis implies actively seeking out and addressing differences or deviant cases rather than treating deviant cases as (statistically) uninteresting / insignificant go into detail to see if the overall argument e.g. needs modification or if it holds. As such, validity is about showing examples from different angles, also deviant cases.

Good-quality research satisfies the following points: thinks theoretically through and with data, it develops empirically sound, reliable and valid findings, it uses methods which are demonstrably appropriate to the research problem and if possible, it contributes to practice and policy.

To ensure the reliability and validity of the research findings, the researcher employed varied strategies. Primarily, when developing structured interview and FGD guides, tools that had been used in other similar research studies were consulted and attempted to adapt. The completed instruments were given to colleagues who have expertise in the field as well as to instructors of academic institutions in the area under study. Moreover, to ensure reliability of the instrument, pilot test was carried out. The feedback obtained employing the aforementioned strategies were used to revise the tools. Although, the guides had been originally developed in English language, they were translated into local language and the interview was also conducted accordingly.

CHAPTER FOUR

DATA ANALYSIS AND INTERPRETATION

4.1 Background of the respondents

The overall objective of the study is to assess the effect of social exclusion and the psychological, economic and social effects of women affected by leprosy and identify areas for social work intervention strategies to improve the life of leprosy patients. To achieve the objective, of the study incorporated twenty women leprosy victims' respondents. Seven key informants and four focus group discussion from PAL and non-PAL women in the surrounding were used in the study.

Respondents of the in-depth interview were twenty in number all were women leprosy victims' ranging from 38-75 years of age. They all are orthodox religion followers. With regard to their educational level except three of them illiterate, others are literate ranging from ability to read and write up to grade 12.Regarding KII five of them had a BA degree while one was 12 complete and one ability to read and write. Five of the key informants were experts from government sectors at Woreda level concerned bodies, one from the Ethiopian National Association of People Affected by Leprosy and one from the Addis Ababa Association of People Affected by leprosy. Out of the four FGD, two was held with women affected by leprosy, one with non-affected women and the other with men affected by leprosy.

Regarding the physical damage, out of the twenty women leprosy victims, in two of them there was not apparently seen any damage. Eighteen of them were either their hand or leg was physically damaged. One of the KII held at the association level lost both his hands and legs. The age of Key informant interview ranges from 24 to 56, two female and five male. The age of the focus group discussions held with women of PAL, and with women of non-PAL and with men affected by leprosy ranges 45-70, 26-40 and 30-50 respectively.

Regarding key informants 'work experience it varies from one to the other. The minimum being two years and the maximum is twenty years of experience. All the key informant respondents were not leprosy affected with the exception of one. When we come to the background of the FGD, there were four FGD groups. One of the groups who were affected by leprosy had six participants three of them literate of the maximum grade 5 and three of the others illiterate. The other FGD with women of non-PAL were also six number all literate that ranges from grade 3-10. The FGD held with women leprosy victims had a damage in their face, around eyes, hands and legs. The FGD with men in leprosy were also six in number that ranges from grade 6 to 12.

Table 5.Women's leprosy victims/Respondent's Martial status, place of living before and after onset of leprosy,

No. of Respondents	Marital status		Place of living Place of living	
	To PAL	To Non-PAL	Before onset of leprosy (region)	After onset of leprosy
1st	Widow		Amhara	Each of them came to Addis Ababa and began their treatment at ALERT and continued to live in that specific areas allocated around Saint G/Kiristos's Church /socially excluding themselves / Out of the twenty respondents only one is from Tigray, nine of them came from Amhara region and ten from Oromia region
2nd	Married		Tigray	
3rd		Separated	Amhara	
4th	Widow		Amhara	
5th	Separated		Oromia	
6th	Widow		Amhara	
7th	Married		Oromia	
8th	Widow		Oromia	
9th	Widow		Amhara	
10th	Married		Amhara	
11th	Married		Oromia	
12th	Married		Amhara	
13th	Single		Amhara	
14th	Married		Amhara	
15th		Widow	Oromia	
16th	Separated		Oromia	
17th	Widow		Oromia	
18th	Married		Oromia	
19th	Single		Oromia	
20th	Widow		Oromia	

As it can be observed from table 5, out of the respondents seven were married, eight of them widow, two of them single, and three of them separated. Almost all women respondents who were victims of leprosy get married to people affected by leprosy.

According to the data, the respondents have been under medical care from 6 months to 10 years. The data obtained from respondents of women affected by leprosy, other concerned key informants and the FGD was categorized under six thematic areas. These includes

leprosy as a disease, leprosy and its psychological effect, leprosy and its social effect, leprosy and its economic effect and social work intervention areas.

4.2 Root causes of leprosy

Women respondents were asked how they became aware of their status. They were also asked about their and their family‛s perception about the disease and its cause. Out of the twenty women respondents affected by leprosy only eight (40%) of them felt that it is bacteria or germ. Six (30 %) of them do not know the case and six (30%) of them felt it is either curse or God related.

As per the idea obtained from one of my respondents, leprosy is a disease caused by bacteria. But she felt that she has acquired the disease due to poverty or lack of treatment. She explained the detail as follows.

