Psychosocial Challenges of People with Leprosy and Coping Mechanisms: The Case of Addis Tesfa Hiwot in Arsi Zone

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Abstract

The objective of this study was to describe the psychosocial challenges of people with leprosy in Addis Tesfa Hiwot. In conducting the research qualitative method was employed. The study area was selected purposively because it was known for long time as colony of people with leprosy. Ten people with leprosy were selected purposively based on the criteria and also five informants were used. Face-to-face semi structured interviews were used to investigate the psychological, social challenges of people with leprosy and coping mechanisms. The findings show that, almost all respondents didn’t have awareness about the cause and transmission of leprosy. The study was also found that, a great number of people with leprosy struggle with psychological and social problems. They felt unhappy, stress, hopelessness, lowered social relationships and also faced social stigma especially outside their colony even many of them didn’t go out from their home. It was also found that, their children also faced huge psychological and social challenges only because of their parents’ status. The study found that people with leprosy in Addis Tesfa Hiwot faced huge psychosocial challenges. The researcher suggests that it is necessary to give awareness to the public as well as to people with leprosy in order to reduce the psychosocial challenges. Besides, there were many people with leprosy in Addis Tesfa Hiwot who need support. So, the government and nongovernmental organizations should be done a lot in supporting them.
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Abbreviations

MOH - Ministry of Health

MB - Multibacillary

PB - Paucibacillary

WHO - World Health Organization

MDT - Multidrug Therapy

GLRA - German Leprosy Relief Association

SNNP - Southern Nation and Nationalities of People

ILEP - International Leader in Education Program

ENAELP - Ethiopian National Association of Ex- Leprosy Patients
Chapter One

Introduction

1.1 Background of the Study

Leprosy is one a tropical disease that affects mostly the skin and nerves, causing change of tissues and damage feeling in outlying nerves of the fingers and feet, slimy skins of nose, throat, and eyes. It is one of the critical public health problems affecting all people in the developing countries (Lata & Rebecca, 2006).

There is no strong evidence about particular way of leprosy transmission method. However, transmission of disease through physical contact with untreated sick individual is assumed that the key mode for its transmission. So, persons living the same house or who are in near interaction with untreated patient have highest possibility of being bare to it (MOH, 2008).

Leper colonies are in numerous parts where the leprosy is widespread (Fuhrmann, 2015). Pocket of great endemicity stay in certain parts of various countries of which Angola, Bangladesh, Brazil, People’s Republic of China, Democratic Republic of Congo, Ethiopia, India, Indonesia, Madagascar, Mozambique, Myanmar, Nepal, Nigeria, Philippines, South Sudan, Srilanka, Sudan and the United Republic of Tanzania can be mentioned (WHO, 2015).

Ethiopia has grieved from a great prevalence of the disease, and is certainly said to have been one of the states extremely posh by leprosy. The disease had been recognized in Ethiopian in initial times as lamts (አማርኛ) (Pankhurst, 1984).

In Ethiopia, there is too little thoughtful of the infection; the sickness is surrounded by numerous legends and stigma (Mahider, 2013). The social stigma handed down from generation to generation is additional problem to cure than the disease itself. The biggest problem today is how
to eliminate the deep rooted social stigma of leprosy. The stigma of leprosy is an actual trend that affects physical, emotional, societal and financial wellbeing of the victims.

In Ethiopia, a large number of Ethiopian National Association of Ex-Leprosy Patient (ENAELP) members are the greatest communally, financially and physically affected communal collection in the nation. Greatest numbers of infected peoples are uneducated, unemployed and living on begging. Nearly all are out-of-the-way from the public because of leprosy stigma existing in the country (ENAELP, 2004).

The happening of defect in leprosy is the greatest significant as the communal comeback to persons hurt by the disease connected deformity and their family are frequently heartbreaking, cruel, and unfeeling attended with offence, isolation and the careful assassination of those affected. This leads to stigma with a harmful effect on the pride and behaviors of those individuals with leprosy. Therefore, they will develop irritation, pain, and hostility and indication a liking to live some place where no one knows of their times past (Kaur & Brakel, 2002).

