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Exploring the Living Conditions of People Affected by Leprosy: The Case of Zenebework Area, Addis Ababa City

BY

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This is to certify that the thesis prepared by Yonas Sirak entitled "Exploring the living conditions of leprosy affected people: The case of Zenebework Area, Addis Ababa City" submitted in partial fulfillment of the requirement for the Degree of Masters of Arts complies with the regulation of the university and meets the acceptance standards with respect to originality and quality.

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List of Acronyms

AANLRA	Addis Ababa National Leprosy Rehabilitation Association
ALERT	All Africa Leprosy, TB, Rehabilitation, Research and Training Center
ENAELP	The Ethiopian National Association of EX-Leprosy Patients
FMOH	Federal Ministry of Health
IJCH	International Journal of Community Health
IJM	International Journal of Micro Bacteriology
ILA	International Leprosy Association
ILEP	International Federation of Anti-Leprosy Association
MB	Multi Bacilli
MDT	Multidrug Therapy
MOH	Ministry of Health
MOPH	Ministry of Public Health
PZWH	Princess Zenebework Hospital
SIM	Sudan Interior Mission
TB	Tuberculosis
TBL	Tuberculosis and Leprosy Control
WHO	World Health Organization

Abstract

This study explores the living condition of people affected by leprosy around Zenebework area, Addis Ababa. To this end, a qualitative design with a case study approach. In-depth interview and observation tools were used to gather information in this study. Participants' opinion was gathered from purposefully selected ten in-depth interview participants and seven key informants. An effort has been made to explore the living condition of leprosy affected people. Thematic analysis was used to analyze the data. As the finding of the study show, participants realize the reason for their physical damage is due to lack of knowledge about the disease and early detection of the patients. Because of the stigma attached to the disease leprosy patients suffer from psychological problems like anxiety, depression, and lack of self-confidence. The study also shows that the stigma attached to the disease was the major causes of affected people in psycho social and economic dimensions. The finding of the study suggested that how affected people cope the stigma associated to the disease, the need to raise community awareness about the cause and transmission of the disease. This study also tried to show the role of the social worker in improving the living conditions of social workers. In conclusion, the study appeals for social work practice, program development, and policy makers to mitigate the problem attached to the affected people.

Key words*:* anxiety, depression, self-confidence, stigma,

Chapter One

Introduction

1.1 Background of the study

Atinkut et al. (2018) found out that Mycobacterium leprea is a bacterium that causes leprosy. It has also a rod shape with longer incubation period. Leprosy is a disease that mainly attacks the skin and the peripheral nervous system. As a result, it causes a viable consequence on the body such as impairment and incapacitation (WHO, 2018).

Naaz et al. (2017) found out that nerve damage due to leprosy and its complications (leprosy reactions) can cause disability if they are not treated early. Therefore, early detection of the patient is decisive for the appropriate treatment. Regarding leprosy, in most cases, affected people are weak in their economy.

Despite the physical damage, leprosy causes various implications on the affected people. For years, leprosy has been regarded as assign of fear and social isolation; consequently, affected people are exposed to stereotypes. The difficulties in relation to the disease are not merely physiological, but they are also psychosocial that causes economic deprivation and social marginalization. However, a great achievement is made in the medication of the physical aspect while most of the problem associated with the psychosocial is lagging behind (International Federation of Anti-Leprosy Association [ILEP], 2003). ILEP noted that although leprosy is the most feared and isolating disease for years, there is still less achievement made in treating the psychosocial problems.

According to WHO (2002), leprosy is now found in parts of Asia, Africa and central and South America. The distribution and prevalence of Leprosy is neither uniform nor random. In

some parts of Africa more men than women are diagnosed with leprosy but there are some African countries where more women than men are affected (WHO, 2002).

According to Berhe et al. (1990, p.259), organized treatment of leprosy started in Ethiopia in 1934 at the previous Princess Zenebework Hospital (PZWH) which was built by the Sudan Interior Mission (SIM) in the outskirt of Addis Ababa. Giel and van Luijk (1968) reported that the impact of leprosy concerning the different social aspects seems very huge because little is known about the factors affecting the life of people affected by leprosy. Giel and van Luijk (1968, pp.328-334) also state that "The Princess Zenebework Memorial Hospital is the center attracting the patients though some patients may have come to Addis Ababa because of the greater opportunities for survival in the capital".

A leprosy control program lead by the Federal Ministry of Health (FMOH, 2008), as scored extraordinary achievements in reducing the prevalence rate of leprosy in Ethiopia. However, the annual new case detection did not show comparable decline. Though, Ethiopia was achieved the elimination target of leprosy that is 1 case per 10,000 according to the WHO standard in the year in 1999, there are areas of high endemic at sub national levels where the leprosy prevalence is still higher.

There is also a prevailing context for leprosy to occur. Challenges and Hackathon (2014, p.15) stated that "It is more common in communities where people are living in crowded conditions, poor sewerage, nutrition, and poor standard of living; where people's immune system are not strong and they are unable to fight the disease."

The selected area for this study is highly associated with the prevalence of leprosy. As the disease demands long-term medication, there were trends for infected people to settle in the area.

Therefore, it would be wise to study the living condition of affected people by leprosy on three major areas like physical, psychosocial, and economic aspects.

1.2 Statement of the Problem

A number of studies have been conducted globally and in Ethiopia on the various aspects of people affected by leprosy. Mostly in Asia, there are studies conducted on various implications of leprosy on the affected people, such as the impact of leprosy on the quality of life, the knowledge and attitude of community on leprosy patients, prevalence of mental distress, and measuring leprosy stigma and so on.

Joseph and Rao (1999) conducted a study on the impact of leprosy on the quality of life. It has discovered in a society where indigence, analphabetism and poor sanitation is common leprosy being a supplemental load it influences the quality of life. The study also found out that women score better than men nearly in all aspects regardless of their secondary position in the society. This entails that there is considerable willingness among women to admit their circumstance.

Moreover, Van Brakel (2003) conducted a study in India on a review of literature. There is no acceptable parameter formulated to measure stigma. However, there were attempts made to determine the intensity and quality of stigma associated to leprosy. It also found out that the repercussion of stigma are extremely large in influencing the lives of many people and leprosy control programs. The study also signifies irrespective of cultural variations the implications of leprosy are alike.

Noordende et al. (2016) have studied the impact of leprosy on marital relationships and sexual health among married women in Nepal. The findings of the study showed that many women, regardless of leprosy and disability status, experience marital problems and sexual

abuse. There is also lack of knowledge on the cause and transmission of leprosy among the affected women and their community members.

In the Ethiopian context, the following studies have dealt with the implications of leprosy on affected people. Tesema and Beriso (2015) studied the awareness and stance of community on leprosy affected patients in Kuyera of South east Ethiopia. The finding of the study reveals among 296 participants more than half which is 69.26% had no positive outlook towards leprosy. However, four fifth of the respondents had little awareness about the disease. Moreover, the majority had knowledge about the multiple causes of leprosy.

Similarly, Atinkut el al (2018), also conducted a study on the knowledge, belief and attitude of community on leprosy in Gindeberet, west Shewa, Ethiopia. The findings indicate that among the study participants below half of them had low level of awareness towards the disease. On the other hand, the majority of the respondents had no positive feeling about leprosy.

Tadele (1985) found out in a literature review on the new development in The National Leprosy Program of Ethiopia and issues of integration. He found out that the reduction of leprosy is associated to socio-economic development.to that ends, leprosy should be perceived as a social disease. Tadele also suggested to the development of the entire socio-economic conditions, leprosy control practices must be related to the primary health care system.

Leekassa et al. (2004) studied on the prevalence of mental distress on inpatients in Alert Hospital at Addis Ababa, Ethiopia. They found out there is 12 times risk for leprosy affected people to acquire mental distress.

To summarize, even though numerous studies have been conducted on the people affected by leprosy, very few studies have been conducted on the living conditions of people affected by leprosy. The existing study on the living conditions of leprosy is conducted in Asian

context and cannot give a holistic picture of our context. The existing literature in Ethiopia also focuses on the specific aspect of leprosy, not on the overall aspect of leprosy. But none of them has focused on the overall living condition of leprosy affected people.

Thus, the present study sought to fill one of the existing gaps by exploring the living conditions of leprosy in Ethiopian context with a specific focus on the Zenebework area of Addis Ababa, Ethiopia. More specifically, the study will explore the opportunities and challenges among the leprosy affected people in relation to their living conditions.

1.3 Objectives of the Study

General Objectives

The main objective of this study is to explore the living conditions of leprosy affected people who live in and around Zenebework area in Addis Ababa.

The Specific Objectives are to:

- explore the physical conditions of leprosy affected people in the area;
- assess the psychosocial conditions of leprosy affected people
- describe the economic conditions of leprosy affected people
- examine the implication of leprosy on the living condition of affected people;
- assess opportunities and challenges faced by leprosy affected people in the study area.

1.4 Research Question

- What are the physical conditions of leprosy affected people in the area?
- What are the psychosocial conditions of leprosy affected people?
- What are the economic conditions of leprosy affected people?
- What are the implications of leprosy on the living conditions of affected people?
- What opportunities and challenges are there due to leprosy on affected people in the area?

1.5 Operational Definitions

Anxiety – a psychological problem posed on leprosy affected people

Coping mechanisms – the strategies employed by the affected people to multitude of challenges

Deformity – abnormal body structural change due to leprosy infection

Depression – psychological distress of leprosy affected people following their infection of leprosy

Disability – inability of leprosy affected people as a result of injury because of leprosy

Discrimination – disfiguring affected people as a result of their infection

Early diagnosis – premature or early detection of leprosy patients

Employment – the potential jobs available to the people affected by leprosy

Impairment – lasting injury on the body due to leprosy

Living condition - this is the condition of affected people with respect to psycho social and economic aspects

Orthotic – a supportive device attached to a limb

Prosthetic – an artificial substitute for a limb

Psychosocial – the psychological and the social aspects of leprosy affected people

Self-confidence – lack of self-reliance of leprosy affected people as a result of the disease

Social participation – the social involvements of leprosy affected people in their community activities

Stigma – the situation to marginalize leprosy affected people due to leprosy

1.6 Relevance of the Study

As it is stated in the statement of the problem, there are a number of studies conducted on people affected by leprosy. However, there is insufficient literature on the living condition of people affected by leprosy. As a result, this study will fill the gap of literature available in multifaceted aspects of living conditions of people affected by leprosy. In addition, the study contributes to a body of knowledge regarding the versatility nature of leprosy affected people.

At the end, this study provides an opportunity for stakeholders to consider the living conditions of leprosy affected people so that it can be used for program development, intervention schemes, and for policy making as well.

1.7 The Scope of the Study

The study is demarked either in its spectrum or geographical coverage. Therefore, the scope of the study is very much limited to a certain aspect like physical, psychosocial, and economic conditions on the people affected by leprosy. This study is confined to a specific location in Addis Ababa, which is Zenebework Area.

1.8 Limitation of the Study

The study is a case study using a qualitative approach and it is difficult to generalize about universal conditions. Due to covid-19 and the state of emergency, it was impossible to conduct focus group discussions. The research is also limited to see only three major aspects of living conditions such as physical, psychosocial and economic aspects, but it doesn’t cover the broad life dimensions of people affected by leprosy.

Chapter Two

Literature Review

This chapter reviews literature on the nature of leprosy as a disease and its implications on the living conditions of the affected people. This section contains issues like historical overview of leprosy, the biology of leprosy, and the impacts on the affected people. Finally it overlooks the history of leprosy in Ethiopia and its association with the area of study.

2.1 Defining Leprosy

Leprosy also used interchangeably for Hansen's disease. It is named after the Norwegian physician, Dr. Armauer Hansen, who has discovered the causative agent *Mycobacterium leprea* (First, 2003). White and Paredes (2015, p.80) mentioned that Leprosy, also known as Hansen's disease, is a chronic infectious disease to human beings by *Mycobacterium leprea*. They also noted that leprosy mainly attacks the nerve endings and the integument. However, it also affects areas like eyes, membranes lining with mucus, bones and testicles. Joel (2002, p.346) stated, "Leprosy is a chronic, infectious and debilitating disease. For it has been known for its social stigma and physical deformities. Patients face social rejection due to the prevalent beliefs regarding its hereditary and contagious nature."

2.2 Historical Overview of Leprosy

Even though leprosy is most famous in ancient China, Egypt and India; it was certainly known in India around 600BC (Davey, 1987, p.15).He also noted that leprosy is mentioned in the third book of mosses with Leviticus, dictating how to behave towards 'lepers' considering the disease as plague. However, in the New Testament leprosy affected people got significant attention and mercy by Jesus.

Sandle (2013, p.4) observed that leprosy being the oldest disease it has diffused to the world through movement of people, forceful subjugation, and territorial expansion. The transmission of leprosy was also related to long distance trading of items by different roots. There were also historical efforts and political commitments as a global health problem to eradicate leprosy.

According to Messele (2005) report it was 1973 a Norwegian physician Hansen discovered *Mycobacterium Leprae*, as the cause of leprosy. That is why the name of the disease is interchangeably known as "Hansen's disease". He also noted that before this discovery there were assumption that it was punishment from God for one's own sin, sorcery, gene mutations and sudden alteration of temperature

2.3 Leprosy in Ethiopia

Duff (2005) and Messele (2005) both acknowledged that the existence of leprosy in Ethiopia is before 16th century. Furthermore, Messele (2005) mentioned that it is Francisco Alves a Portuguese diplomat who identified the existence of the disease in Ethiopia. Messele also suggested that the occurrence of the disease is as a result of long distance trade and cultural relations with others.