> "We were living in Amhara, Debra Sina. I was not neat and our living standard was poor and miserable. Some kind of strange white mark that at times becomes red like pepper appeared on my body. No one knows about the disease. As the disease began its effect on my hand at early age of my child hood and I could not move my finger as I like, my parents were angry at me and forced me to move my fingers as before properly. No one understands me at the time. Since it is uncommon in the community, most people do not have an understanding about the disease. When it aggravates the situation on my body, my family brought me to the then 'Borchole" in Addis Ababa for checking my blood and get treatment. Borchale referred me to the then Zenebework Hospital. For the confusion of all about the disease and lack of treatment on time, my fingers my toes crippled and become disabled. Leprosy is not a familiar type of disease in our community. People in my locality do not know all about the disease and they do not know that I have been exposed to leprosy"

For the question how they acquired the information about leprosy almost all have initially faced some kind of mark or injured on the skin and later they had got the information about the case from friends and relatives except one out of them that visited health facilities know the case after two years of severe damage of her leg that exposed her to disability.

One of the women respondent affected by leprosy told us that

> "I was exposed to leprosy when I was a child and I am the only one from the family that acquired the disease that I felt that it is my destiny. I still do not know the cause of the disease why I am infected by it. Leprosy was known in my village or the rural area and named as '**Tiliku Beshita'** meaning the 'The Great disease' that made it something terrifying. My children are also free from leprosy.'

One of the key respondent from government sector told that she come to know about leprosy after she has been employed in this Woreda. She felt that leprosy is not hereditary but something that may come after birth .Still she does not have clear information about the cause. The other respondent also explained that Woreda 1 and the near byWoreda 5 have many victims of leprosy. He said that the belief that leprosy is hereditary created deep rooted stigma and discrimination among the peoples of victims.

4.3 The effects of leprosy on affected women

4.3.1 Leprosy as a disease and its physiological effects

Leprosy if it is not treated on time has a consequence of losing the hand, leg etc. or that can be exposed to disability. Besides, it is easily infectious before getting the medicine.

One of the respondents that came from region at the age of 15 in 1984 E.C.25 years ago says

> "I came to Addis Ababa for treatment after two years. Initially I went to health station where I was living in Tigray. On my skin particularly on my face and leg white strange mark appeared and checked. I went up to Lalibela and finally I was referred to Alert Hospital Addis Ababa. I came to Alert after two years but for I stayed there I lost one of my leg. The other problem that I felt is that for I was sleeping with my youngest brother before I got the treatment, my brother had also been exposed for it is infectious disease. '

Leprosy as a disease faced each of the respondents at different age. Seven of the respondents told that they are exposed during child hood and do not know exactly their age. Four of them at 15, six at 18, seven at 11, two at 9 and one at 5.

The respondents of FGD also raised how the effect of leprosy severely exposed many to disabilities. As leprosy strongly damaged the sense of feeling. Many women and men travelled long distance and unknowingly damaged their leg.

4.3.2 The psychological effect of leprosy

There was interview with respondents to measure the psychological effects of women in leprosy. All respondents respond as they self-confident and self-respect. For the question of preference to be alone or separated from the society only 5 (25%) of them respond as they feel loneliness and wanted to separate themselves from others. However. All respondents respond as they do not have any hatred towards society, relatives and to non-PAL. Regarding feeling of inferior to others, 3(15 %) of them feel inferior to others. As it can be observed from the description except a few respondent many of them felt positively about the inner feeling about themselves.

One of the respondents that she estimated her age to be about 70 years told us that her feeling due to leprosy.

> ‘I came from Jimma. I am exposed to leprosy after I gave birth to three children. I had been treated at hospital level in Jima and later on I am referred to the Zenebework hospital. I got the information as I am victim of leprosy after I have been referred. I followed the treatment for one year and six months. I do not know the origin and how I am exposed. Others member of the family do not have. I felt that it is just a destiny. There is a local saying that ‘sometimes out of many beans one may not cooked well’ and my case is just like that. In some family, you may observe all members be infected and you may feel hereditary. Since I made my living here in this particular area, I do not go anywhere far out of my surrounding. At the moment, I am a grandmother my children and grandchildren came to me but I do not go to their home for I feel they do not be depressed by their neighbors and friends. Even I do not go to wedding of immediate relative. I would like to protect the feeling of my family members though sometimes they insist me to mix with other community.

4.3.3 The Economic effects of leprosy

Some of the respondents were employee in their own village organized in association and working by their level and are paid monthly salary. But that is not the case of all women affected by leprosy. The FGD with both the victims of leprosy and those who are not victims of leprosy revealed that the main economic effect of leprosy is that when the person affected by leprosy becomes disable, it is difficult to have one's own income. The regular income of leprosy victims is beggary. They further revealed many led their life by begging and educated their children. Nowadays their children of course they are free from leprosy and have been employed and are found in different position that made their family stop begging and lead a decent life.

One of the respondents told that

> 'As a victim of leprosy I lost my hand, the major challenges I encountered is unable to work and become the beggar that strongly harm my felling and made powerless for lack of money and economically become dependent.'