The study was conducted in Addis-Tesfa Hiwot which is one of the leper colonies where people with leprosy are found. The place was established in 1954 E.C. According to the information that the researcher got from people with leprosy in Addis-Tesfa Hiwot, the place was established by them with the help of a nongovernmental organization. However, the place was given by the government to them. Many of these people had shifted from ALERT Hospital to that area after accomplishment of their medical treatment. The main reason for they had gone there was in order to protect them from begging. For the time being, there was no housing facility that was built by any concerned body. However, they cut the forest around their village to build their homes. The Swedish organization attempted to create some job opportunities like farming, wood
works and small shopping enterprises. This minimized some psychological, social and economic problems at that moment. However it didn’t prolong more than 20 years, so it is easy to recognize as the colony faced psychosocial and economical challenges for years.

The researcher knew closely such people for many years and observed their difficulties. The intention of this study was to identify the living conditions in which this people are, where the findings are expected to contribute knowledge on the area.

1.2 Statement of the Problem

Leprosy is a chronic, communicable and devastating disease. Individuals with leprosy are hurt from not merely bodily pain but besides mental and communal wellbeing difficulties. They are not accepted by the people that distress their right to survive as ordinary persons can do (Rafferty, 2005).

For years, it has been recognized for bodily malformations that lead to communal shame. Persons with the disease look communal refusal because of widespread faith concerning the infectious flora. Communal rejection and its emotional impact on affected person’s lead to their separation (Kaur & Brakel, 1999).

Noticeable damages or action limits or merely due to the disease, numerous individuals practice psychosocial difficulties (Brakel, 2000). In many cases, the bodily malformation or damage for the disease ensued in the stigmatized attitude of community to societies with leprosy. This stigmatized approach break downs communal link of the individual inside the community, and consequences separation and insight of persons with leprosy from the community. Furthermore, their household who have not completely infected by the infection became, distinguished and ignored and excluded from the public (ENAELP, 2004).
In Ethiopia, existing researches have looked at modes of medical detection and treatment on newly leprosy patients at ALERT center. Unlike the previous researches on medical detection and treatment on newly leprosy patients, this study gave more concern to the psychosocial challenges of people with leprosy, who are living with difficulties for many years at leper colony.

1.3 Research Questions

The following research questions were set to guide this study:

1. What did the awareness of people with leprosy look like about the disease?

2. What did the psychological challenges of people with leprosy look like in Addis Tesfa Hiwot?

3. What did the social challenges of people with leprosy look like in Addis Tesfa Hiwot?

4. What are the impacts of parental leprosy on children’s social life?

5. How do people with leprosy cope with the difficulties?

1.4 Specific Objective of the Study

1. To assess the awareness of people with leprosy about the disease.

2. To assess the psychological and social challenges of people with leprosy in Addis Tesfa Hiwot.

3. To assess the experiences of the children born to the victims.

4. To study the coping mechanisms used by people with leprosy.
1.5 Significance of the Study

This research will help to Ethiopian National Association of Ex-Leprosy patients (ENAELP) and other nongovernmental organizations to understand the various painful experiences of people with leprosy face up in Addis Tesfa Hiwot. It will help look at the challenges and the gaps on the type of support they need for victims.

It will initiate government and nongovernmental organizations and the community as a whole to be more conscious about the issue in order to take actions on the plight of such people.

It may serve as a reference for other researchers who may be interested to make investigation in a similar area.

1.6 Scope of the Study

This study primarily focused on the psychosocial challenges of people with leprosy and coping mechanisms. The study focused on one leper colony, Addis Tesfa Hiwot, a village approximately 148 kilometers south east of Addis Ababa.