According to Tadele (1981) there were no written materials available about leprosy before 20th century. However, leprosy patients got help from the Ethiopian Orthodox Church because it had a saint who was a leprosy patient known as Gebre-Kirstos. This is still the major reason to found deformed leprosy patients in large number around churches in search of alms whenever there are feast days. He also noted that the first modern leprosy treatment was started in Harar by a French citizen called Feron. In addition to this, Tadele asserts that a special hospital for leprosy patients built at Addis Ababa in 1930 with the help of Sudan Interior Mission

(SIM). At the end, to satisfy the growing leprosy patients' demand the first leprosarium launched in the former Princess Zenebework Memorial Hospital (PZWH), which is now called ALERT in November 1932.

Feenstra and Visschedijk(2012) set forth until 2001 in Ethiopia leprosy medication was given by assigned individuals at leprosy specialized hospitals. Nevertheless, by the end of 2001 the prevention of leprosy integrated to the primary health care system. It was important in identifying the disease at premature level of development and completes MDT.

2.4 Institutions for Leprosy

During 13th century when leprosy becomes prevalent, patients were officially isolated in the times of crusades. After the discovery of the first medicine in 1940s, there was a step wise divert to outpatient treatment (Sermrittirong et al, 2014, p.150). Even though WHO (2000) disclose the importance of institutional isolation is over, the discrimination associated with leprosy remain as a past time experience across the globe.

> There are specialized organizations and institutions established over years to deal with the people affected by leprosy. These institutions are recognized as Leprosaria. Today, they are also named as sanatoria, colonies, asylum or hospitals as they are descended from the Lazarest of medieval Europe. Today, the common name that we use to identify institution that is actively engaged to address leprosy and a leprosy related issues are known as Leprosarium (First, 2003, p.10)

2.5 Diagnosis and Treatment

According to International Leprosy Association [ILA], (2002) even though the ability to identify skin lesions on an anesthetic path is unable to behold 30% of the Multi Bacilli (MB) case, the detection of leprosy is simple. ILA (2002) stated that "out paramedical personnel needs

to recognize at least two key signs of leprosy: an esthetic skin lesions and enlarged nerves. This involves training, supervising and monitoring junior health care staff as well as offering refresher training at some intervals".

WHO (2006, p.19) reported that out Multidrug Therapy (MDT is the most efficient curable mixtures of three drugs that overcome drug resistance. However, no one should dare to treat leprosy by a single drug from the MTD as it develops drug resistance. WHO (2018) there are two types of leprosy based on skin lesions, bacterial load, nerve involvement and identification of bacilli on slit-skin smear. First (2003, p.6) noted that among the components of MTD Rifampicin is very important to treat both MB and Pauci Bacillary (PB). First also found out that MTD has been supplied without fee by WHO since 1995. Nippon Foundation donated MDT until 2000 and Novartis until 2020. He also sought that in the eradication of leprosy 1 case for every 10,000 persons was achieved globally in 2000.

2.6 Transmission of Leprosy

Job (1981:69) found out that leprosy is an infectious disease that can be transmited from one person to the other with a causative agent of *Mycobacterium Leprae*. There are two mechanisms for the transmission of the disease the origin of the infection and the way of entry. However, enough is known about the causative agent, way of transmission; it is still oddly mysterious. First (2003, p.9) affirms that the reason why long ago people tend to consider it as genetically transmitted disease as it appears within families. However, these days only some portion of a family affected by the disease.

Chiyaka et al. (2013) mentioned that leprosy being an infectious disease has slow development of transmission by having contact with the affected person. Droplets of infections from the nasal cavity are the major disposal for the pathogens to enter through sensitive

membranes lining the body and cuts in the skin. Living in an intimate contact with an infected person is the necessary condition to acquire the disease.

2.7 Prevention of Leprosy

Chaitany et al. (2017) mentioned case identification and Antimicrobial Chemotherapy therapy is a method employed by World Health Organization to prevent and eradicate leprosy. The activities of inspected Chemotherapy with attendant that not comply and absence of detecting drug-resistant *Mycobacterium Leprea* on a daily basis result in incomplete Chemotherapy that casus to fall back, reinfection, and drug resistant strains of *Mycobacterium Leprea*.

Naaz et al. (2017, p.226) stated that:

> Early detection of all patients before they develop disabilities, prompt treatment with uniform MDT regimen shortening the duration and inclusion of persons affected by leprosy will be the key tenets of the global leprosy strategy for the next 5 years (2016–2020) universal elimination of leprosy towards zero disabilities.

2.8 Impacts of Leprosy

First(2003)found out that untreated leprosy results in physical damage that develops from primary to secondary of stages of impairment. Primary physical impairment can be characterized by the invasion of bacillus on most body membranes that are lining with mucus. Consequently, there would be damage to the body parts where there are concentrations of bacteria what is known as leprosy reactions. It's this time the affected person loses nerve sensation. He also noted that if it is untreated it develops to cause secondary physical impairments, a stage where contracted and paralysis of limbs are formed. Finally, it damages the inner tissue and bones so as to cause disability.

Noordende et al. (2016) sought that stigma is the most implication that leprosy cause. Leprosy patients are exposed to varieties of stigma and discrimination, like social exclusion, attack, losing a job, having low self-esteem, and disrespect from their own community. Therefore, due to low social status and interpersonal relationships affected people are vulnerable to psychological problems.

It is apparent for leprosy affected people to be economically poor. Whenever the disease progress it causes deformity and becomes a barrier to the affected people to Cary out their socio-economic activities (Ramona et al, 2017).

Alam et al. (1997) suggested leprosy for long time remembered for its misperceptions, magical and erroneous related to it. Long ago leprosy was regarded as a repayment for doing sin and good punishment as a result there were tendencies to consider it as genetically transferred. However, with this all mythologies leprosy is highly communicable and contaminated disease.

2.8.1 Physical Impacts of Leprosy

WHO (2018) showed that, untreated leprosy results in physical impairment that causes deformity. There are deformities and disabilities because of leprosy. Such impairments could have manifestations in two stages of development: primary and secondary impairments. First (2003, p.9) also stated that:

> although leprosy is seldom fatal, it can cause a whole range of impairment, deformities and physical disabilities, contracted fingers and toes, ‘drop-foot’ and ‘drop-wrist’ thickening skin(especially on the face and earlobes), nasal deformity, facial paralysis, loss of eyebrows, and blindness. Some of these problems are caused directly by the disease: otherwise, its secondary result.

2.8.2 Psychological Implications of Leprosy

Adhikari et al (2013) observed that when a person tested positive for leprosy there is a great challenge on the psychosocial than the physical repercussion. Stigma is the major psychosocial consequence inflicted on the affected persons due to leprosy. However, Zodpey, Tiwari, and Salodkar (2000) render that disabilities and deformities due to leprosy cause activity incapacitation and lower their psychological state of mind.

Gurvinde (2016, p.166) also exhibited persons affected by leprosy are obliged to be alienated from their place of origin and ostracized. Among the psychiatric disorder showed in leprosy affected people depression is the most widespread. Premature diagnosis and medical attention of psychiatric disorder among leprosy patients are strong psychotherapeutic actions to be taken.

To avoid the effects of leprosy and to battle the prejudices about the people affected by leprosy, there must be integration of activities. There should be cooperation and integration among the public and service providers to promote and eradicate leprosy (First, 2003).

2.8.3 Social Impacts of Leprosy

Harvinder and Brakel (2002, p.346) noted that leprosy is an infectious disease that causes social stigma. The reasons for social stigma are the mythologies about leprosy: supernatural punishment from God, its infectious nature, and the physical disabilities of affected people. They also found out community's outlook towards the disease is one of the undesirable psychosocial consequences on the affected people, apart from the physical deformities. Prolonged physical and psychosocial limitations of the affected people gradually castigate them from the society. Therefore, due to deficiency of assistance and lack of self-confidence usually affected people end up beggars.

According to a report made by Sirinivasan (1999, pp.121-192), leprosy affected people not only suffer from psychological disorder, but also physical impairments. Consequently, patients may be exposed to limitations of activities in their daily routines. The visible deformity or being identified as leprosy patient deters their social involvement, formally known as 'disabled'. With all these factors and the prolonged restrictions in social participation, forced them to be castigated and rejected by the society.

2.8.3.1 Challenges on Marriage

According to First (2003) observations researches have shown that, divorce occurs when one partner has leprosy. Usually the one who take the initiation to separate is the one with the disease. Once positive for leprosy infection, many young women will still give up hope of marriage. Desalegn (2014, p.17) mentioned that, marriage between leprosy affected person and none affected one is impossible in Ethiopian community.

2.8.4 Economic Challenges of Leprosy

The manifestation of stigma and discrimination has influenced the economic rights of people affected by leprosy. Park (2007, p.146) revealed socioeconomic status is affected by leprosy. Poor sanitation, low economic status, and living under crowed are buffering situation to be infected by leprosy.

Tekle-Haimanot et al (1992, pp.157-68) observed that regarding employment, in Ethiopia, about 95% of the population was found unwilling to employ or work with leprosy affected persons.

Desalegn (2014:17) stated that "in Ethiopia some community members that are affected by leprosy have organized themselves and took a sort of vocational trainings to work on income generating activities. In this regard, the *Blulign* self-help association can be a model and still

operational. The majority, particularly those who are physically impaired, took beggary as a means of earning their livelihood". Desalegn also noted that; there is a mutual understanding between leprosy affected people and the society, begging as a proper means of earning their livelihood. Therefore, employment and self-employment has been denied as a source of income in leprosy affected people in Ethiopia.

2.9 Theoretical Framework

Theories have been developed from different field of studies in relation to the living condition of leprosy affected people. Particularly, sociological theories are very relevant with respect to challenges like psychosocial, economic, and coping strategies. For the sake of clarity and relevance to this study, only selected theories have been discussed here. The problems of psychosocial, economic and coping strategies of leprosy affected people should be considered to explore their living conditions. Therefore, the ecological systems theory will be one of the frameworks for analysis. Economic and psychosocial are factors that influence the living conditions of leprosy affected people. The bio psychosocial approach is used to interoperate the factors that influence the living conditions of leprosy affected people. This approach is selected because it looks leprosy affected people as an individual with inner drives and as a cultural being. According to the bio psychosocial theory all the factors affecting the living conditions of leprosy affected people is as a result of the individual views and community outlook towards the disease.

Finally, ecological system and the social constructionist theories and the bio psychosocial approach guided this study since people affected by leprosy are vulnerable groups of society who are affected by the social and the physical environmental factors and needs to be addressed holistically.

2.9.1 The Ecological System Theory

The ecological system approach encourages social worker to think behind the scene and further from what is immediate and obvious. Therefore, it's up to the social worker to think and practice on the broader canvass (Howe, 2009, p.118). People and their problems are understood in a broader context in the ecological systems theory. In the ecological system theory people have biology, psychology, and their own social context (Coady & Lehmann, 2008, pp.89-90).

The theory recommends a multidimensional approach for understanding human behavior holistically. It can easily accommodate the multidimensional environment like physical environment, culture, social institutions, social structure, families, and communities (Hutchison, 1999, p.35). Another illustration of the relationship between systems perspective and behavior stated that "behavior, events and social processes cannot be fully understood in isolation, but only in relation to one another. Systemic influences may be direct and indirect; connections may not be obvious" (Payne, 2002, p.12).

This is one of the theories that help to understand the living condition of affected people within multidimensional environment. This theory further enables us to see the problems of leprosy affected people in relation to their biological, psychological and sociological context.

2.9.2 The Social Constructionist Theory

Constructionists stress on the presence of different cultural realities; there is no specific objective reality that is formed during people's interaction. In realizing human behavior, the social constructionist perspective targets on actors, in a way they create social realities and the consequent action followed due to such creation. Therefore, the realities constructed by actors play role in switching configuration of persons and events (Hutchison, 1999, p.49).

According to Coady (2007, pp.401-405), constructionists believe that the role in the creation of their own realities and it is created as a response given to an external stimuli. Past experience, conceptualizations and associations affect meaning making as reality is changing, rather than unchanging situation. As a result, while some meanings are rather static across time, other meanings are highly subject to reconstruction.

The social constructionist theory helps to understand the impact of socially constructed realities on the people affected by leprosy. There is a socially constructed misconception about the disease cause, mode of transmission, and treatment result for stigma and discrimination that affects the overall life conditions of people affected by leprosy.

2.9.3 The Bio psychosocial Approach

The Bio psychosocial approach allows the social worker to view a person holistically, as both an individual with inner biological drives and as a social and cultural being. Each component in the system whether biological, psychological or social is intertwined with every other component (Wormer, 2007, p.32). The bio psychosocial approach provides a carefully balanced perspective, which takes into account the entire person in his or her environment and helps social workers in screening and assessing an individual from a multidimensional point of view. The approach considers three overlapping aspects of the patient's functioning: "bio" refers to the biological and medical aspects of the patient's health and wellbeing; "psycho" refers to the patient's self-worth, self-esteem, and emotional resources; and "social" refers to the social environment that surrounds and influences the patient (Beder, 2006, p.4).

In this study the Bio psychosocial perspective is used to assess the participants from the multidimensional point of view and to understand their living conditions as a result of leprosy.

Chapter Three

Research Methodology

The study employed qualitative inquiry with primary data collection methods including: in-depth interviews, key informant interviews, and direct observation. Also as a secondary source of data, documents are reviewed from different sources such as books, magazines and reports.

3.1 Research stance

Both Stake (1995) and Yin (2003) base their approach to case study on a constructive paradigm. Constructivists claim that truth is relative and that it is dependent on one's perspective. This paradigm "recognizes the importance of the subjective human creation of meanings, but doesn't reject outright some notion of objectivity. Constructivism is built upon the premises of a social construction of reality (Searle, 1995). One of the advantages of this approach is the cloth collaboration between the researcher and the participant, while enabling participants to tell their stories (Crabtree & Miller, 1999). Through these stories the participants are able to describe their views of reality and this enables the researcher to better understand the participants' actions (Lather, 1992; Robottom & Hart, 1993).

Constructivism is useful as the philosophical framework for this research. Stake (1995:99) stated that among the many roles of researchers, gathering and interpreting data is essential: "most contemporary qualitative researchers nourish the belief that knowledge is constructed rather than discovered. The world we know is particularly human construction". Stake (1995) also defines constructivism as a belief that knowledge is made up largely of social interpretations rather than awareness of an external reality.