The FGD with women of non-PAL revealed that some of the people affected by leprosy want to work if there had been a condition set in their level. They also raised Ra'iy Women's association as the only organized association that creates employment opportunity for the victims by their level. There is no much effort from government and NGO's to organize and create income generating activities to leprosy victims.

For the FGD respondents questions posed in relation to economic effect of leprosy, they clearly stated that if the victims of leprosy have some kind of disability that is apparently seen, the possibility of being employed is almost nil. The FGD respondents openly disclosed that

> "There is no leprosy victims particularly that has visible physical damage employed in both government and private organization. As an illustration, a neighbor of them who was victims of leprosy employed for a guard in private house, he was fired when known he is a leprosy victim".

4.3.4 The social effects of leprosy

The whole issue of social exclusion emanates from the misconception of the community about the root causes of leprosy. People affected by leprosy have their own bondage for they are settled in specific area.

In this regard respondents were asked questions for measuring social effects of leprosy victims. Questions forwarded to the respondents were if the victims have respect to close family and relatives, respect to the surroundings to PAL and Non PAL, segregated/separated by oneself. Participate in social Affairs in the community, compare with the society of non-PAL, and if they are member of IDIR (either men or women) or any other form of CBO. Almost all respond positively that they have good communication and conducive environment. On the contrary, one of the women victim respond accordingly about the whole situation

> “There is a change of attitude following the introduction of modern medicine. We cannot deny the change in stigma and discrimination though there is still a gap that has to be worked on. Although we are free from the disease, we ourselves create the stigma and discrimination. We have to ask ourselves to what extent we are trying to approach the large community. Are we not refrain from them? Is really the community that create social exclusion or not? Although begging is disgusting and it is the last option for leprosy victims, the community is generous in supporting the beggar who are disabled that helped many to lead their life and made them educated their children. The society made a favor for such miserable victims of leprosy and today there are many off springs of the victim that worked in big organization of the country such as Ethiopian Airlines, Ministry of health etc. hence, the effort has to be from the victim’s side too to be free and assimilate oneself to the community. In the large community of leprosy patients, there is still a feeling of inferiority”

Similarly, discussion with the FGD participants also revealed that

> ‘Leprosy is a skin and a public disease that has strong hatred among the community. It stigmatize and isolate the victims of leprosy from the large community. It made the victims not to have a positive attitude about oneself, made to lose self-confidence and esteem. Leprosy made many of them to isolate themselves from their beloved, relatives, friends and neighbors. Victims alienate

> themselves while they love and do have affection. Women victims of leprosy greet people covering their hands under their clothes for they worry for non-PAL.

The discussion with the FGD strongly argued that there is a social exclusion of women affected by leprosy but many of them may talk about how they lead their life in harmony with the non-PAL. Women in leprosy began their life around this study area and accustomed of it. However, they do not want to be seen out of this village for they are not comfortable. The same idea was raised by KII respondents that victims of leprosy live in the confined place and do not want to assimilate themselves with non-PALS. Even if they come due to health problem or any other case, they just maintain and stay. They exclude themselves from others.

CHAPTER FIVE

DISCUSSION OF THE STUDY

This section presents the discussion of the findings under different themes in light of research objectives, research questions and related literatures. The major themes in relation to various literature includes the root causes of leprosy, and the effect of leprosy on women leprosy as a disease and its physiological effect, the psychological effect of leprosy, the economic effect of leprosy and the social effect of leprosy.

5.1. Root causes of leprosy

The whole issue of social exclusion emanates from the misconception of the community about the root causes of leprosy. There is different misconception about the causes of leprosy. Leprosy affects the body‘s nervous system, skin, eyes, and muscles that alarmed people to respond to the situation. Hence, there is a need of awareness creation at all level about the root causes of leprosy.

Although leprosy patient respondents currently have known the scientific causes of the disease, they do not deny that they used to have believed that it was caused by something related with some bad deeds, evil spirit and or is God given. They also indicated that their relatives have still believed that leprosy as being caused by the committing of immoral deeds, evil spirit, superstitions and the like

With regard to how the disease is contagious, the findings show that some of the respondent did consider it as contagious but not hereditary. (Menberu et al., 2001), strengthened the idea that it is contagious. Because the bacillus *Mycobacterium leprae* can be transmitted to other people, leprosy is contagious. People undergoing treatment for the disease, however, do not transmit the disease. How *Mycobacterium leprae*is passed from one person to another is still not entirely clear. However, since there is evidence that the bacillus can survive for some time outside the host, it is now thought that leprosy is spread through the respiratory tract. Multibacillary cases will have many bacilli in the mucous lining of the tract, which can be expelled by coughing and sneezing. One problem in leprosy work is the lack of a universally effective vaccine. The tuberculosis vaccine BCG has been moderately successful in preventing the disease, but cannot be considered as a complete cure. Research must continue to be conducted.

5.2. The effects of leprosy on affected women

5.2.1 Leprosy as a disease and its physiological effect

As it can be observed from the data on prevalence at the country and regional level, the number of leprosy victims of men exceeds that of women. During the interview with different respondents, they mentioned leprosy is more apparent on men and even those who come from regions are mostly men. One concrete idea is that men diagnose themselves and come for treatment. However women may not get out of house due to gender norms and socio-cultural influence and do not diagnosed and hence may not be known the situation they are in.