1.7 Limitation of the Study

Due to the inferiority complex that goes along with it, communication with this people is understandably a difficult task. Some of the respondents were not willing to be recorded for their own reasons. Besides, time and financial constraints were also the major limitation of this study.
Chapter Two

Review of Related Literature

2.1 Leprosy

Leprosy is an infectious disease that causes painful white areas on the skin and can destroy nerves and flesh. It is a bacterial infection that can progress gradually and causes destruction or damage on the skin, nerves in the ends of the hands and feet, and membranes in the nose, throat, and eyes. Damage of the nerve in leprosy causes loss of sensation. Consequently, fingers and toes become injured and causing leprosy related deformities. The loss of sensation in the fingers and toes raise the risk of damage. The infection of the disease is distinguished by unusual changes of the skin. These abnormal changes, called lesions, are at initial flat and red. Up on extension, they have rough shapes and a typical appearance. The lesions are usually darker in color around the ends because the bacilli grow best at lower temperatures (Lata & Rebecca, 2006).

According to MOH (2008), disabilities are graded as follows:

Grade 0: no loss of sensation or visible deformity or damage has been identified.

Grade 1: no visible deformity but loss of sensation has been identified.

Grade 2: in this kinds of disability visible deformity and damage has been identified. This includes wounds and ulcers.

Leprosy is a chronic disease which can be traced back thousands of years. It was described in earlier time in Egypt and Indian. It is thought that leprosy was brought to Europe by the army of
Alexander the Great after returning from India. During that time, the communities had seen leprosy as the will of God or as a punishment by God (Sermrittirong & Brakel, 2014).

According to MOH (2008), leprosy patients are classified as:

Multibacillary (MB) leprosy: when the patient is encountered by six or more skin lesions.

Paucibacillary (PB) leprosy: when the patient is encountered by one to five leprosy skin lesions.

Pure neural leprosy: when the patient has no any skin lesion, however obviously thickened nerve with or without signs of nerve injury.

2.2 Global Overview of Leprosy

Leprosy can be cured if treated with a combination of drugs. As WHO figures and as reported by 130 countries, the universal annual detection rates have reduced from 2004 - 2010. At the beginning of 2010, the prevalence of leprosy registered cases were 192,246. From these new cases, 95% were identified worldwide during 2010 in Angola, Bangladesh, Brazil, China, Democratic republic of Congo, India, Ethiopia, Indonesia, Madagascar, Mozambique, Nepal, Nigeria, Philippines, Sudan, and United Republic of Tanzania. The above countries show high prevalence of the disease (WHO, 2015). WHO elimination plan based on the broad widen accomplishment of multidrug therapy (MDT) has lead to a vivid decline of the prevalence of registered leprosy. MDT has an impact on the prevalence of leprosy because of the significantly reduced duration of treatment (MOH, 2008).

2.3 Leprosy in Ethiopia

Ethiopia is one of the countries of the origin of leprosy. Though, there is no unambiguous documentation about it. Leprosy was recognized as a major health problem since the 1950’s and
then the attempt to manage leprosy was happened by the establishment of a National leprosy office in the Ministry of Health with the support of German Leprosy Relief Association (GLRA). A structured leprosy control program was prepared within the Ministry of Health (MOH) in 1956 and an in depth policy was issued in 1969. The leprosy control program was relatively vertical and well funded and has scored remarkable achievements in decreasing the prevalence of the disease, particularly after the introduction of Multidrug therapy (MDT) in 1983. But, the annual new cases detection did not show comparable decline (MOH, 2008).

Large numbers of new cases were diagnosed at health facilities. For instance, 4000-4500 new cases were diagnosed between 2004 and 2010; While Ethiopia has reportedly met the elimination target. The variation now is that the country has a much decreased control intensity relying with fewer energetic leprosy experts connected to control than decades ago (Kebede, et al., 2012). On the other hand, the research article by Tigist, Meaza, and Yonas (2015) showed that the existence of both Grade 1 and 2 disabilities in Ethiopia is very high.

In Ethiopia, there are three main regions where leprosy is endemic; these are Oromiya, Amhara and SNNP in the central and South Eastern highlands. Since 1994 the country started thinking of introducing the program on combined Tuberculosis and leprosy while the program implement in 1997 (Athieno, 2005).