This research is based on the interpretations of participants that are affected by leprosy in and around Zenebework setting of Addis Ababa city.

The other stance recapitulate the research project is the paradigm or the world view chosen by the researcher. Guba (1990, p.17) observed that paradigm or world view is “a basic set of belief that guides action”. Gephart (1999) has classified research paradigms in to three philosophical distinct categories as positivism, interpretivism and critical post modernism.

For the purpose of this research, the researcher combines social constructivism with interpretivism in that reality consists of people’s subjective experience of the external world.

According to Blaikie (2000, p.115) realized that, interpretivists are more interested in understanding what the social world produced in their consistent activities. Theses daily activities of the social actors comprised of meanings and interpretations. Therefore, to understand the world of social actors we need to interpret activities jointly vested in their language that make up their reality.

Therefore, in this study the researcher employs combining both social constructivism and interpretivism paradigm or world view.

3.2 Research Design

Research design is very important to know what the study is all about and where the researcher’s stand is. Mason (2002) observed that whenever thinking about qualitative research, one must reject the idea of research design. This is due to the nature of qualitative research. It is exploratory, fluid and flexible, data-driven and context sensitive. Therefore, it would be both harmful in effect and not possible to write an entire advance blueprint.

However, this is a case study with exploratory purpose at one point in time using a qualitative approach. The study aimed to explore the living conditions of leprosy affected people in and around Zenebework area of Addis Ababa city.

3.2.1 Qualitative Research

According to Hancock, Windridge, and Ockleford (2007), qualitative research method aims to provide rich data and deeper understanding of the phenomena. Qualitative method employs to capture the behavioral and perceptions of leprosy affected people about leprosy and its consequences on their living conditions. The rational for employing qualitative method is that, qualitative research method aims to address questions concerned with developing an understanding of the meaning and experience of humans' lives and worlds (Davidson, Fossey, Harvey, & McDermott, 2002).

3.2.2 Case Study Approach

Qualitative case study research is used as a major approach for this study. Yins (2009) have described the various techniques for conducting successful case study research. Furthermore, Creswell (2007) identified three types of case study based on the intent of the case analysis. This study applies a single instrumental case study that focuses on an issue and selects one bounded case to illustrate the issue.

This study focuses on the people affected by leprosy at Zenebework area. The approach used in the study is important to justify and get clear picture of the living conditions of people affected by leprosy.

3.3 Research Site

This study was conducted in and around Zenebework area of Addis Ababa City. The selected area for conducting this study is a village, which is established along with the establishment of ALERT Hospital in 1934 (Mesele, 2005). The research site is located in Wereda 01 Kolfe Keranyo Sub City, Addis Ababa. The total size of the population of the area was estimated at 76,076 (Central Statistics Agency, Appendix IA, (2007)). Historically, people who settle in this area are in search of medication for leprosy from different parts of the country.

Therefore, in this study the site is selected purposively on the pre-assessment during the observation of the researcher. Besides, during observation the researcher observed that there are many leprosy patients or leprosy affected people in the area selected. Moreover, there are numerous NGO's and self-help associations like AANLRA (Addis Ababa Leprosy Rehabilitation Association) and Blulign.

3.4 Selection of Participants

People affected by leprosy are selected using purposive sampling technique. Kothari (2004, p.15) described this technique as "purposive or deliberate selection of particular units of the universe for constituting a sample which represents the universe.

Regarding sample size, Mason (2010), after revising different scholars' ideas, suggested that five to twenty-five individuals are important as subjects in a given study. In this study, 10 participants, of whom five males and five females, are selected from the leprosy affected people. In addition to their sex, age is also considered so as to maximize differences. Creswell (2007, p.126) illustrated "such approach is usually considered to maximize differences while starting the study aiming at increasing the findings to reflect potential perspectives for a qualitative research"

The researcher selected these participants as they are affected by leprosy, and based on their knowledge about the community they are living in. The rest of the study participants are seven key informants, two of them are professionals from AANLRA, and the other three are from the *Blulign* Self-help Association established by the people affected by leprosy. The researcher has also included other two key informants, a medical doctor who is in charge of leprosy affected people at ALERT Hospital and a social worker at Medhin Social Center, and an NGO closely working with leprosy affected people. Finally, semi structured and unstructured interviews are administered so as to collect detailed information on the living condition of people affected by leprosy.

3.5 Inclusion Criteria

Burns and grove (2003, p.234) defined eligibility criteria as "a list of characteristics that are required for the membership in the target population." Therefore, all participants in this study are leprosy affected people that are living in and around Zenebework except those who are professionals working with them. Moreover, participants need to satisfy the following inclusion criteria.

Willingness to participate in the study.

- Leprosy affected people that are living permanently in the area.
- Age is between 30-62 years for those who participate in the in-depth interview in order to look at the living condition of affected people in all aspect.
- Professionals having work experience with affected people.
- Affected people working in the *Blulign* self-help association who have good knowledge about the target community.

3.6 Data Collection Process

According to Yin (2009) suggestions, multiple sources of evidence are advantageous to have a careful case study because the study would be as strong as possible. Furthermore, Prasad (2005) reported the essence of method refers to the appropriate strategies of data collection and procedure.

Thus, the first step is to go to the research site and to look for important persons who buffer the communication between the researcher and the potential participants. I have clearly explained the purpose of the study to the participants to avoid the communication barriers and build trust. This was an important step to have the consent of the interviewees, for those who meet the eligibility criteria. I have also arranged an appointment with the participants regarding where and when to conduct the interview. Finally, I have prepared all the necessary materials to conduct the interview like note books and a recorder.

3.7 Sources of Data

In conducting the research, primary data sources were used. Concerning primary data, in-depth interview was applied with the selected participants to come up with detailed information on the living conditions of leprosy affected people. In addition, key informant interview was made with participants that are considered to be knowledgeable on the living conditions of affected people.

3.7.1 Primary Data Collection

Primary data provides first-hand information directly from the source. If such collection methods are carefully applied with the right tools, they will be reliable and accurate. Concordia University (2010, p.1) emphasized that “A primary source is a document created at the time of your research subject, about your research subject”. According to Kothari (2004, p.95), primary

data is derived through observation or direct communication with the participants in the form of direct or indirect interview of the participants.

3.7.1.1 In-Depth Interview

To explore the living condition of leprosy affected people, the researcher has developed an interview guide with open ended questions. According to Burns and Grove (2003), interview guide enables the researcher to have control over the process of collecting relevant information on the issue of interest. Open ended questions were chosen as they allow participants to have freedom in expressing their feelings and opinions. Ten participants were selected for the in-depth interview among which age and sex were proportionated and diversified so as to represent the target community.

The contents of the interview were designed to be relevant with living conditions of leprosy affected people so that they can answer the points indicated in the research questions.

3.7.1.2 Key Informant Interview

Seven key informants were selected on the basis that they are affected by leprosy, and on the knowledge they have about the people affected by the disease. Two key informants were from the Addis Ababa National Leprosy Association, and they are professionals that are working with leprosy affected people. The other three were active members of the *Blulign* Self-help Association established by the leprosy affected people. The researcher has also included other two key informants: a Medical Doctor who is working at ALERT Hospital and a social worker at Medhin Social Center, and an NGO closely working with leprosy affected people.

Semi structured and unstructured interview were administered so as to collect detailed information on the living condition of people affected by leprosy.

3.7.1.3 Non-participatory Observations

The researcher has made observations of the area through a structured checklist. During observations I have gone deep to the village, where the affected people live, and observe their daily routines, interaction among themselves and with their neighbors for few weeks to realize the real life situation in their natural settings. For the sake of observation, I have conducted some of the interviewees in their house. I saw that they are living in poorly constructed and very old houses. It was also observed that affected people are highly dependent on their family members in carrying out household activities. Finally, because I myself administered the interview, I was able to observe the level of their physical impairment due to leprosy.

3.8 Method of Data Analysis

Data analysis is one of the important stages in research development. According to Strauss and Corbin (1994) there is a consistent reciprocal relationship between data collection and analysis in qualitative research. Qualitative researches reveal raw data in the form of text during data collections which need to be explained and brief so as to generate identifiable themes.

In this study, the researcher adopted thematic data analysis method in which data obtained by in-depth interviews, and observations were analyzed. As there are no ‘quick fix’ techniques in qualitative analysis, the process involves all the stages indicated in the thematic method. Pope and Mays (2006) wrote, “Qualitative research is an interpretative and subjective exercise, and the research is intimately involved in the process, not aloof from it”.

In the first stage, transcriptions of all data were made from interviews, possible records, and hand written observational notes. According to Lacey and Luff (2007, p.20) stated that:

At this stage, non-verbal cues such as silence that may communicate embarrassment or emotional distress or simply a pause for thought was transcribed. Words and phrases such as 'well…., I suppose…..' are important elements of conversation and should not be ignored. Laughter and gestures were given additional meaning to the spoken words; as a result, the researcher himself was conducting the transcription process.

The next step was organizing the data collected. To make the data easily retrievable, the researcher gave code or number to each interview and breaks up field notes into identifiable sections as to the date or the context. I was giving pseudo names and code numbers to the original informants, but for confidentiality reason, I destroyed the files after the completion of the project.

At the familiarization stage, the researcher read the data again and again, listening to the records, making memos, and summarizing the data before the formal analysis. This stage is also essential for this study as the researcher was doing it by himself.

After familiarization of the data collected, some preliminary coding was made. Certain ideas crop up in the transcript readily, and the researcher was giving them preliminary codes. After giving the first provisional codes, the researcher began the process of categorizing and analyzing the data that are likely to be modified later. Codes were identified from the terms of the participants or may be a name given by the researcher to include a variety of ways that participants express in an underlying concept.

In the final stage, the researcher tried to identify themes or emergent concepts, and engaged in re-coding to develop better defined categories. Generally, there would be more data to analyze, and the processes above generate many themes and categories to be developed and refined.

Eventually, a research report and presentation of data was produced that can be utilized for different purposes. The data obtained from the participants were themed into the main areas of research objectives that are physical, psychological, and economic condition of people affected by leprosy. Moreover, it could show the variation of living conditions among gender, sex, how they consider their living condition, and their coping mechanisms.

3.9 Quality Assurance

Quality assurance is decisive for qualitative research to maximize the trustworthiness and internal validity; as a result, the researcher used a method of data triangulation from different sources such as in-depth interviews, key informants and observations. This study was conducted without previous research influence; and hence, it emphasizes on the research questions and the purpose of the study.

The researcher also states what the participants said word by word, and paraphrases their feelings in the finding. Creswell (2003) stressed that in some research situations, power can easily be abused and participants can be coerced into study. Individuals involve voluntarily and collaboratively during the process that helped to achieve the purpose of the study. To reduce power differentiation, the interview was conducted by the researcher. The relationship between the participants and the researcher was collaborative as well as participatory to meet the purpose of the study.

3.10 Ethical Consideration

During the research process and at the time of interviews, interviewees were briefed on the purpose of the study, benefits, potential risks and the confidentiality of their participation. There was a structured consent form to get participants willingness on the study and to assure

their informed consent. If participants want to leave or terminate from the research, they had the right to do so any time without any reservations.

Furthermore, in the research process, participants got the maximum care to ensure their confidence and anonymity. Settings for interviews were as private as possible so that participants could feel freedom to express their thoughts, and their information kept confidential. The researcher used codes that can only be understood by him to identify participants. All the social work professional ethical considerations and principles were applied during interview. The researcher has served water and cookies during interview. During the interview, due to the corona virus pandemic, either the researcher or the interviewee were obliged to use face masks and kept their distance.

Chapter Four

Data Presentation, Analysis and Discussion

4.1 Data Presentation and Analysis

This section contains presentation of data collected with the appropriate tools from the participants of the study. The major themes along with the subthemes and all the findings of the study are presented under this section. The purpose of this research is to explore the living conditions of leprosy affected people who live in and around Zenebework area in Addis Ababa. To achieve the purpose of the study, 10 leprosy affected interviewees took part in the in-depth interviews. 7 key informants, who were selected on the basis of their knowledge and work experience working with the affected people in the area, were also interviewed. For reporting purpose, and to protect participant's identities, each participant was given a pseudonym.

4.1.1 Background of Participants

During the course of data collection, a total of 17 participants were interviewed among which 10 were leprosy affected people selected for the in-depth interview and 7 were key informants.

Participants of the in-depth interview are permanent residents in the research site. All of them were affected by leprosy having different level of impairment. Among those participants, 3 of them are severely impaired having visible physical deformities; particularly, one of the participants has lost both legs. The rest of them (7 participants) have relatively minor impairments on their hands, eyes and faces. Regarding their sex, equal numbers of participants were involved in the in-depth interviews. Seven of the participants were married, whereas, the rest of them were single, widowed and divorced. And their ages range from 30 to 62 years.

In this study, seven key informants were also interviewed; they were selected on the basis of their knowledge and experience working with the affected people in the research site. Three of the key informants were from *Blulign* self-help association. They are members and workers at the at *Blulign* recreational center for the last 8 years. These key informants, apart from their knowledge about the target community, they all are affected by the disease. The rest of them (four key informants) were professionals working with the affected people in the area. One key informant is a medical doctor from ALERT Hospital, and two social workers from the AANLRA, and the last key informant was a social worker from Medihin Social Center, an NGO working with the affected people. Concerning their educational background, all of the key informants from *Blulign* were high school graduates while the rest were bachelor degree holders.

Study Findings

Three major themes emerged from the data collected: the living conditions of leprosy affected people, implications of leprosy on affected people, and opportunities or positive lived experience of affected people.

Although the themes are discrete, there is a considerable overlap among them. Participants also responded to interview questions addressing more than one theme.

4.2 The Living Conditions of Affected People

This being one of the major emerged themes, there were also recurring subthemes like the physical, psychological, social and economic conditions of leprosy affected people.