On the other hand, for the question who is most affected by leprosy as a disease? The FGD with non-PAL revealed that women are severely affected by leprosy due to the gender norms and lack of access and control of economic resources. The respondents told that women affected by leprosy do not go to health posts on time or may not go, they used traditional medicine instead of going to modern medicine. The respondents sadly raised when women prepare food, she is exposed to sever disability. She may be cut by knife or get fire but for her body doesn’t sense that and reacts accordingly, she loses her fingers.

One of The FGD respondents raised to what extent the disease killed their sensory.

> ’It was one night that she slept in the same room with her friend victims of leprosy. In the morning the bed sheet and matters was in blood and she, the victim herself unknowingly was asking what blood is that. When she was told that there is a blood in her hand she did not notice at all. Surprisingly rats in the night ate her wounded fingers and lost four of her fingers.’

The participants added that women in leprosy strongly hurt and exposed to disability for they do not protect themselves and felt that they can do anything. Many women in leprosy do not wear shoes or may not have the proper shoes and they travel long distance unknowingly that it may damage their leg

5.2.2. The Psychological effects of leprosy

The FGD respondents of women not affected by PAL told me that leprosy is a disease strongly affects the life of victims of leprosy. They said that it makes the victims not to have a positive attitude about themselves. It really made them lose their self-confidence and self-respect. For example they raised an incident that they went to the funeral around the center of the city and when getting back home one of victims of leprosy that went together to the funeral refused to eat lunch in the tent of the mourn house. She felt embarrassed of herself for she has lost her fingers and did not want to be seen by others and stayed without eating lunch.

One of the women respondents that came from the region says:

> ‘When I compare my earlier life with my current situation, it is really hurting. The fact that I am alienated from friends and unable to get them is quite difficult for me to accept the situation I am in. Besides, I lost my confidence and prefer to be alone and I felt inferior to others.

The FGD respondents strongly raised that though in this particular Woreda as many of the victims of leprosy made their living here for many years more or less they are not psychologically depressed but when they go out from the village, there is a different condition. They further raised that women affected by leprosy are not free to invite others on non-PAL to their home though they have good relationship and they are fond of them. They worry for the feeling of others who are not affected by leprosy.

As it was indicated in the finding, some of the major emotional problems which leprosy patients feels includes depression, shame, dependency and even aggressiveness. The study also found out that, leprosy can affect the mentality of its victims by lowering their self-esteem, confidence and their dignity. These findings are consistent with several studies. Kufman et al (1986) demonstrated that depression is a very common reaction to loss of parts of the body or loss of body function such as appearance of deformity. (Menberu et al., 2001) also contribute idea which supports the above finding. In that work it was stated that, saddest of all, even people affected by the disease will believe many of the myths about leprosy as a result suffer from low self-esteem.

The finding of the study also showed loneliness as a major psychological problem which people living with leprosy encounter. As most of the FGD stated, the major reason for such a feeling to develop is the fact that leprosy patients are mostly separated from their families as well as their beloved ones. Supporting the above finding, Dennis (1987), contended that, loneliness may expose persons to trauma. Consequently, those persons may get in post-traumatic problem unless they get appropriate counseling and support. In addition, due to either their loneliness or stigma attached to the disease, peoples with leprosy have high risk to be exposed to mental health and committing suicide. The finding of the study also showed that many leprosy affected people are hiding themselves from other people. They mostly tend to develop a sense of being secret. Similarly (Menberu et al., 2001) stated that one should not be surprised if people affected by leprosy continued to hide their condition from employers, colleagues and others, since they know that the consequence of its discovery would be worse.

5.2.3. The Economic effect of Leprosy

The results of the study revealed that there is a strong relationship between leprosy and poverty. Some of leprosy patient respondents and key informants have stated that if it is untreated the disease is mostly led to physical deformity, crippling the body or it might incapacitate people. People living with leprosy might end up being bed ridden and became economically dependent

Based on the findings from both the in-depth interview and the FGD, the other reason for leprosy affected people to be economically dependent or weak is that the stigma attached to the disease. Most leprosy affected people left their land and other properties behind fearing the social stigma and they resort to begging as a coping mechanism. To show how begging is important for the survival of leprosy affected people, (Menberu et al., 2001) stated that with the presence of a number of challenges leprosy affected people have encountered. For instance, many people affected by leprosy are unable to obtain paid work because of prejudice. Begging is often the best paid and least physically damaging job for people disabled by leprosy.

The other finding of the study was that some respondents have reported that persons with disabilities in general and leprosy patients in particular were and are suffering from getting equal opportunity in the job market. As they reported they often face unjust treatment when they are applying for a job. Respondents told the researcher that employers were mostly not confident with PWD‘s in which leprosy patients are incorporated. Besides, some employers do not want to hire them for fear of losing their customer. These findings are consistent with Terusew (2005: 176-177) who demonstrated that PWDs encountered serious challenges in obtaining jobs even though they were equipped with the necessary skills through training and education. According to his findings, employing agencies disqualified candidates with disabilities regardless of eligibility for the job.