2.4 The Cause and Transmission of Leprosy

Investigations indicated that leprosy is caused by bacteria. Mycobacterium leprae, which is rod-shaped organism, causes leprosy. It is uncertain how the disease is transmitted from person to person; about half of patients diagnosed with the disease show a history of close contact with an infected family member. A large number of Mycobacterium leprae bacilli in their nasal
secretions are found in untreated infected patients, it is considered that transmission may take place by nasal droplets (Lata & Rebecca, 2006). The disease leprosy is caused by Mycobacterium leprae which was discovered by the Norwegian man, Dr Armauer Hansen, in 1873. Leprosy had been called by the scholar’s name Hansen’s disease, after him (Luka, 2010).

The eradication of leprosy throughout the world has not been ended twenty years of MDT. Leprosy patients are infectious and the organism can stay possible outside a human host for long periods of time. The average incubation period of the disease is about ten years. Therefore, these factors make it tricky to entirely eradicate the disease (Walker & Lockwood, 2006).

2.5 Treatment, Prevention and Control of Leprosy

There were misconceptions about treatment, prevention and control of leprosy. Whereas leprosy is curable, prevention and treatment is becoming effective. The most commonly used drug for leprosy treatment is dapsone. However, the coming out of dapsone-resistant strains encouraged the introduction of multidrug therapy. The combination of dapsone, rifampin, and clofazimine are known as MDT, all of which are powerful antibacterial drugs with minor side effects. The type of leprosy has an impact on duration of treatment. This may differ from six months to two years or more (Lata & Rebecca, 2006). The early detection of degradation in nerve function and the fast beginning of steroid therapy are necessary to reduce nerve damage and thus preventing disability. Injured neuropathic areas should be sheltered from extra injure by inactive the area and any secondary infection treated with suitable antibiotics. Surgical intervention may be vital to bring into contempt necrotic tissue and permit drainage of any collection (Walker & Lockwood, 2006). Leprosy reaction is an immunological reply to the bacterium. The majority of the problems connected to leprosy are mainly caused by the damage that obtains from leprosy
reactions. Early treatment and sufficient management of reactions are therefore essential activities (MOH, 2008).

Leprosy is curable however the deformities and nerve damage related with leprosy are often permanent. The goal of WHO Action Program for the elimination of leprosy around the world is not likely to be achieved (Lata & Rebecca, 2006).

2.6 Psychosocial Impacts of Leprosy

Misconception about leprosy can put the patients in different psychosocial difficulty. Lepers may shunned by the rest societies. Structural change from normal or deformity in leprosy is also main problem causing severe socio-economic and psychological consequences to the people with leprosy and their families. It is stated that the proportion of families having patients with deformities facing problems was ten times higher than those having patients with no deformities (Kopparty, Kurup, & Sivaram, 1995).

Due to the negative outlook of the society towards people with leprosy, difficulty of divorce, joblessness and dislocate from area of residence are common in people with leprosy (Singh, 2012). Throughout history leprosy related stigma has been resulted in social and psychological problems (Tigist, Meaza, & Yonas, 2015).

Disability is an umbrella term casing any injury, activity limitation or participation restriction of affecting person. Visible deformities and disabilities are the major contributors of stigma development in people with leprosy and it also create negative attitudes towards leprosy among unaffected people (WHO, 2010). Due to its social and psychological consequences, leprosy is expressed as complex human problems, which direct to discrimination, stigma and prejudice. It
is stated that equal rights for people with leprosy to build up their full potentials, is an issue of human rights (Calcraft, 2007).

The introduction to the universal declaration of human rights, adopted in 1948, recognizes a right that cannot be taken away, intrinsic dignity and the equal rights of the human family as the basis for freedom, justice and peace in the world. Till now, the stigma related with leprosy remains the most continual and all-encompassing form of social injustice, prejudice and discrimination that society has forced up on its member human beings. People of all ages whose lives have been affected by leprosy have had their most critical human rights deprived of by virtually every culture and major religion throughout time. Some of the basic rights denied include: The right to liberty of movement; the right to relations; the right to education; the right to work and the right to freedom from humiliating treatment (Arega, 2004).

Leprosy related stigma is a worldwide phenomenon, happening in both endemic and non-endemic countries. The consequences of leprosy related stigma can vary from the psychosocial dysfunction to segregation, refusal and participation restriction. In spite of the difference in occurrence of different types of stigma, its severity and nature, the risk factors connected with stigma are extremely similar. They include observable impairments, disability, low socioeconomic status, low education and the various feeling regarding leprosy (Adhikari, et al., 2013).