4.2.1 Physical Conditions of Affected People

According to the observation of the researcher during the in-depth interviews, reactions of leprosy were visible on all of the participants. It was one of the physical consequences of

leprosy that cause burning, arthritis, joint pain, lack of sensation and rash on their body. Among the in-depth interview participants, three of them are severely impaired with active reactions and forced to visit the health centers frequently. The participants of this study also have problems of partial or full loss of sensation on their hands, eyes and legs due to the sensory nerve damage because of leprosy.

The majority (eight) interviewees confirmed that when they realize the infection for the first time, they consider it like any other disease due to lack of knowledge. However, in course of time they realize its adversity on the physical health and its castigation. They also understood that what makes the disease more difficult were the visible consequences of physical deformity and the following amputations. The inflicted castigation also forced them to feel as inferior and different not only from others but even from their own family members. From those participants point of view, they were the only to be infected among their family members; therefore, there were a tendency to consider them as if they were unlucky and even cursed.

Furthermore, the adversity of physical harm due to leprosy was illustrated by two of the in-depth interviewees as follows:

Girma is originally from Ginchi, Oromia region. He came for leprosy treatment at the age of 15; currently, he has deformities on both legs. He told the researcher:

> *I am originally from Ginchi and came to Zenebework for treatment. When I get infected of leprosy, it was a myth for all members in my family. During that time, I was losing sensations and there were blisters of wounds on my legs. Consequently, my father took me to have traditional medicines, and finally to a holy spring at Shewa Robit to get cure of the disease. What happened was the revers as I have lost my sensation. I couldn't withdraw my body quickly and I got the worst injury on the limbs. After sustaining*

serious damage on my limbs, my father took me back to Ginchi to a nearby clinic where I got referred to ALERT. Even though I got permanent damage on my limbs, I got help in deterring further damage at ALERT Hospital. The very reason to have deformities on my legs and hands is due to the lack of knowledge and reluctance of my family to take me to the hospital. If my father took me at early times of the infection, I would have not been deformed.

Girma understands the permanent damage to his limbs due to the lack of knowledge and reluctance of his father to take him early to the appropriate hospital. From his outlook, early detection of leprosy is very important at least to prevent physical impairment and deter further deformity. It is the natural trait of the disease to cause impairment and deformity unless it is treated timely. His father's knowledge and preference to take him to traditional medicines and holy water treatment both took a significant time, which in turn gave rise to the incubation span of the infection.

Another in-depth interview was conducted with Abebe who is originally from Menz at the age of 42. He was physically harmed due to leprosy. It was also observed by the researcher during the interview that he has lost one of his legs and moves using a supportive device. He further told the researcher why he has got the impairment:

I got the disease at the age of 20 and no one in the family knew what the disease was and where to go. However, my mother took me to a traditional medicine center where I got primary treatment. But there was no sign of healing. Rather, it became worse and I got back home. After a while, there was an assessment for trachoma by a non-governmental organization in the village where I lived. When they saw me for the first time, they were worried and disappointed that I was late for early treatment and recommended me to ALERT Hospital where I got full

treatment. From that time onward, and after completing treatment, I established a family to stay here. What I want to tell you is that if I had the chance to come early to Addis Ababa, I might not be this much impaired.

Abebe aware lack of knowledge about the disease and its symptoms deluded his family not to act quickly; as a result, he got deformed. Therefore, from his observations, lack of knowledge about the disease leads him to complications and deformity.

Therefore, one of the findings of this section is that interviewed participants realize the cause of their physical impairment or deformity is due to lack of knowledge and early case detection.

A social worker key informant working at AANLRA provided two similar points like the above interviewees. The first point is that most active leprosy patients admitted to the rehabilitation center have a problem of sensation due to dead nervous system. Therefore, they teach and advise them about possible preventive measures to take care of their body. He also stated as an instance that "in some cases, when they come here, their condition may be minor, but unfortunately, due to lack of preventive measurements, they will be exposed to further amputation." The second point raised by the informant was that most patients come to either Alert or AANLRA after the leprosy reactions reach their climax. Another key informant from AANLRA also stated that "the reason for deformity for most leprosy affected people coming to the rehabilitation center is due to lack of proper treatment and early diagnosis in their community of origin. As a result of misdiagnosis and lack of early case detection, most of them end up with different levels of impairment.

In addition, a key informant, a medical doctor at ALERT Hospital, stated that "once people develop reactions of leprosy even though they are taking drugs, it is unlikely for most of them to avoid overall injuries in their daily activities due to lack of sensation".

The other social worker from Medhin Social Center stated that:

Most of the affected people that we are working with have blisters and wounds on their body as a result of losing nerve sensations. The infected wound again affects their day-to-day activities. Besides, the physical impairment creates bad odor because of the infected wound and that in turn causes further castigation and lower their self-confidence.

From her experience, the above key informant saw that the blisters and the wounds which are visible on their body with the unpleasant odor is the reason for their castigation.

Munira is originally from Gunchire, Gurage zone. She is at the age of 40 and one of the severely deformed participants. She has this to say about her physical conditions:

I was affected by leprosy at the age of 13. At that time, I developed a blister on one of my legs, but no one knew that it was leprosy because there was no such a case in my family line. My father took me to a clinic which was established by an NGO. It was there where my case was identified as leprosy. All the family members were anxious about my result, and after a while, they brought me to ALERT Hospital. I was treated as an outpatient; however, it was difficult for my father to stay here with me. Therefore, we went back to the Gurage zone with a medicine. After some years, I was admitted to ALERT and my leg was amputated due to the injuries on it. When I lost my leg, it was a big change in my life. I felt depressed and desperate to see my families and relatives back home. From that time onwards, I have decided to live in this area. Now I use supportive devices to move.

In the past unlike today, it was easy to obtain supportive device. We are forced to wait for a long time. This is another challenge that worsens our physical conditions.

According to her perception, leprosy, apart from its physical impairment, also has consequences like castigation and psychological problem. The researcher has also observed the shutdown of the improvisation center for the development of prosthetic and orthotic appliances. The shutdown of the center was temporary because they were unable to import raw materials used to manufacture prosthetic and orthotic devices. The center temporarily shut down because of COVID-19 and the following state of emergency. However, due to financial problems and governmental bureaucracies the center manufacturing capacity has declined.

The other finding is leprosy patients with visible blister or wounds are more likely to be castigated than those without visible wounds. The other reason by key informants set forth the disfigurement and stigma of the affected people is due to the unpleasant smell of the wounds. Therefore, it can be confirmed that visibility of wounds and unpleasant smell as a result of leprosy are important reasons for stigma and discrimination. It is also found out that, the shortage of prosthetic and orthotic devices became additional burden to leprosy affected people.

4.2.2 Psychological Condition of Affected People

In relation to the psychological conditions of interviewees, the result of the study reveals that there are resultant anxiety, depression and lack of self confidence among the affected people. Particularly, when they were in their community of origin, the derogatory words like *'komata'* harmed their psychology.

One of the interviewees with visible physical deformity stated that "in the previous times, I felt depressed, and preferred to stay alone, hated myself, and even sometimes wanted to commit suicide all of a sudden." The other participant from the in-depth interview was Tesfaye,

who is originally from Amhara Sayint. He was married and had two children during the onset of the disease. He explained his situation as:

> *I was a hard working farmer on a plot of land at Amhara Sayint. I had a family, and also had good relationships both with members of my wife's and mine. After I got infected, my marriage was immediately terminated and lost my children. It was the hardest moment in my life. Everything was dark and did not know what to do. I asked myself why this happened to me. I also feared the long term misery due to the chronic nature of the disease. I considered myself lonely, unique, and even helpless. However, with the help of God, I left the area for good and I came here. Even though I have accepted the reality and got older with the disease, I will sometimes be agitated when people see me as suspicious.*

Tesfaye realized his situation as desperate and helpless, when he knew infected of leprosy. From his understanding, following the detachment from his family, his psychology was distorted, and he developed negative traits like being unique and lonely. These can show the self-destructive or antisocial behaviors that could be motivational features to commit suicide.

During the in-depth interview, there was also similar view from another interviewee, who was originally from Gojjam. She has the following to say about her situation:

> *I had prior information of the disease because there was a man among my relatives who contracted the disease. I was also old enough to realize the symptoms it poses; as a result, I was scared and sad. I also knew that people would attach it with religious values and regard such a person as cursed. I also felt that way. Then with the assistance of my mother, I left the area to join ALERT Hospital. At the hospital I got relief when I saw many people who were in a similar situation like me.*

From the above participant's point of view, it was apparent that the reason for psychological stress and fear was the outlook of the community towards the disease. It is also depicted that the wrong perception of the community regarding the disease is the pushing factor for one to castigate him or herself. In most cases, leprosy affected people do have a tendency to believe the mythologies about the disease and suffer from low self-confidence.

One of the key informants working at AANLRA reported in the interview:

In most cases they are sensitive to words that you are using while talking to the affected people. It is because they regard themselves as inferior and do not have self-confidence. They split words and divert meanings in a way they wanted to. Therefore, they have different psychology. One should understand the way they make meanings due to the nature of the disease.

According to the report of a physician key informant from ALERT Hospital, the degree of psychological stress varies among the leprosy affected people on the basis of visibility. He further explained that those who have visible consequences of leprosy like skin patches, nodules, severe deformity on the face, hands and feet have more distorted psychological make ups. But those who do not have visible symptoms of leprosy are relatively confident. Finally, he stated that "in most cases they are patients with bad tempers, even sometimes they insult themselves as 'who cares for a leper'. If someone responded them, they act very aggressively, but we know how to treat them on a daily basis."

From the physician point of view, it can be inferred that visibility of leprosy reactions are one of the psychological distress among affected people.

Meseret is an in-depth interview participant who is originally from Merabete. She has the lowest leprosy reactions on her body. Regarding her psychological condition, she illustrated the following:

> *Usually affected people behave accordingly particularly with non-affected individuals. They first try to manipulate his or her perception towards them, and then they act confidently. I believe this is very wrong because the underlying condition for their peace of mind depends on external conditions. Therefore, they prefer being reserved even in matters that benefits them. In the contrary, I consider every one as being equal and try to express myself whenever necessary without reservation.*

Meseret realized the situation as it is her confidence that matters during her interpersonal relations either with infected or no infected individuals. From her point of view, one can see that there is a tendency among affected people to stigmatize themselves. Further observations made by a social worker from the AANLRA put that leprosy affected people reject themselves with a preoccupied mindset of being rejected by others. Such self-isolating behavior is a problem to achieve what they aspire.

4.2.3 Social Participation of Leprosy Affected People

Concerning the social activities, the most determinant factors are the stigma and discrimination attached to the disease. From the information obtained during in-depth interview, none of the participants were born in the research site even though they are permanently living in the area. Nine of the participants came to this area because of the discrimination and stigma not only by their community of origin but also by their own families. Only one participant came to the area for treatment and later on afraid of the stigma back home, and found a way out to live here.

Hasen is a 56 years old man from Amhara Sayint. He is married and has two children. He stated his situation as:

> *I was the only person among the family members to be infected by leprosy. I have got married and have three children, but unfortunately, following the leprosy reactions, my marriage ended up in divorce. Even though my physical condition was not deformed, my wife left the house with the children. Her families agreed with what she has done to me. In addition to this, my elder brother told me, 'don't spoil our family name. Either you disappear or I will shoot you dead'. It was at that time when I left the area for good and never looked back.*

From the above point of view, it can be asserted that the degree of stigma and disfigurement is very huge. The marital castigation reported by the above participant shows that it is hard to the extent of breaking ones blood line.

From the in-depth interview, seven participants were married before the onset of the disease. All of these participants were divorced and forced to leave their place of origin due to the imposed stigma and discrimination. Even those who had children were unable to see them due to the fear of transmission of the disease. Similar idea was made by one of the key informants from *Bulign*. He was married and had two kids. He stated:

> *When I was affected by the disease, there were also recurring symptoms on my face and blister wounds on the leg. Some people around me understood the type of the disease by its symptoms and a rumor flourished in the neighborhood. At that time, my wife stayed a while being disappointed, confused and feared of the transmission of the disease. Finally, she left me leaving her children behind. With the assistance of my mother, I came to Addis Ababa for treatment and I ended up living here. After I setup things for me, I*

brought my children to live with me as their mother was not willing to raise them anymore. Later on, I heard that she got married to another man to live her own life. From that time on wards, she has never met either me or her children. I do not also go there because of the severe stigma I face due to the impairment I have from leprosy. Currently, I get married to a woman who is affected by leprosy though I don't have any children with her. We are still living together.

The above key informant realized the perception of the community towards the disease is one of the influential factors for the discrimination and stigma. From his insight; marriage partners and family members prefer to terminate their relation with the affected person, due to the fear of stigma and transmission of disease.

The other participant was Alganesh who is originally from Raya Kobo. She was in an arranged marriage by her families and moved to Gonder. Once up on a time, she showed leprosy reactions; consequently, she was thrown away by his families and returned to Raya Kobo. From that time onwards, because of the stigma attached to her and her family, she left the place for good. She also further stated, "Sometimes, things happen for a purpose. I had no children from my ex-husband, but now, thanks to God I got married and have three children". Because of the wrong perception attached to the disease, from that time onwards, no one dares to ask her family for marriage. Therefore, it can be seen that the castigation due to the disease is not only up to the individual but also the family and community as a whole.

One of the key informants working in the rehabilitation center justifies the reason of divorce for the affected people as:

During my stay in the rehabilitation center, I have observed many of the affected people staying alone without any connection with their spouses and children, if they have any.

This is because their families and spouses are unwilling to come and visit them due to fear of disease transmission. Consequently, affected people try to find an option to live permanently in this area.

Apart from the main social impacts of leprosy, which is stigma and discrimination, seven of the participants were obliged to terminate their marriages. The stigma is very severe when they were in their community of origin. From the information obtained during the in-depth interview, three participants were able to marry non affected spouses while they are living in the research site.