However, it is hard for leprosy patients to cope up with the stigma. The finding shows that although some of the victims engaged themselves in small businesses, most of their products were hardly able to get any market. Most people do not tend to buy what was produced by leprosy affected people. Frist (2001) stated that even if they are capable of producing saleable goods, the public may not wish to buy these goods because of fear of contamination. This is especially true with agricultural produce.

5.2.4. The Social effect of leprosy

As it can be observed from the finding of the study or the respondent's response, it seems that the people affected by leprosy are living in good condition. People of PAL's are not as such psychologically depressed. However, one of the women affected by leprosy/respondents said that people of PAL and Non PAL are leading their social affairs together and there is improvement in many aspects. But she felt that most of them are in the same kind or in similar situation and that is why there is no as such social exclusion and that they do not feel too much.

The respondents of the FGD with women of non- PAL also revealed that as people affected by leprosy made their living in this surrounding for many years, they accepted and are comfortable. However, they do not want to get out of this village or area. They further strengthened the social exclusion of people affected by leprosy in this Woreda or area victims of leprosy came from all over the country for treatment and after they are cured they made their living place around here ALERT and Saint G/Kiristos church or Woreda 1.

According to IDEA (2000), fear of persons affected by leprosy, their segregation, isolation and discrimination by the society has been the day to day experience since ancient times and this has contributed to this millennium, when the leprosy cure has been made fast and apparently efficient. The social ill is still untouched such that it is shameful to be found leprosy disabled. Their exist a number of derogatory words and proverbs, which label affected persons and their families, despise and repel them not fully to participate in the socio economic activities of the society that deprived them of equal opportunity like any citizen in the country

What was stated above might be supported by the societal misconception appeared in various societies including Ethiopia. People have a wrong perception about leprosy, they consider the disease as the worst of all disabilities as seen in the expression *"TilkuBeshita* meaning that the great disease.

With regard to the stigma attached to the disease and societal segregation, the finding of the study shows that, almost all leprosy affected persons are forced to hide themselves from their relatives, as not to be stigmatized and not to disgrace their family in their communities, and migrate to areas very far from their birth places preferably to leprosy colony settlements. This is not a common practice by persons with other disabilities

Leprosy in the family makes a marriage arrangement difficult, if not impossible. As opposed to the finding and Scott, Heinjer (2004) sees leprosy patients 'difficulty to find ones non leaper spouse as positive due to the fact that its rate of diverse becomes less. This study shows to what extent it was difficult to get married to non-PAL. Out of the twenty respondents, only the two who got married to non-PAL were relatively have not any problem observable in their body that may support them to get married to non-PAL. Besides, all of the respondents came from rural or place of origin and did not get back to their family, relatives and friends due to the misconception about the disease in the community.

Even ALERT that used to support victims of leprosy is no more helping at this time that exacerbates the situation of women victims badly. One of the respondent said that

> "The case of leprosy is still an issue. It would have been good if the effect of leprosy had stopped on us and the others at least be saved. But still many victims came to Addis Ababa, ALERT hospital. At the moment though there is significant change on the social exclusion, stigma and discrimination, ALERT that used to support the victims for many years is not supporting the poor at the moment. It is just becoming a place of testing rather than a place of getting being cured. At this moment many are being exposed to disability for lacking due attention by the health professionals. Even the medicine is not satisfying as before.'

Both the in-depth interview and FGD result showed that, getting non leprosy affected spouse is a difficult undertaking for those leprosy patients. This finding is supported by, Scott (2006). The study also found out that leprosy affected people have been have been neglected from participating in various social engagements and denied access to some social services.

CHAPTER SIX

CONCLUSIONS AND RECOMMENDATION

6.1. Conclusions

The finding was able to show that the adverse effect of leprosy on both the victim and the society is very huge. Although, leprosy is a bio medical problem it also accompany other psycho social and economic problems which require a holistic approach to address it. Besides, the study was also able to reveal that the psychosocial and economic problems of leprosy have got a devastating effect on the wellbeing of the patients in a much higher degree than its physical effects.

In conclusion, the psychological, economic and social needs of leprosy sufferers particularly women victims in Ethiopia are similar to those of leprosy sufferers in other parts of the world. The need for self-acceptance, social acceptance and People with leprosy view their life and the way in which they conceptualized the disease is decisive factors for their levels of mental health. The intensity of emotions experienced by leprosy sufferers immediately after diagnosis underscores how important it is to have support immediately available. The extent to which the psychosocial and economic needs of leprosy sufferers will be met depends in part on the way in which they are treated by their support systems. These systems include patients, families and relatives, employers, medical doctors and hospital staff. Community acceptance are the major solutions to cope up with the psychosocial and economic challenges faced by people affected by leprosy.

The disease lacks due concern by ALERT. Sometimes such dangerous infectious disease is being considered as allergic case and in the meantime people affected and exposed to disability. Hence, comprehensive study has to be carried out and such neglected issue has to be seen from different angels. /FGD/. Respondents also added that at the moment ALERT is for those who have money and can pay for the health service and engaged for general treatment. Sometimes victims of leprosy check their position at ALERT but forced to buy medicine from outside. Hence, women in leprosy particularly for they do not purchase medicine on the time may be exposed to another damage /FGD/.