In addition, the physical aspects may influence people to developing psychological, economic and social problems which have difficult effect on quality of life. Moreover, quality of life, activity limitations, participation restrictions and perceived stigma are difficult among people with leprosy related visible impairments (Adhikari, et al., 2013).
2.6.1 Social Stigma

Social stigma is a situation in which an interaction among individual people in a society or between the people outlines the rights and duties of each others. It drives from the ideas of hobbies, looks and involves people giving up freedoms in return for benefits.

The psychosocial problems that are usually associated to stigma are people’s self-esteem, social category, job opportunities, job security, family relationships, and friendships. People have missing their families, children and even spouses because of fearing of stigma (Singh, 2012). The root of stigma development was found to be the visibility of the disfigurements and disability enlarged by the stereotypes of the society, knowledge and the status of the person in terms of economy, education and capability to participate in society. The maximum perceived stigma score was found in illiterate people with leprosy (Adhikari, Kachler, Chapman, Raut, & Roche, 2014).

2.6.1.1 Types of Stigma

Stigma can be stated in different ways. Commonly, three kinds of stigma are associated with people with leprosy. Experienced stigma indicates to the actual discrimination or acts practiced by people with leprosy while perceived stigma indicates to the advancement of fear within people with leprosy where the fear may take place out of potential discrimination from family members, friends or society. As a result of both enacted and perceived stigma, a person over a long period of time may think what others feel and say about him, resulting to the loss of self-respect and self-esteem which is referred to be a self-stigma or internalized stigma. Stigma has an impact on the psychosocial wellbeing of people with leprosy (Adhikari, Kachler, Chapman, Raut, & Roche, 2014). Stigma is negative outlook to human differences. These may be lead to
visible differences in behavior. If these are related to health conditions, we call this responses ‘health-related stigma’ (ILEP, 2011).

2.6.1.2 Causes of stigma Due to Leprosy

According to ILEP (2011), there are many different causes of stigma. These may vary according to the health condition. Out of these, fear is the most common one. This may be fear of catching a disease that is infectious, such as leprosy. In the case of leprosy, it may be fear of the physical consequences that can result from leprosy. The fear not being able to marry or of one’s children not being able to marry on account of having leprosy. Unattractiveness is the second one. People with visible impairments on their face and body parts may be rejected just because of the way they look, people with facial skin lesions may be treated likewise. Values and beliefs make up the third category. These play a powerful role in creating or sustaining stigma. Beliefs regarding the cause of conditions such as the cultural beliefs that leprosy is hereditary may cause whole families to be stigmatized. Policies and legislation are still other causes. Policies about how and where conditions are treated may cause stigma. This is typically seen when conditions are treated in separate location such as a leprosy clinic.

2.6.1.3 The Effect of Stigma

Researches indicate that stigmatized person can feel fear or shame which can lead to anxiety and depression. Due to this, or because of expected stigma, people with leprosy may no longer involve in any social activities and social participation. Social exclusion affects the economic situation of people with leprosy and their house hold and thus causes poverty (ILEP, 2011). Persons with stigmatizing situation practice troubles in their marriages or difficulties in getting married and in their employment or getting employed. Their community relation such as social
relationships and friendships are affected. Their families may practice reduced educational opportunities, and inequalities between those people with leprosy and those who are not. All of these negative aspect obtain from poor community knowledge of the disease, and the misconceptions held about them (Luka, 2010).

Stigma attached to these victims has more effect on educated women and in combined families. Because of the fear of infecting family members, women experience continue aloof and care constantly bothered about divorce (Vyas, Dudani, & Chaudhary, 1982). People with leprosy develop feelings of being unhappy, confused, negative responses from other because of their unusual appearance, feeling of inferiority and lack of motivation, and social exclusion due to stigma (Lusli, et al., 2015).

Birke (2004), the chair person of ENAELP, reported that people have been deprived of their right to live at their birth places, the right to get an education, the right to get employment, and so on. This has arisen mainly from the social isolation and psychological impact on those people with leprosy. Society segregates people with leprosy because of lack of awareness about the cause of leprosy and an overstated fear of the disease.