Regarding marriage, findings revealed that participants who were married before the onset of the disease ended up in divorce. There were two justifications. The first was as a result of fearing disease transmission. The second one was due to the community's wrong perception and the resultant stigma and discrimination.

Affected people also have roles and participations in any kind of social activities whether it formal or informal. Like in any other parts of the country, there are informal organizations like *idir, equb, tsiwa, and senbete* in the area. According to the data from AANLRA, there are 2800 affected members among which the majorities are living in this area. However, according to a social worker from Medihin Social Center, most of the informal institutions like *idir* are formed by both affected and non-affected people. Therefore, there is no as such a unique informal institution setup for affected people. From the data obtained that even though leprosy affected people participate on social issues, their role is limited to certain aspects. According to one participant from *Blulign, "*Some activities demand physical labor; due to impairment and deformity, the role of affected individuals is limited to the area of coordinating activities, and this is done with the full consent the *idir* members."

With regard to the role of affected people in the formal organizations, one of the social workers from Medihin Social Center stated that “In this area there are formal organizations working with the affected people. Especially the affected people are actively participating in the issues that matter to them. For instance, Medihin and AANLRA are NGOS in which leprosy affected people are actively participating.” During the observation of the rehabilitation center, most affected people seem to have strong attachment and a sense of belongingness to AANLRA. They are actively participating in the jobs created by the association. According to a social worker, except the professionals, all of the workers are either from the affected people or members of their family. They are primary customers of the recreational center at AANLRA because they have developed a sense of ownership.

The same story was observed at Medhin Social Center. In the interview, a social worker stated the following about the activities of affected people:

> *In our organization, we have a program to maintain the houses of affected people every year using a lottery method. We also hire teachers and provide tutorials in all academic subjects for their children. We have been working this for the past 40 years and affected people are very much integrated and actively participant in our programs.*

Therefore, it can be confirmed that because of their physical deformity, there are limitations in utilizing both in formal and informal organizations within their context. They are more likely to participate in formal organizations if they get something as a reward. For instance during observations, leprosy affected people do houses that are under constructed, the houses are very old that require maintenance.

Medihin social center has an annual program to repair houses that need maintenance. Thus, leprosy affected people are very much ager to participate in such a program. From the data

collected during the in-depth interview, five participants are living in their private houses, which are constructed 30 years ago with the assistance of Norwegian aid. Four other interviewees are living in the so called *kebele* houses in the form of rent, and only one participant lives with his family. During the in-depth interview, it is also observed that households are very old and some of them are covered with plastics. In addition to these; affected people live in poor hygienic conditions due to poor sewerage disposal, communal toilets that are not clean and old pipelines that are vulnerable to contamination.

A key informant from Medihn social center stated:

> *The area being a leprosy colon, houses were constructed without plan. Most of the houses are confined and overcrowded in a small place. There is only a narrow space between each household. The houses are very old and require maintenance. That is why our organization is involved in a program to maintain the houses for the affected people.*

From the above key informant's perspective and the data collected; almost all participants are living in poorly constructed, very old, and unsuitable housing conditions.

There is also a tendency to be reluctant in attending occasions like weddings particularly when it is held outside their neighborhoods due to fear of stigma. The data also depict affected people have limitations to participating in formal organizations unless they found it useful.

In terms of their access to services like transportation, affected people face the worst stigma. With regard to public services like taxi and buses, they witnessed the worst marginalization. In this connection nine out of the ten participants do not want to use taxies because of the negative outlook or unwillingness of drivers towards them. Therefore, most of the participants prefer to use public buses even though the stigma is still there. One participant further stated, "I usually use a bus every morning. People do not dare to sit next to me. When

people see my disability there is a tendency to leave their sit, but I don't still know whether they do it for sympathy or fear."

A social worker from AANLRA observed that most of the leprosy affected people are desperate in their relations to their previous families due to fear of stigma in their community of origin. They are provided with a petty job during their stay at the center so that they can accommodate their food. Nevertheless, they are not satisfied with this and look for a better job to setup their future life here. Therefore, they are unwilling to recover and go back home due to the stigma by the community of their origin. This is illustrated further by:

A key informant from *Blulign,* who is affected person by leprosy, when he states that "I am the chairperson of the *idir* in which I am member. Everyone knows my background that I am affected by leprosy. There are also non affected members, but none of them are discomforted by my leaderships." In contrast to this, a female participant from the in-depth interview affirmed that people invite them to wedding ceremonies, but they never allow us to take part in food preparations.

Regarding wedding and occasions, the participation of affected people depends on the context where it is served. For instance, one of the participants from the in-depth interview stated:

> *I have attended a wedding party organized outside this village once. It was a cocktail held at Ambassador Recreational Center. It was magnificent, but people were not comfortable and showed sympathies for me when I was invited to it like them. That was totally an embracement for me. Therefore, from that time onwards, I do not want to weddings and occasions happening outside my neighborhood.*

From the above participant's outlook, it can be inferred that people's wrong perception towards affected people leads to self-exclusion.

Another in-depth interviewee shares his idea as follows:

Most people outside our setting have a mental picture that all affected people are beggars so that they don't treat us equally. Rather, they want to bring us food outside. Even if we are attending the ceremony, they know our appearance discomforts their guests; as a result, they prefer serving us in a corner where no one can see us. That is why I don't want to take part in occasions held by non-affected individuals outside our context.

From the above participant's view, it can be elicited that there is a tendency to self-exclusion among leprosy affected people. They also do not prefer to attend occasions held outside their settings due to fear of stigma and discrimination.

The finding depicted that people affected by leprosy do participate with limitation of activities in informal institutions like *idir, equb, tsiwa, and senbete*. Therefore, they are participating with a limited role.

4.2.4 Economic Conditions of Affected People

Economic condition was one of a major themes emerged during the in-depth interview of the participants. There was also a recurring sub theme which is employment condition of the affected people.

During the observation of the research site, the area was characterized by fragile and intricate economic structure. In addition to this, the area is overwhelmed with poor people like beggars; there are many commercial sex workers within small bars so called '*komaris*', and generally, it has intricate economic structure.

One of the key informants from Medihin Social Center illustrated the economic condition of the area like this:

> *Economically, most leprosy affected people in this area are poor because most of them are deformed and they are dependent on others for their living. There are significant numbers of beggars among the affected people; they are always appearing at Gebrekrstos church and the neighboring market place looking for alms. However, there are also affected people involved in small businesses, handcrafts and self-help associations like Blulign.*

The other supporting idea is raised by a social worker at AANLRA. He observed that in relation to his experience at the rehabilitation center, most affected people in this area have a begging experience at least once before they set up a stable life. They consider begging as a survival mechanism and it is common among deformed.

Therefore from the perceptions of the above participants, most leprosy affected people are living under poor economic conditions. From their point of view, leprosy inflicts physical mutilation on the affected people; as a result, they become dependent on other people for living. Regarding the economic situation of participants, findings of the study revealed that there is apparent relationship between leprosy and poverty.

The finding of the study depicted that the reason for the economic subordination of affected people is the nature of the disease at least for two reasons. The first one is the physical incapacitation of affected people due to the progressive nature of the disease. The other one is the social stigma attached to the disease.

4.2.4.1 Employment Condition of the Affected People

With respect to employment, the data at hand reveal that only six out of ten are employed. The rest are unemployed; three of them are baggers, who are seeking alms to earn their living. One participant is idle and dependent on his family.

Alganesh is one of the participants who are employed at AANLRA, and she is a widow. She has this to say about her employment status:

> *Previously, I was a house wife and I was totally dependent on my husband. After the death of my husband, life became difficult for me. I sometimes had no food at all. My hands are wrinkled due to the disease. I also lost two of my fingers; otherwise I am healthy and able to do relatively easy work. I have applied for three jobs, but I secured none of them due to my physical impairments. Finally, I went to the rehabilitation center where my husband used to work. They allowed me to work the job behave of my deceased husband. Now I am working in a shift basis only half a day. I earn 900 birr per month, but still not enough to secure a living. However, my child works and subsidizes the household otherwise we cannot sustain.*

Alganesh realized her situation; although she is capable of working, no one dares to employ her due to the physical impairment. From her perspective, it can be seen that there is a tendency to prefer relatively easy among leprosy patients.

Leprosy affected key informant from *Blulign* observed that, affected people are among the subordinate groups regarding employment opportunities. This happens at least for two reasons: first because of their physical inability to work on heavy duties that demand physical fitness. The second one is due to the negative perception of employers towards the affected people.

Tesfaye is currently working as a guard in ALERT Hospital. He pointed out that, affected people want to have relatively easy jobs. They usually prefer to work as gardener, guard, and begging are considered to be a means of livelihood among leprosy patients because of their physical incompetence.

Alula is relatively the youngest participant of the in-depth interview at the age of 30. He was at the rehabilitation center waiting for a second surgery; currently, he uses a supportive cane for mobility because of the previous amputation. He has lost his former job because of the first amputation he has got on his leg. He is afraid that it is difficult to work his former job, because it demands physical fitness.

A key informant from *Blulign* considered that:

> *I had the ability to get a job easily before the onset of the disease. I was one of the hard working employees in the animal farm at Debrezeit. After I got affected by leprosy; my efficiency declined, due to lack of the physical ability that the job requires. My employer was unwilling to let me have other position, which is relatively easy. Thus, the job became difficult for me so that I resign.*

The above informant perceived that he lost the job because of the physical limitations caused by leprosy. Therefore, from his understanding this can be considered as employment discrimination against affected people. Otherwise, he would have got an alternative job.

The finding of the study reveals that affected people lose jobs due to their physical inabilities and the employers' perception towards the disease.

4.3 Implications of Leprosy on the Affected People

Leprosy has multifaceted impact on the affected people. The first impact is on the human biology. Due to its progressive nature and lack of early treatment, it results in physical deformity.

The physical deformity has an impact on the limitation of activities. According to the information from the in-depth interview, three of them are severely impaired due to leprosy and have a problem in carrying out their daily routines. Girma stated that “Regarding activities that require physical labor, I am totally dependent either on my wife or children. I have problems while using toilets and handling household duties. The only thing I can do is begging; through which I earn a living”.

Girma endorsed that affected people with serious physical deformities are totally dependent on their families for physical labor.

The implication of leprosy is sequential and it is very huge. The physical problem leads to stigma and discrimination, which further causes inequalities among the affected people. The multidimensional discrimination of the affected people regarding marriage, social participation, economic conditions, and employment opportunities are stated above.

4.4 Positive Lived Experiences of Affected People

People have multiple problems because of leprosy. Most of the challenges and negative consequences of leprosy are stated in the above sections. However, there are also opportunities or positive lived experiences among leprosy affected people.

Positive lived experience being one of the major themes, there are also sub themes like coping strategies to physical impairment and coping mechanisms on multifaceted stigma and discrimination.

4.4.1 Coping Strategies to Physical Impairment

All participants of the in-depth interview have different level of physical impairments as they are losing nerve sensation. Therefore, it is common for them to be exposed of fire and suffer injuries in their daily routines. However, due to these problems, they have developed survival

mechanisms to avoid possible injuries and wounds. For instance, outside home, they use prosthetic and orthotic mobility devices to move from one place to another. Three of the in-depth participants are severely injured and uses supportive devices for their mobility. According to a key informant from the AANLRA, household safety measure training is given to the female leprosy affected persons. To avoid burning injuries at home they are suggested to use long padded spoons and utensils while cooking to avoid direct contact with fire and hot metals.

The above precautions and use of supportive devices is a coping strategy to the problems in relation to their physical deformities.

Meseret is originally from Merhabete, at the age of 50. She has a coping mechanisms illustrated bellow:

> *I use prosthetic leg using supportive cane. This is because during amputation, I lost the fingers on both legs and it was terrible for me to keep my position up right and balance. However, I took physiotherapy for two months to keep my balance. Now I can go anywhere with the help of these devices.*

Meseret perceives that once deformity is inevitable, she found a way to compensate mobility using artificial limbs and supportive devices.

From the data collected during the in-depth interview, participants who are physically impaired have blisters and skin rashes that possibly develop ulcers. To prevent further ulceration they use mechanisms like covering their wounds using piece of cloth and ointments or Vaseline to prevent further injuries.

4.4.2 Coping Mechanisms to Multifaceted Stigma and Discrimination.

With the information derived during the in-depth interview, seven participants were married before the onset of the disease. However, when they are affected by leprosy, they were

obliged to get divorced and leave the area. This is the consequences of stigma and discrimination against leprosy affected people.

Tesfaye from the in-depth interview further illustrated:

After treatment at ALERT Hospital, I was planning to go back home, to see my wife because were not certain to terminate our marriage. However, I heard she got married forced by the in-laws while I was at the hospital. Therefore, it was worth nothing for me to go back home. With the help of my father, I started a new life from the scratch around this area. My father was also happy with my decision, because he wanted to keep the family's dignity. Now I got married to an affected woman and have two children.

According to Tesfaye's perception, he wanted to live his place of origin with his wife. However, due to the termination of his marriage and the potential stigma he decided to live here. From his stand point, because he has lost his marriage and due to the potential stigma waiting back home. He uses leaving the place of origin for good and establishing a new life with his own type as a coping strategy.

Therefore, the findings depict that there is a stigma and discrimination against their marriage because of leprosy. The other two participants, who were single before the onset of the disease, were obliged to leave their community of origin and preferred to marry their own type. However, they left their place of origin for treatment due to fear of stigma they were not willing to go back home. Such denial to the community of origin because of the imposed stigma can be considered as coping mechanism.

The data collected about social participation of participants confirmed that affected people face stigma and discrimination. Mulunesh, a female interviewee realized that non affected people invite them on occasions. However, we are not allowed to take part in food preparations.

The other two female participants also claim similar point that “we know that our non-affected neighbors do not want us to participate in the preparation of food. Therefore, we don’t dare to do that as if there is mutual understanding”.

Whenever there is a major social event like wedding outside their setting, leprosy patients do not want to go. This is evident during the interview of an impaired participant.