6.2. Recommendation

- The government has to design special support for women in leprosy. for example shoes has to be provided to protect them from fire and any other damage/FGD/- As there is program for disability by government, there should be special support and care for leprosy patients. /affirmative action Esp. the CBO who work on children, women etc has to focus too on women's leprosy
- A comprehensive research has to be for leprosy victims are found in different settings. Some supported by NGO, lead there life begging, and created self-help employment opportunity, those who are supported but also lead their life begging
- At Woreda level due attention has to be given for leprosy is a public health and infectious. Hence, the government /executive bodies has to give due attention. As the FGD revealed that 'some health experts at Woreda level themselves do not have the clear information on the cause of leprosy instead they felt as hereditary. Moreover, there is stigma and decimation of women in leprosy among health extension workers.
- KII at Woreda level with expert of MSE rose as the issue of leprosy is rampant in this Woreda out of the five branches leprosy victims can be engaged in manufacturing, trade and service provision activities per their choice. The expert rose victims of leprosy organized themselves and their organization made its own effort however the victims themselves do not want to get organized with non-PALs. The other gap identified during discussion was that women in leprosy do have a problem to work on big buildings that have stairs. The other attitudinal problem is people in leprosy on the one hand they organize themselves and try to engage in income generating activities and on the other hand there is a situation that they beg on religious holiday in front of the churches. Besides, there is a resistance on the side of the victims of leprosy while the government provides alternative opportunities for their development in all endeavors.
- As the discussion with KII, there is a change in stigma and discrimination for the confined place for them earlier has now been occupied by other dwellers of the city. Besides, there is a change of attitude among the educated society than illiterate community. However, still there is a need of awareness creation.
- As the discussion with KII revealed there is attitudinal problem for the victims that is expecting to be supported / subordinate feeling. For ex. 48 Women organized in poultry after a while left and get back to the feeling of being supported.

- Victims themselves lose the courage to be with non-PAL. On the community side too there is a deep rooted negative attitude. The physical damage or the injury itself made them discriminate themselves. Therefore, there is a need of social mobilization.
- Consultancy service for PALs to strengthen psychologically as they can live, work and be changed
- Awareness creation at community level about leprosy /the cause, what is all about it, protection methods etc has to be consistently organized?
- Since one of the major problem faced by leprosy affected people is the social stigma attached to it, the only way to stop the stigmatization of people affected by leprosy is to do away with the situations that caused the stigma in the first place: Raising public awareness, educating clients (leprosy affected people) about the disease how it is caused, transmitted, prevented and cured. Leprosy affected people are suffering more from psychosocial and economic problems than the biological pains the disease causes. To tackle this problem, designing implementation and evaluation of a training program for leprosy field workers regarding the effective counseling of leprosy sufferers and the development of strategies to de-institutionalize leprosy sufferers and to integrate them into the community is very crucial. It would be better if integrating leprosy work into non-medical program, addressing the general population be implemented.

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APPENDICES

Appendix A

Indira Gandhi National Open University

School of Social work

GRADUATE STUDIES

Consent form

Date________________ Place________________ Time_________________________

Introduction

Good morning/ good afternoon. You are being invited to participate voluntarily in the study entitled that ―the psychological, economic and social problems of Women affected by Leprosy in Addis Ababa. My name is Rahel Hiletework. I am a master‘s student at Indira Gandhi National Open University School of Social work

The purpose of this study is to gather information on how your experience is on the social, psychological and economic situation of leprosy patients in general with particular emphasis on women. You will be asked to discuss your thoughts, experiences and feelings related to the psycho-social and economic situation of leprosy. Your interview will be recorded. The interview will take approximately 45 minutes of your time.

The questionnaire has five parts. The first part inquired the background information or some personal questions including your age, marital status, religion, ,level of education and the like followed by questions pertaining to occupation, diagnosis, attitudinal assessment/self-esteem, prevalent problems and types of intervention. The questionnaires are prepared as part of a study that is undertaken as a partial fulfillment of the requirement for the degree of Master social work for graduate studies. The interview will take place in a convenient place. You may stop the interview at any time and can end your participation in this study if you wish. You may refuse questions if you want. You are free to ask questions and receive answers at any time throughout this study.

I kindly request an honest answer so that the study reflects the fact. Thank you in advance for your cooperation.

Are you willing to be interviewed? Yes ______________ No____________

APPENDIX B

Indira Gandhi National Open University

School of Social work

GRADUATE STUDIES

Questionnaire 1In-depth interview to be completed by persons Affected by Leprosy (PAL)/ 20 women/

I. Current Personal Data
(Characteristics of the interviewee (indicate the right answer by circling the number or filling the blanks)

1. Name_______________________________________ Age________(completed years)
2. Current Address Region________________ sub city_____________ Woreda ________________ house no.____________________________
3. Religion 1. Orthodox 2. Catholic 3. Protestant 4. Muslim 5. Traditional 6. Other (specify) ____________________________________
4. Marital status 1/ Single 2/Married to PAL 3/ Married to non-PAL

   4/Divorced 5/ widowed

   If divorced or separated, why?1/because of leprosy 2/ because of other reason
5. Level of Education 1. Illiterate 2. Literate

   If literate 1. Church School 2. Koranic School 3. Literacy Campaign/traditional

   4. Modern – Grade completed ______________

6. Family size/ people living together/ ________________

7. Do you have children? 1/ Yes_______________________2/ No________

   If, yes how many? __________

8. Are your children of school age? 1/ Yes _____________2/ No ____________

   If yes, do they go to school? 1/ Yes _____________2/ No __________________

If No, why?

1/ Economic reason 2/ Feeling of segregation as a family member of PAL

3/ Need for labor force in the family 4/Other________________________________

9. House ownership

1/ Owned house 2/ Rented house / Government or private/

3/ subordinate /institution or family 4/ homeless

5/ If other specify___________

II. Occupational status

1. Occupation/main source of income 1. Farming 2. Cattle breeding 3. Commerce 4. Civil servant 5. Domestic work/maid 6. Factory 7.Handicraft 8. Housewife 9. Not working (Pensioner etc.)10. Other (specify) __________

2. Average monthly income of the family

1/ No income 2/ 100 birr and less 3/ 101-150 birr 4/151-200

5/ 201-250 6/ up to 300 7/ if more specify__________________

3. Do you have any other /additional income? 1/ Yes ________2/ No____________ if yes,

Specify________________ Monthly average income_______________

I. Diagnosis

1. Place of onset the case/leprosy Region _____________Woreda_______________

2. Year of onset __________________ Age at on set_________________

3. Place of living before on set a/ Rural b/ Urban

4. Place of living after onset 1/ Different from before onset with non-leprosy 2/ different from before onset with leprosy people 3/ the same as before onset with non-leprosy 4/ the same as before onset with leprosy patients 5/ in a settlement for leprosy affected persons 6/ othersspecify____

5. How did you come to know about the case/leprosy? 1/ told by family/relatives 2/ told by health professionals/ 3/ told by other person 4/ getting information on the symptoms from media 5/ told by local healers 6/ other/ specify ________________________

6. What symptoms did you see? ________________________

7. What actions did you take? 1/migrated to another place to hide myself

From surrounding 2/ went to local healers 3/ went to health services

4/ went to religious place/ for holy water 5/ other____________________

8. Treatment taken 1/Local medicine/ healer 2/Rituals /religious, traditional

3/ modern medicine 4 / holy water 5/other_________________________

9. When did you take the modern medicine 1/ Before MDT 2/After MDT?

10. How long do you take modern medicine? ________________ No. of years

11. How long did you take traditional medicine? _______________No of years

12. What happened when you take traditional medicine? 1/loss of sensation

2/ Disability/ loss of fingers, legs, eye sight

3/cured d/other________________

13. How did you stop taking the modern medicine? 1/ on my own

2/ advised by physicians 3/discouraged by others

4/ other specify _________________

14. Did it relapse? 1/ Yes________________2/ No________________

15. If yes, to 14what Acton did you take?

Did you take modern treatment again after relapse? 1/ Yes______2/ No____

16. If no, what other action do you take? Specify________________

17. Are you still taking the modern medicine? Yes__________No__________

If no, why? __________________________________

II. Attitudinal Assessment and Self esteem

1. What do you think the cause of the disease/leprosy? 1/ curse 2/ calamity/God related or spiritual 3/ hereditary 4/ Germ/ bacteria 5/ other/Specify_______________________
2. Have you been employed after onset? Yes_____________ If yes, in the former status or job changed? ___________________________ No _____________if no why? ____

3. Do you have any employment problem after onset of the disease? 1 /yes 2/ No

   If yes, why? 1/ Because I am disabled by leprosy and I am not fit for work 2/no one has wanted to employ me 3/ I prefer to be self-employed. 4/ I cannot find work that fit my disability 5/ due to employment problem like any other citizen 6/ other specify__________

4. How the problem on employment opportunity can be solved?

   1/ lobbying with policy makers for employment. 2/ Awareness creation in the society about the PAL 3/ creation of Income generating activities in our own settlement