Grma illustrated the situation that he has encountered:

> *Usually, the participants of a wedding outside our community setting are non-infected people. As you know a wedding occasion is a place where people enjoy and entertain. Thus, with this feature of mine I feel uncomfortable to be there. I have a supportive cane with artificial leg so that people could see me as if I am different. They may also think that I go there for begging rather than being invited. I have encountered such a situation at least twice. Therefore, I prefer not to go in an occasion like this.*

From the above participant’s view, he took self-stigma or self-exclusion as a means of coping strategy concerning occasions held outside their context.

There is circularity in the data collected regarding the coping strategies of participating in major social events. Discrimination occurs on occasions held outside their context and usually by not affected partaker. To that end, as a coping strategy they only prefer to attend occasions held within their settings.

The stigma and discrimination over employment is associated with the degree and visibility of impairment. The physical deformity of leprosy decreases effectiveness in carrying out one’s duty. Consequently, they prefer to have jobs that are relatively easy and not physical demanding. The other discrimination is when visible leprosy reactions appear on their body while they already had a job. This usually happens fearing the disease transmission by both

employers and employees. Hence, this is context oriented discrimination over employment when they are in another setting.

For instance, one of the participants from the in-depth interview primarily showed leprosy reactions while he was working at Debrezeizt on a private farm. After he had completed the treatment; he went back to the work, but he faced the worst stigma fearing disease transmission. He also asked the manager to give him another job, which is easy but he was denied. Finally, he came back to this area to look for another job and settled a living.

Like marriage most participants got discrimination over their job, their primary coping strategy is quitting their job and leaving the area for good.

From the information derived during the in-depth interview, there is a tendency for participants to select jobs due to their physical deformity. The above point is further reinforced by Hasen one of the in-depth interviewees. He has confirmed that:

> *Due to my impairment, I usually prefer to work easy jobs. For example, I work half a day as a guard at AALRA Hospital and the other half day I work as a gardener. I do this because of my inability to do hard jobs, that is why I compensate what I lost doing two jobs.*

The above participant developed a strategy to work on two easy jobs. This can be considered as a strategy to compensate what he has lost due to the physical impairments. Thus, it can be seen that, there is a mutual selection between the jobs and the affected people as a result of physical deformity. In such a case, affected people use coping mechanisms like having two relatively easy jobs.

Chapter Five

Discussion

This section presents the discussion of findings under the sub themes in relation to the research questions and the relevant literature. The major themes that are discussed in relation to the literature encompasses: the living conditions of leprosy affected people, implication of leprosy on the affected people, and opportunities or positive lived experiences.

5.1 The Living Conditions of Affected People

This section is one of the major themes emerged during the finding of study. It includes the following subthemes that are discussed below.

5.1.1 The Physical Condition of Affected People

Regarding the physical condition, persons affected by leprosy are usually deformed unless they get early diagnosis and treatments. One of the findings of this section is that participants realize that the causes of their physical disabilities are due to lack of knowledge and early case detection. Similarly, Naaz et al (2017, p.226) stated “that early case detection, regular and complete treatment, and early detection of impairment and disability have played a pivotal role in reducing the disease and disability burden in the community”

Likewise, Hackathon (2017) observed that for the medication of leprosy raising the consciousness level of the society is crucial. Leprosy affected people can be cured if they are able to identify premature signs and with the knowledge of the disease. Deformity because of leprosy can be prevented by accessing early treatment. In contrast to this, most leprosy patients detect the disease very late after they have developed impairments.

The other finding is confirmed that visibility of wounds and unpleasant smell as a result of leprosy are important reasons for stigma and discrimination. The other empirical evidence

could be a report made by First (2003) if leprosy is not treated it shows visible symptoms on the body. The major symptoms are mass of nodules, skin rash, and lesions on the skin, blisters, and deformities on the face. Leprosy affected people look in different and ugly, as a result they encounter stigma. Leprosy incapacitates affected people; therefore consider them as being burden to the society. According to First, one of the reasons for stigma and discrimination is the visibility of impairment.

5.1.2 The Psychological Condition of Affected People

In relation to the psychological conditions of participants, the result of the study reveals there are resultant anxiety, depression and lack of self confidence among the affected people. Particularly when they were in their community of origin, the derogatory words like '*komata'* meaning '*leper'* hurt their psychology. Study conducted on stigma also signifies that ostracism is very common among leprosy patients. Due to the outlook of the society, leprosy affected people are subjected to derogatory words, rejection and even to murder, and in some communities these still continue. Similar point Alam et al (1997, p.18) observed that reactions of affected people towards the community's attitude can be manifested by some accepting the disease as unlucky, and others prefer to flee to a place where they can hide themselves from such hostile community. Subramansam (1999) explored in Ethiopia, leprosy is also given a name '*kumtina*' that denotes the level of deformity or mutilation.

It is also depicted that the wrong perception of the community regarding the disease is the pushing factor for one to castigate him or herself. In most cases, leprosy affected people have a tendency to believe the mythologies about the disease and suffer from low self-confidence. Those who have visible impairments due to leprosy usually have poor psychology; as a result, they lose their confidence, feel loneliness, and hate themselves. Van Brakel (2006, p.346)

reported that affected people not only face physical impairment but also suffer from psychosocial repercussions due to community's attitude. He also notes that the long-term physical and psychosocial restrictions slowly push the leprosy affected persons out of the society. With lack of support and self- confidence, some recovered leprosy affected persons end up as beggars. Similarly, Sermrittirong et al. (2014) also found out that psychologically, leprosy affected people deteriorate from mental tension, distress, long-term lowering of enjoyment, in some cases self-kills.

5.1.3 Social Participation of Affected People

The finding about the social participation of the affected people is that the most determinant factor is the stigma and discrimination associated to the disease. There are multiple aspects of stigma on the affected people in relation to social participation. According to Alam et al. (1997, p.18), because of the associated discrimination and deformity, leprosy becomes the most feared disease. It also results in socio economic hardships to the affected people. Also, mythologies and faulty beliefs about leprosy are flourished in all segments of societies, even today. The age old stereotype against the disease and the social impacts are an insult to the disease.

Regarding marriage, findings revealed that participants who were married before the onset of the disease end up in divorce. There were two justifications: the first was due to the community's wrong perception and the apparent stigma and discrimination. The second one is as a result of fearing disease transmission. Similar idea was reported by (Mesele 2005). He stated that whether being leprosy affected person or an affiliation with them is very difficult to get married. Fearing that leprosy is hereditary disease, marriage isolation is not only for the affected person but also for those who have affected families. According to First (2003), most Research

has shown that in marriages where one partner has leprosy and separation occurs, the spouse with the disease often initiates the split. Once diagnosed with leprosy, many young women will still give up hope of marriage. According to the observation of Desalegn (2014, p.17), in Ethiopia marriage between family members of a person affected by leprosy and other community is impossible.

Findings on the participation of leprosy affected persons either in formal or informal organizations confirmed that because of their physical deformity, there are limitations of activity in utilizing both formal and informal organizations. There is also a tendency to be reluctant in attending occasions like wedding particularly when it is held outside their setting due to fear of stigma. Furthermore, Sen (2002) observed that people affected by leprosy are not considered to carry out some social activities like others do. Thus, they are not taking part in community based organizations, formal and non-formal community activities.

The finding depicts that people affected by leprosy participate with limitation of activities in informal institutions like, *idir, equb, tsiwa, and senbete*. Therefore, they are participating with a limited role. People affected by leprosy do not prefer to participate in major social events like weddings, particularly if it is outside of their setting. Even within their own community, their participation is limited to a coordinating role and in activities that are suitable to them due to their physical impairment. A research conducted by Melake (2008) strengthens the above point that affected people took insignificant role in the leadership even though they participate in informal organizations with healthy people.

It can be revealed that because of their physical deformity, there are limitations in utilizing both in formal and informal organizations within their context. They are more likely to participate in formal organizations if they get something as a reward. For instance: during

observations, leprosy affected people do houses that are under constructed, the houses are very old that require maintenance. Similarly, Susanto et al. (2014, p.15) stated that “it is more common in communities where there is overcrowding, dirty water, poor nutrition and poor standard of living. People living in such areas do not have strong immune systems, and they are unable to fight the disease”.

5.1.4 Economic Condition of Affected People

The finding of the study depict that the reason for the economic subordination of affected people is the nature of the disease at least for two reasons. The first one is the physical incapacitation of affected people due to the progressive nature of the disease. The other one is the social stigma attached to the disease. According to WHO (2010), the stigma and discrimination on leprosy affected people has influenced their economic rights. ENAELP (2001) observed that most employers do not want to have an employee from persons affected by leprosy; as a result, affected people are deprived of the employment opportunities. Even though affected people and their families are competent to have jobs, they must hide where they came from. Another report illustrates that there is limitation of activities in using hands among the leprosy affected people because of loss of sensation. Therefore, due to dead nerves, hands develop injuries and ulcers that lead to removal of the limbs that deter further activities (van Brakel, 2012).

The finding of the study depicted that the reason for the economic subordination of affected people is the nature of the disease at least for two reasons. The first one is the physical incapacitation of affected people due to the progressive nature of the disease. The other one is the social stigma attached to the disease. Likewise, Deepak et al (2000, pp.417-420) state that “social stigmatization is frequent so that affected persons with clear signs of chronic

manifestations are often unable to work, or to marry; they become dependent for care and financial support leading to insecurity, shame, isolation and consequent economic loss."

5.2 Implication of Leprosy on the Affected People

The implication of leprosy is sequential and it is very huge. The physical problem leads to stigma and discrimination, which further causes inequalities among the affected people. Atinkut et al (2018) stated that 'mutilation; rejection and exclusion from society are the scary image of leprosy as a social disease. Because of the stigma associated to the disease, affected people suffer from physical, psychological and social incapacitation

It is also depicted that the wrong perception of the community regarding the disease is the pushing factor for one to be discriminated. In most cases, leprosy affected people do have a tendency to believe the mythologies about the disease and suffer from low self-confidence. A research made by Scott (2006) argues that; the psychological make ups and the behavioral patterns of affected people are determined by the disease. Affected people when first diagnosed for leprosy they become desperate and victim of emotional intensity. Therefore, segregation and deprivation of the affected people is suitable for anxiety.

5.3 Positive Lived Experience of Affected People

This section discusses the coping mechanisms as opportunities and positive lived experiences of affected people. This being a major theme, the following subthemes are discussed below:

5.3.1 Coping Strategies to the Physical Impairment

From the data collected during the in-depth interview, three participants have blisters, wounds, skin rash and impeding ulcers on different parts of the body, particularly on the limbs.

For these, they use mechanisms to cover their wounds using patch or piece of cloth and also use ointments like Vaseline to avoid the skin rash. Likewise, WHO (2009) noted that precautions to be taken by leprosy affected people to handle dry skin and prevent further injuries. To avoid wounds affected person should immerse the dry skin.

To the stigma they face during marriage and discrimination, and over employment, they usually use similar form of coping mechanism, which is changing the place or migration. Usually, they also terminate a marriage as a solution. Supportive argument made by Mesele (2005) stated that "affected people get divorced because of either fear of transmission or discrimination of the community".

5.3.2 Coping Mechanisms to Multifaceted Stigma and Discrimination

All participants of this study depict that there is stigma and discrimination against their marriage because of leprosy. The other two participants, who were single before the onset of the disease, were obliged to leave their community of origin and prefer to marry their own type. However, they left the place of their origin for treatment though all of the participants were not willing to go back home. Such denial to the community of origin due to the enacted stigma can be considered as coping mechanism. According to First (2003), most researches have shown that regarding leprosy affected people marriage is termination with the initiation of non-infected partner. After being diagnosed positive for leprosy many young women lose hope to get married. According to Desalegn (2014, p.17), in Ethiopia marriage between family members of a person affected by leprosy and other community is impossible.

Like marriage most participants get discriminated over their job, their primary coping strategy is to hide their situation or quit their job and leave the area for good. Likewise, First (2001) found out that affected people usually tend to hide their situation from the employers,

friends and others. They do this fearing the stigma associated to the disease and loss of their job. A similar report by Calcraft (2004) states “put that stigma is more apparent whenever there is visible deformity. A person with visible deformity is more likely to lose his/her job due to the associated stigma. Apart from the stigma on deformity, there is also inability to do physical work”

Therefore, it can be seen that there is a mutual selection between the jobs and the affected people as a result of physical deformity. In such a case, affected people use coping mechanisms like having two relatively easy jobs.

Chapter Six

Summary, Conclusion and Recommendations

6.1 Summary

This chapter encompasses the summary of findings, conclusion drawn from the results and the recommendations made by the researcher. The main objective of the study is to explore the living conditions of leprosy affected people in the case of Zenebework area, Addis Ababa. The specific objectives were to explore the general living conditions of leprosy affected people in the area, examine the implication of leprosy on the living condition of affected people, and assess opportunities or positive lived experiences.

The study utilized both primary and secondary source of data. The primary data were collected by conducting both in-depth and informants' interviews. Written documents were also used as secondary sources.

6.1.1 Summary of Findings

Three major themes emerged from the data collected: the living conditions of leprosy affected people, implications of leprosy on affected people, and opportunities or positive lived experiences of affected people.

Participants realize that the causes of their physical condition are due to lack of knowledge and early case detection. The other finding is that the visible blister wounds on their body result in unpleasant smell that further leads them to castigation. From their point of view, in addition to the physical harm that leprosy imposes, the shortage of prosthetic device worsens their physical conditions.

There are resultant anxiety, depression and lack of self confidence among the affected people. Particularly, they were in their community of origin, the derogatory words like

'*komata*' hurt their psychology. It is also depicted that the wrong perception of the community regarding the disease is the pushing factor for one to castigate him or herself. In most cases, leprosy affected people have a tendency to believe the mythologies about the disease and suffer from low self-confidence.