   4/ advocating employment of PAL 5/ /Assisting self-employment activity

   6/ /other specify______________________

5. Do you have self-confidence? 1/ yes 2/No3/ I do not know

   If no, why? ____

6. Do you have self-respect? 1/ yes 2/No 3/ I do not know if no why?

   ____

7. Do you have respect in your close family/relatives? 1/ yes 2/ No 3/ I do not know if no, why? ____

8. Do you have respect in your surrounding by PAL and non-PAL? If not, why?

   ____

9. Is your marriage partner and your children with you after onset in a positive mood?

   1/ yes 2/ No

   If no, why?____

10. Do you feel loneliness and hate yourself? 1/yes 2/No

    If yes, why? ____

11. Are you segregated or separated by yourself/by the society/ relatives and friends?

1/yes 2/No If yes, why? ____

12. Do you have a feeling of hatred towards society and relatives? 1/yes 2/No

    If yes, why? ____

13. Do you have a feeling of hatred towards non PAL's? 1/ yes 2/No

    If yes, why? ____

14. Do you feel inferior to other persons? 1/yes 2/No

    If yes, why? ____

15. Do you participate in social affairs in the community? 1/yes 2/ No

If no, why? ____

16. Do you compete with the society of non-PALS? And lead your family with full courage?

1/ yes 2/No If no, why? ____

III. Prevalence and Trend of Leprosy

1. Is the case of leprosy increasing or decreasing? 1/Increasing 2/ Decreasing

   3/ No change 4/ I do not know

2. Are there new cases/ affected by leprosy? 1/Yes 2/No

3. Are people affected by leprosy exposed to disability? 1/ yes 2/ No 3/ I do not know

4. If exposed, can you guess the extent? 1/ high 2/ medium 3/ low 4/ I do not know

5. Is the service/MDT treatment and other provided by ALERT adequate? 1/yes 2/No

   If not, why? _________________

6. Do you have the Knowledge, Attitude, and Practice (KAP) program in the victims and around the community level by ALERT or any other organization?

   1/ Yes _______No ______If yes, what do you understand from the situation? Explain____

7. Who is most affected by leprosy? Adult Men/Adult women/youth/children/ girl child/ boy child/ Aged man/ Aged woman /Multiple choice can be given/

   What do you think the cause/reasons for the most affected group?

   ____

8. Do you /as a group have a power with your community/collective action to make voice/ for your common problems /affairs? 1/ yes 2/ No

   If yes, what kind of progress you make? Explain____

If not, why?

Explain____

____

9. What are the major challenges? specify

____

10. What do you recommend to improve the socio-economic problems of PALs in general and women in particular?

____
____
____

Key informants Interview 1.

/KII/ for Women's Affair, Youth and Sport, ENAPAL, Religious, Community leaders etc.

Part I: Personal information
Name ____ Sex____________ Age______

Educational status_________________________ Occupation /Sector ____________________

1. Do you and your family know about leprosy? What are the causes for it?
2. How does leprosy affect the health and wellbeing of individuals, families, groups, and community?
3. What do you think about the psychological effect of leprosy on the affected persons?
4. What are the social and economic effects of leprosy?
5. How do you perceive the reaction of Leprosy patients towards the social stigma and discrimination?
6. How do the family members respond to the people affected by leprosy? How about friends, neighbors, & community?
7. How do the people around you and the community understand the causes, aggravating factors and the social effects of leprosy?
8. Have you or your family experienced negative effect on involving and benefit from social services? Can you tell us some of those experiences, if there is any?
9. How does people affected by leprosy's personal relation with other people? Does it have similar effect on the family members?
10. Did PAL's face any kind of discrimination and stigmatization for being affected by leprosy? Probe, how do you cope up with it? If there is any?
11. What do you think the economic effect of leprosy on the affected persons?

12. How do you explain the economic situation of people affected by leprosy? Probe, what coping mechanism did they use?
13. What is/ are the main source of livelihood of people affected by leprosy?
14. What are the Coping strategies to overcome challenges related the psycho social and economic effect of leprosy?
15. What do you suggest for improving the psycho- social & economic situation of leprosy patients? Probe, what coping mechanism did you utilized to overcome these problems?

Key informants Interview 2.

/KII/ for Health officers and Social workers

Part I: Personal information
Name ____ Sex_____________ Age______

Educational status___________________________ Occupation /Sector ______________________

For how long you have been working here /in the Woreda? ___________________________________

1. What is the magnitude of leprosy in this area?
2. How is the trend of leprosy in this area? Is it increasing or decreasing?
3. At what age group the leprosy is most prevalent?
4. Who most affected in terms is of sex and age? Why?
5. What are the major health effects of leprosy? Please list them
6. What is the major social effects of leprosy? Please list them.
7. What are the major psychological effects of leprosy? Please list them.
8. What are the major economic effects of leprosy? Please list them.
9. What activities have been done to solve these effects and the gaps?
10. What do you recommend in the future to mitigate the effects of leprosy?
11. What do you observe about the leprosy status of women in the health facility or community?
12. What do health professionals /social workers know and understand about leprosy?
13. What are the health professionals /social workers experience of victims of leprosy in general and leprosy women in particular?

14. What is your experience on leprosy related social stigma and discrimination? What social wok interventions could be put in place to improve the living conditions of people with leprosy?

15. Were issues relating to leprosy discussed as part of your work? If yes, how do you describe those issues?
16. How confident did you feel working with the issues related to leprosy?
17. What are the training needs regarding leprosy amongst health professionals/counselors or social workers?
18. What should be the role of Health professionals or social workers to solve social, and psychological effect at different levels?

IV. Focus group guide for leprosy patients and Non leprosy patients/ independent discussion

Discussion Themes

1. What does leprosy mean to you?

2. What are the Psycho-social effects of leprosy?

3. What are the Economic effects of leprosy?

4. What are the Coping strategies to overcome challenges related the psycho social and economic effect of leprosy?
5. What do you suggest for improving the psycho- social & economic situation of leprosy patients?

Thank you for your cooperation!!!