Concerning the social activities, the most determinant factor seems the stigma and discrimination attached to the disease. In relation to marriage, findings revealed that participants who were married before the onset of the disease end up in divorce. There were two justifications: the first was due to the community's wrong perception and the apparent stigma and discrimination. The second one was as a result of fearing disease transmission. The finding depicts that people affected by leprosy participate with limitation of activities in informal institutions like *idir, equb,tsiwa* and s*enbete*. Therefore, they are participating with a limited role.

The reason for the economic subordination of affected people is the nature of the disease at least for two reasons. The first one is the physical incapacitation of affected people due to the progressive nature of the disease. The other one is the social stigma attached to the disease. The finding of the study revealed that affected people lose jobs due to their physical inabilities and the employers' perception towards the disease.

6.2 Conclusion

With seventeen participants, the researcher has made an effort to explore and find out the living condition of leprosy affected people related to the physical impairment, the implication of

leprosy on social participation, marital relationship and employment in light of stigma and discrimination.

Based on the findings of this research, it is possible to conclude that people affected by leprosy have limitation of activities due to the impairment and progressive deformities on their limbs. Furthermore, leprosy affected people are exposed to injuries while carrying out their daily routines as they have lost their sensations.

From the study, it can also be concluded that people affected by leprosy are obliged to terminate marriage due to the stigma and discrimination inflicted on them by their in laws, family, relatives, and the community as a whole.

Related to the social participation of people affected by leprosy, the study affirms that membership and participation of affected people in informal institutions like *Iddir, Ekub and Mahiber* is possible. However, their level of participation is very limited due to their disability. Regarding the major social events and occasions like wedding, affected people do not prefer to attend unless they are within their community setting due to fear of stigma and discrimination.

It finding also it can also be concluded that persons affected by leprosy have low income and get discrimination of employment because of their physical inability. Therefore, even though they have jobs, affected people have low income due to their preference of easy jobs and physical inabilities. However, with all the challenges, leprosy affected people have developed coping mechanisms to the multiple aspects of life.

6.3 Recommendations

The major problem of leprosy affected people is the mythologies and stigma associated with the disease. Thus, there must be awareness creation about the

disease among the wider community to overcome the discrimination of the leprosy affected people.

However, the problems of leprosy affected people are multifaceted. However, there are only few human service organizations working in this area. Even the available organizations do not have social workers to provide counseling and emotional support.

There are also scarcities of mobility devices in the rehabilitation center. The reason is due to scarcity of raw materials; therefore, there must be means to substitute the raw materials and improvise the prosthetic devices.

Affected people are obliged to do jobs that are low income generating or forced to beg on the street due to the physical limitation and stigma. Consequently, efforts should be done to strengthen self-help associations like *Blulign.*

6.4 Implications for Social Work Practice

Social workers should involve in advocacy services to promote equal opportunity for people affected by leprosy, and to alleviate the discrimination and misconceptions against them. Moreover, social workers should involve themselves in public awareness creation activities about the cause and transmission of the disease so that it can be one area of practical interventions.

Social workers should also engage themselves in facilitating the health education system and self-care at the community level to further deter and minimize the disability of affected people. Social work practice should also involve in programs designed to provide psychosocial and economic rehabilitation for persons affected by leprosy.

Due to the stigma inflicted on the leprosy affected people, most of them are vulnerable to psychological problems. However, social workers should involve in the emotional support and counseling of the people affected by leprosy.

6.5 Research Implication

This is a research that made an effort to explore the living condition of people affected by leprosy in a specific setting with limited number of participants. Therefore, a macro level study that involves large sample needs to be conducted.

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Annexes

Annex: Consent form for the people affected by leprosy

I am asked to participate in this study and I have read the information given about the study or the information given is read to me. I hereby agree to participate in this research conducted by Yonas Sirak.

My name is Yonas Sirak from the Addis Ababa university, school of social work, I do this research to the partial fulfillment of master's thesis entitled with 'Exploring the living condition of leprosy affected people: The case of Zenebework Area Addis Ababa , city'. I am informed that I am participating freely and without being forced in any way to do so. I also understand that, I can stop participating at any point if I am not willing to continue and that my decision will not affect me in any way. I understand that this is a research project whose purpose is not necessarily to benefit me personally in the short term.

I am also informed that all data obtained from me will be kept confidential. I am also told that I can get any information regarding the progress or results from study if I need. I have received clarification of matters that were not clear to me and taking into consideration all points mentioned above, I agree to participate in this study.

Participant's name_____ Signature_____

Researcher Name _____ Signature _____

Witnesses' Name_____ Signature _____

Date _____

Profile of the In-depth Interview Participants

S.No.	Pseudo name	Age	Sex	Educational background	Marital status	Place of origin	Religion
1	Alula	30	M	Grade 8	Single	WelaytaSodo	Protestant
2	Adanu	35	F	Illiterate	Divorced	Holeta	Orthodox
3	Munira	40	F	Grade 8	Married	Gunchire	Muslim
4	Abebe	42	M	Grade 10	Married	Menz	Orthodox
5	Meseret	50	F	Illiterate	Married	Merabete	Orthodox
6	Tesfaye	52	M	Grade 4	Married	AmharaSayint	orthodox
7	Hassen	56	M	Grade 6	Married	Kemissie	Muslim
8	Abaynesh	58	F	Read and write	Widowed	Raya Kobo	Orthodox
9	Girma	58	M	Grade 9	Married	Ginchi	Orthodox
10	Mulunesh	62	F	Grade 4	Married	Gojjam	Orthodox

Profile of Key Informants

R .No	Key informant role	Age	Sex	Educational background	Work experience
1	Member at *Blulign*	44	M	Grade 10	8
2	Member at *Blulign*	50	M	Grade 12	8
3	Member at *Blulign*	56	F	Grade 6	8
4	Medical doctor at ALERT, Hospital	37	M	Dermatologist MSC	6
5	Social worker at AANLRA	36	M	BA. Degree	9
6	Social worker at AANLRA	26	M	BA. Degree	2
7	Social worker at Medhin	30	F	BA. Degree	4

Consent form Amharic version

አዲስ አበባ ዩኒቨርሲቲ የሶሻል ሳይንስ ኮሌጅ የሶሻል-ወርክ ድህረ-ምረቃ ትምህርት ቤት/consent form/

ዮናስ ሲራክ እባላለሁ በአዲስ አበባ ዩኒቨርሲቲ የሶሻል-ወርክድህረ-ምረቃ ትምህርት ቤት የሁልተኛ ዱግሪ ተማሪ ሰሆን በአሁኑ ጊዜ የሁለተኛ ዴግሪ ማሟያ የሚሆን ጥናት በአዲስ አበባ ከተማ በዘነበ ወርቅ አካባቢ በሚገኙ የስጋ-ደዌ ተጠቂዎች ላይ እያካሄድኩ እገኛለሁ፡፡

ይህ ጥናት “የስጋ ደዌ ተጠቂወች የኑሮ ሁናታ” በሚል ርእስ የሚከናወን ሲሆን አላማውም ስጋ ደዌ ጋር የተያያዙ የአካል ጉዲት በስጋ ደዌ ተጠቂዎች የቀን ከቀን ክንወኔወች ላይ ያለው ተጽእኖ ፤የስጋ-ደዌ ተጠቂዎች ጋብቻ ሁኔታ ላይ ያለው ተጽእኖ፤የስጋ-ደዌ ተጠቂዎች ማህበራዊ ተሳትፎ እንዱሁም የስራ ተሳትፏቸውን ተሞክሮ ማጥናት ነው፡፡

በመሆኑም ለዚህ ጥናት ለሚውለው ቃለ መጠይቅ ተሳታፊ በመሆንዎ በቅድሚያ አመሰግናለሁ፡፡

በዚህ ቃለ-መጠይቅ ለይ መሳተፍ ሙሉ በሙሉ በፍቃዮኝነት ላይ የተመሰረተ ነው፡፡ ያልተስማሙበትን ጥያቄ አለመመለስ ወይም ቃለመጠይቁን መቀጠል ባልፈለጉ ጊዜ ማቋረጥ ይችላሉ፡፡

ቃለ መጠይቁ ረዥም ጊዜ የማይወስድ ቢሆንም፤ የእርስዎ ተሳትፎ እና ሁለንም ጥያቄዎች መመለስዎ ለጥናቱ አጅግ መሰረታዊ ጠቀሜታ ይኖረዋሌ፡፡በቃለ-መጠይቁ ጊዜ ስምዎ የማይመዘገብ በመሆኑ የሚሰጧቸው ምሊሾች እና ሃሳብ አስተያየትዎ በሚስጥር የሚጠበቅ ይሆናል፡፡ከዚህ ቃለ-መጠይቅ የሚገኙ መረጃዎች በዚህ ጥና አላማዎች ብቻ የሚውሉ ሲሆን እርስዎ በዚህ ጥናት በመሳተፍዎ ምንም አይነት ችግር አያጋጥምዎትም፡፡

በድጋሚ ስለተሳትፎዎ እያመሰገንኩ ማንኛውም ጥያቄ ወይም አስተያየት ካለዎት መጠየቅ ይችሊለ፡፡

ቀን……..

የተሳትፎዎ ስምምነት ፊርማ……..

In-**depth interview guide: To the leprosy affected people**

The following Questions are designed in order to conduct interview with persons affected by leprosy for the thesis project titled "The Living Conditions of Affected by Leprosy at Zenebework area in, Addis Ababa".

The interview will be vital input for this study. Accordingly I demand your kind help to participate in this interview. Moreover taking how much essential your answer will be for the study, I will appreciate very much your genuine answer for each question. If you have any question or comment you are free to share with the interviewer.

Research site……

Date……

Time…….

Part 1. Demographic background

Name……..code……

1. Sex male…….. Female…….
2. Age……
3. Religion …….
4. Ethnicity…….
5. Educational status……..
6. Number of children……
7. Birth place…….
8. Marital status…….
9. How long have you stayed here……..

Part 2. Question related to the general living condition of participants

Question related to housing

1. Do you have a house to live? If yes, is it private or rental?
2. If it is private, how is the legality?
3. How many rooms are there?
4. Does the house access to electricity?
5. Does the house access to water?
6. Does the house have private /communal toilet?

Question related to health

Physical condition

1. How did you know your infection was leprosy?
2. Do you have physical impairments due to leprosy?
3. At which age you get physical impairment?
4. Which part of your body affected by leprosy?
5. How you manage the physical impairments to carry out your daily routines?
6. Are their supportive materials available for you?
7. What protective materials you use to deter further injury and impairment

Psychological conditions

1. How do you feel about your impairment?
2. Can you tell people's outlook towards your impairment?
3. How you think others view towards your impairment?

Question related to social participation, access to social services, and food security?

1. How is your relationship with your neighbors?

2. How is your intimacy with your neighbors?

Participation in informal social institutions

1. Do you have idir, ekkub, or mahiber?
2. Are all members of the informal institutions?
3. How is your participation as a member or leader?
4. What looks like your participation in relation to your infection?
5. What role you carry out in these informal institutions?

Participation in social events

1. Do you participate in social events like wedding, graduation, any celebrations in the community?
2. What do you feel when you participate in these social events?
3. What others feel your participation in social events?

Participants access to health service and school

1. Are there schools nearby for your children?
2. Are the schools affordable to you?
3. Are there health centers nearby to you?
4. Are the health centers affordable to you?
5. Are there any social services available to the community?
6. How many times a day your family members get a meal?

Questions related to participants' marriage and family relationship

For those who were married before the onset of the disease

1. Did you have children?
2. What was the reaction of your spouse and in-laws?

3. What was the reaction of your parents, relatives and neighborhood?

4. Are you still together with your children and wife? If not why?

For those who were single before the onset of the disease

1. What was the reaction of your parents, relatives and neighborhood?

2. Are you married now? If yes how did you get your wife?

3. Do you think leprosy affects a person from having marriage?

4. Is your wife a woman affected by leprosy? If not, what is her outlook towards the disease?

5. Do you have children? Are they free from leprosy?

Questions related to participants' economic conditions

For those who are employed

1. How do you get the job?

2. Does your employer know that you are affected by leprosy? if so what is his/her reaction

3. What are the impacts of being infected over your employment?

4. What are the reactions of other employees towards you?

5. How do you manage the challenges at work place?

6. Does the income adequate to handle your living?

For those who are self employed

1. What kind of business you owe?

2. What implications have leprosy on your customers?

3. How you manage the implications of leprosy on your business?

Part 3.Question related to the implication of leprosy on the living conditions of people affected by leprosy

Question related to social stigma and discrimination

1. Have you experienced stigma and discrimination because of leprosy? If yes, how and where?

2. What kind of stigma and discrimination do you face while accomplishing your daily routines?

3. How do you manage the stigma and discrimination you face?

Implications on marriage and family relationship

1. Does leprosy affect one from getting married?

2. What do you think others perception towards affected person regarding marriage?

3. What kind of stigma and discrimination you experience regarding marriage

4. How did you manage the enacted stigma and discrimination towards marriage?

Implication on economic condition of participants

1. Do you think leprosy affects economic conditions of a person? If yes, how?

2. What kind of economic discrimination one can face due to leprosy?

3. How did you manage the discrimination over economic conditions?

Part4. Questions related to opportunities or positive lived experiences of participants.

1. What opportunities or positive lived experience are there for the person affected by leprosy?

2. What strength can you mention for the affected people?

Coping mechanisms related to physical impairment

1. How do you manage to carry out your daily activities along with your physical impairments?

2. What mechanisms you use to deter the physical impairments?

Coping mechanisms to stigma and discrimination on social participation

1. How do you manage the stigma and discrimination inflicted on your social participation?

Coping mechanisms to discrimination over economic conditions

1. What mechanisms or strategy you use to handle discrimination over economic conditions?

2. What mechanisms you use to maximize your income?

Coping mechanisms towards stigma and discrimination on marriage and family relationships

1. If you were married before the onset of the disease how you handled your marriage?

2. If you were single during the time of leprosy infection how you handled discrimination over marriage?

Part 5. Questions related to challenges of leprosy

Physical challenges of leprosy

1. What physical challenges are there due to leprosy?

Psychological challenges of leprosy

1. What are the psychological challenges of leprosy on the affected people?

2. What is the community out look towards leprosy?

Economic challenges of leprosy

1. What are the economic challenges of leprosy on the affected people?

In-depth interview guide Amharic version

ቃለ-መጠይቅ ቅጽ አንድ(In-depth interview)

የሚከተሉት ጥያቄዎች የተዘጋጁት ከስጋ-ደዌ ተጠቂዎች ጋር ለሚደረግ-መጠይቅሲሆንቃለ-መጠይቁ የሚካሄደው በአዲስ አበባ ከተማ በዘነበ ወርቅ አካባቢ ከሚኖሩ ስጋ-ደዌ ተጠቂዎችን የኑሮሁኔታ ለማጥናትነው፡፡ጥናቱ የአዱስአበባ ዩኒቨርሲቲ ድህረ-ምረቃ ዲግሪ ማሟያ የሚውል ይሆናል፡፡ ቃለ-መጠይቁ ስምንት ክፍሎች ያሉትሲሆን ለተሳትፎዎ በቅድሚያ አመሰግናለሁ፡፡

ክፍልአንድ፡ በዚህ ክፍል የተካተቱ ጥያቄዎች የተሳታፊዎችን ግለመረጃ እንዱሁም ማህበራዊ እና ኢኮኖሚያዊ ሁኔታዎች የሚዳስሱ ይሆናል፡፡

1. አድራሻ

2. ጾታ ሴት ወንድ

3. እድሜ

4. ሀይማኖት

5. የትምህርት ሁኔታ 1. ያልተማረ 2.ማንበብእናመጻፍየሚችል 3.የመጀመሪያደረጃትምህርት 4 ሁለተኛ ደረጃ እና ከዚያበላይ

6. የቤተሰብ ብዛት;

7. በዚህ አካባቢ ለምን ያህል ጊዜ ቆዩ;

8. እዚሁ ነው ተወልደው ያደጉት;

9. ከትውልድ ቦታዎ ወደዚህ የመጡበት ምክንያት ምን ይሆን;

10. በአማካይ የወር ገቢዎ ምን ያክልይሆናል;

ክፍልሁለት፡በዚህ ክፍል የተካተቱት ጥያቄዎች የስጋ-ደዌ ተጠቂ የሆኑ ግለሰቦችን የመኖሪያ ቤት ሁኔታ የሚመለከቱ ናቸው፡፡

11. የሚኖሩበት ቤት የግልዎነው? እንዴት ነበር ያገኙት?

12. የሚኖሩበት ቤት ባለቤትነት ህጋዊነው?

13. ቤትዎ ስንት ክፍል አለው?

14. የኤሌክትሪክ አገልግሎት ተጠቃሚ ነዎት?

15. ንጹህ የመጠጥ ውሀ ተጠቃሚ ነዎት?

16. ቤትዎ የግል መጸዳጃ አለዉ (የጋራ)?

ክፍልሶስት፡ በክፍል ሶስት ውስጥ የተካተቱት መጠይቆች የተሳታፊዎችን ማህበራዊ አገልግሎት እና የምግብ ዋስትና ይመለከታል፡፡

17. የህክምና አገልግሎት የሚያገኙት እንዴት ነው?(ዘመናዊ ህክምና ከሆነ ከየትነው?)

18. በሚኖሩበት አካባቢ የመጀመሪያ ደረጃ ትምህርት ተቋማት ይገኛሉን

19. እድሚያቸው ለትምህርት የደረሱ (7 አመትበላይ) ልጆች አለዎት?(ስንትናቸው?)

20. በትምህርት ገበታ ላይ የሚገኙ ስንት ልጆች አለዎት?

21. ሁለም እድሚያቸው ለትምህርት የደረሱ ልጆችዎ በትምህርት ገበታቸው ላይናቸውን (ካልሆነ ለምን?)

22. እርስዎ እና ቤተሰብዎ በቀን ምን ያህል ጊዜ ይመገባሉ?

23. የወርገቢዎ የቤተሰቡን የምግብ ወጪ ይሸፍናል (በልመና ለሚተዳደሩ ይህ ጥያቄ አይመለከትም)

24. ካልሸፈኑ እንዴት ያመቻቻሉ ?

ክፍልአራት፡

በዚህ ክፍል የተካተቱት ጥያቄዎች የተሳታፊዎችን የጤና ሁኔታ የሚመለከቱ ናቸው፡፡

25. በስጋ-ደዌ እነደተጠቁ ሲያውቁ እድሜዎ ስንትነበር?

26. የስጋ-ደዌ በሽታ እንዳመመዎት እንዴት እንዳወቁ ያስታውሳሉ?

27. በጊዜው የስጋ-ደዌ በሽታበምን ምክንያትእንደሚከሰት ያውቁ ኖሯል? ምን ነበር የሚያውቁትያስታውሳሉ?

28. የትዳር አጋርዎ/ቤተሰብዎ/ ጎረቤቶችዎ እና የመንደር ሰዎች ስለስጋ-ደዌ በሽታ አምጭ ምክንያት የሚያስቡት ምንነበር?

29. ለበሽታው ህክምና ለማግኘት በወቅቱ ለመጀመሪያ ጊዜ ወደ የትነበር የሄዱት?

30. ለምን ያክል ጊዜ የስጋ-ደዌ ህክምና ተከታትለዋል

31. በስጋ-ደዌምክንያትየመጣየጤናችግርበአሁኑሰአትአለብወት?

ክፍል አምስት፡በዚህ ክፍል ውስጥ የተካተቱት ጥያቄዎች የተሳታፊዎችን በስጋ-ደዌ የመጣ አካል ጉዳትን የሚመለከቱ ናቸው፡፡

32. በስጋ-ደዌ በሽታ የመጣ የአካል ጉዳት አልብዎት ?የጉዳቱን መጠን እና አይነት ይነግሩናል?

33.የቀን ከቀን ከንዋኔዎች (ማብሰል፤ መመገብ እና የመሳሰለትን) ለመከወን የፈጠረብዎት እክል ይኖራል? ካለ እንደት እንደሆነ ያብራሩልኛል?::

34. እነዚህን እክሎች እንደት ይወጧቸዋል?

ክፍል ስድስት፡ በዚህ ክፍል ውስጥ የተካተቱት ጥያቄወች የተሳታፊዎችን የጋብቻ እና የቤተሰብ ሁኔታ ይመለከታል፡፡

35. በስጋ-ደዌ በሽታ ከመታመምዎ በፊት አግብተው ነበር?

36. በአሁኑ ሰአት ከባለቤትዎ / ከሌጅዎ ጋር ነው የሚኖሩት?

37. አብረው የማይኖሩ ከሆነ በምን ምክንያት ነው;

38. አሁን ትጠያየቃላችሁ ቅርበታችሁስ ምን ያህል ነው;

39. የማትጠያየቁ ከሆነ በምን ምክንያት ነበር መጠያየቅ ያቆማችሁት?

40. አሁንስ አግብተዋል?

41. የትዲር አጋርዎ በስጋ-ደዌህመም ታመው የውቃሉ የአካል ጉዲትስ አላቸው?

42. የትዲር አጋርዎን የመረጡት በአጋጣሚ ነው?

43. ካላገቡ በስጋ-ደዌ መታመም ሰዎች ጋብቻ እንደዳይመሰርቱ እንቅፋት ሊሆን ይችላልን?

44. የፈቱ ከሆነ እባክዎትን የፍቾዎን ምክንያት ምን እንደነበር ይነግሩኛል?

45. እንዴት ነበር ሁኔታውን የተወጡት?

ክፍል ሰባት፡በዚህ ክፍል የተካተቱት ጥያቄወች የተሳታፊወችን የማህበራዊ ህይወት ተሳትፎ የተመሆከተ ይሆናል፡፡

46. ከጎረቤትዎ ጋርያለዎትን ቅርበት እንዴት ይገልጹታል;

47. ያለዎት ቅርበት ጥሩ ካልሆነ ለምን;

48. በሚኖሩበት አካባቢ የሰፈር ማህበር፤እቁብ፤እድርወ.ዘ.ተተቋት አሉን;

49. በነዚህ ማህበራት ሀአባልነዎት ይሳተፋለK <ተሳትፎዎትስ ምን ይመስላል;

50. ÁK<ƒ አባላት የስጋ-ደዌ ተጠቂዎች ናቸውን?

51. በማህበራት ውስጥ ያለዎት የስራ ድርሻ ምን ይመስላል

52. በአነዚህ ተቋማት ሲሳተፉ የስጋ-ደዌ ተጠቂ በመሆንዎት ሳቢያ የደረሰብዎት እክልይኖራል;እንደትእንደሆነያብራሩልን;

53. ያጋጠመዎት ንሁኔታዎች/እክሎች እንዴት እንደተወጧቸው ቢነግሩኝ

ክፍሌ ስምንት፡በዚህ ክፍል ከተካተቱት ጥያቄዎች የተሳታፊዎችን የስራ ተሳትፎ ሁኔታ የሚመለከቱ ይሆናሉ፡፡

54. የስጋ-ደዌ ተጠቂ መሆን ዎበስራ ሁኔታዎ ላይ የፈጠረው እክል ይኖር ይሆን ;እንዴ ትእንደሆነ ቢያብራሩልኝ

55. እነዚህን እክሎች እንዴት ተወጧቸው;

56. በስጋ-ደዌ በሽታ ከመታመምዎ በፊት የገቢ ምንጭዎ ምን ነበር;

57. ከታመሙ በኋላ የገቢ ምንጭዎን ቀይረዋል;

58. ለምን ነበር የቀየሩት;

59. በአሁን ሰዓት የቤተሰብዎ የገቢ ምንጭ ምንድን ነው;

60. የቀን ስራ/የጉሌበትስራ / ከሆነ በስጋ-ደዌ ምክንያት የመጣብዎ የአካል ጉዳት እክል ይፈጥርብዎትይሆን; እንደት እንደሆነ ያስረደኝ

61. የነገሩኝን እክሎች እንዴት ነው የሚወጧቸው;

62.በግልዎ ስራ /አገልግሎት፤ንግድ/ ከሆነ የሚተዳሩት የስጋ-ደዌ ተጠቂ መሆንዎ ወይንም የአካል ጉዳት መኖሩ ደንበኞችዎ ላይ ተጽእኖ ይፈጥር ይሆን;እንዴት እንደሆነ ያብራሩልኝ;

63. ደንበኞችዎን ለማብዛት /ችግሩን ለመወጣት/ ምን አይነት ዘደዎችን ይጠቀማሉ;

64. (ተቀጥረውየሚሰሩከሆነ) የስጋ-ደዌ ህመም ተጠቂ በመሆንዎ ምክንያት ችግር ገጥሞዎትያውቃል; (ለስራው ብቁ ሆነው ሳለ)

65. ለምን እንደሆነጠይቀውያውቃሉ;

66. እንዳት ነበር በሰዓቱ የፈቱት;

67. በልመና የሚተዳደሩ ከሆነ እንዴት እና ለምን ወደ ልመናገቡ;

Annex E: Key Informant Interview Guide

Name _____

Profession _____

Position _____

Year of experience _____

1. What is the health related, psychological, social and economic implications of leprosy on affected people living around Zenebework?

2. Have you encountered the impact of being affected by leprosy and if you have seen a strength as well?

a) Yes

b) No

3. If “yes” What was his/her justification?

4. What are/were his/her survival strategy to cope up the bio psychosocial and economic challenges that make him/her while living with their community?

5. Do you have any additional comments, including your experience of this interview that you would like to add at this time?

2. Would leprosy related physical impairment cause stigma in daily routines? How?

3. Would leprosy be a problem to a person to get married? Why?

4. Would leprosy be a cause of divorce? How?

5. What would be the condition being affected by leprosy to take part in major festivals/rituals and social activities? How?

6. Would your affection be a challenge or opportunity to participate in local community based organizations? How?

Annex F: Key Informant Interview Guide (Amharic version)

Name _____

Profession _____

Position _____

Year of experience _____

1. የስጋ-ደዌ በሽታ በተጠቂዎች የጠንነት ሁኔታ የስነ-ልቦናና' ኢኮኖሚያዊ ሁኔታዎቸ ላይ በዚህ አካባቢ በሚኖሩ ሰዎቸ ላይ ያለውን ተጽኖ እንዴት ያዩታል;

2. እንዲያዉ በስራዎ አጋጣሚ የተመለከቱት በስጋ-ደዌ በተጠቁ ሰዎቸ ላይ የሚያስከትለውን /ጉዳት/ ተጽዕኖ ወይም የሚያሳዩት ጥንካሬ ካለ;

3. የስጋ-ደዌ ተጠቂዎቸ የእለት ተእለት ተግባራቸውን ሲወጡ ወይም ህብረተሰቡ ውስጥ ሲኖሩ ኢኮኖሚያዊ ወይም ማህበራዊ ተግዳሮቶቸን እንዴት ነው የሚወጡት;

4. ከስጋ-ደዌ ጋር ተያይዞ በስራ አጋጣሚ ያስተዋሉትን የርሶን ልምድ ቢያካፍሉን;

Annex G: Observation check list guide

1. How much leprosy affects the living conditions and opportunities if there is, within their community?

2. What do the psychological situation of affected people within the community?

3. How does the affected people interaction with their treatment and to the hospital?

4. What coping mechanisms do leprosy patients use to deal with the biological, psychological, social, and economic challenges they faced?

Declaration

I declare that “a review on the exploration of leprosy affected people: the case of Zenebework area, Addis Ababa city” is my own work and that all sources that I have used or quoted have been indicated and acknowledged by means of complete reference and that this work has not been submitted before for any other degree at any other institution.

Yonas Sirak Nega

Signature ……

Place: Addis Ababa University, Ethiopia

Date: ……..

This thesis has been submitted for examination with my approval as a University advisor.

Meles Getu (PhD)

Signature ……