The base line survey conducted in different regions of Ethiopia showed that individuals have been deprived of their rights. For example, in Jimma, people with leprosy cannot use river water with other people. In Addis Tesfa Hiwot, people with leprosy cannot get religious services, including funeral ceremonies. In Shashemene, they were powerfully dislocate during the fall of the Durg regime, being forced to leave behind everything they had (Birke, 2004).
2.6.1.4 Factors that Contribute to Stigma Formation

In the research article by Adhikari, Kachler, Chapman, Raut, and Roche (2014), lower education level, economic burden, lack of awareness about the disease and the wrong feeling about leprosy were the major factors contributing to higher level of perceived stigma in people with leprosy. Besides to those socio-demographic factors, the existence of visible deformities, ulcers and disabilities also contributed to higher perceived stigma in people with leprosy.

The issue contributing to the development of stigma in people with leprosy can express the need of intervention programs focusing on health education. Health education has a great impact in both people with leprosy and people hadn’t leprosy which might change the wrong perceptions and might raise understanding of leprosy. Besides to the education and health awareness programs, enabling of people with leprosy by technical education, vocational training and social participation might be useful to increase self-esteem and minimized perceived stigma (Adhikari, Kachler, Chapman, Raut, & Roche, 2014).

2.6.2 Social Exclusion

Social exclusion is the situation of being excluded, particularly from normal society and its advantages. Social exclusion is multidimensional process of progressive social break, coming loose groups and individuals from social relations and institutions and preventing them from full participation in the normal, normatively prescribed activities of the society in which they live (Srikanth & Mishra, 2007). Deep exclusion indicates exclusion across more than one domain or extent of disadvantage, resulting in rigorous negative consequences for quality of life, well being and future life chances. Involvement in economic, social, cultural and political life or its lack is main aspect of many definition of social exclusion (Levitas, et al., 2007). Excluded people
become violent, self-protective, awkward, unsupportive, self-defeating, and close off their emotional responses, appealing in defensive denial. They also carry out inferior on tasks such as intellectual tests (Abrams, Hogg, & Marques, 2004).

Social inclusion refers how a society values all of its citizens, respect their differences, ensures everyone’s basic needs are met, and welcomes and enables full participation in that society (Westfall, 2010). The idea is that being excluded is terrible for people both psychologically and materially. Moreover, it is terrible for the communities in which they live, creating conditions that give rise to disagreement, increased unfairness, and doubt (Abrams, Hogg, & Marques, 2004).

The effects of exclusion are more or less completely harmful, whether perceived in wide terms such as the failure of essential parts of the self or in more detailed terms such as the protective reactions that follow. Of course, the exception is when someone is excluded from an unwanted relationship. Individuals are extremely likely to be the target of exclusion, mainly if they have a poor fit with a group (Abrams, Hogg, & Marques, 2004).

Moreover, individuals may be excluded from relationships either because they belong to an excluded group or because of something unique about them. However, interpersonal exclusion is more potent if it also removes access to an important social network, effectively reducing a person’s social capital. Exclusion based on large scale geographical, religious or ethnic differences where the humanity or rights of entire sections of the global community are diminished or ignored. Processes of exclusion are highly dynamic in the sense that they involve change in a relationship in which at least two parties have potential for influence. For instance, unequal access to power also makes it possible that people may be excluded. Other reasons for
exclusion include the alleviation of discomfort, system justification, and status preservation for members of majority groups. There may also be evolutionary reasons that include avoiding poor partners, those who are diseased and out group members or those who undermine group living. However, reactions to being stigmatized are not always negative (Abrams, Hogg, & Marques, 2004).

The existing skills of people with leprosy after the deformity should taken to decrease the self-stigma and making them self reliant. The agencies and NGOs mainly focusing on the areas where there are highest concentrations of people with leprosy, such as cities with well developed infrastructure and leaving people with leprosy from rural areas and mountainous and hilly areas poorly served, where the government should focus more to decrease the leprosy and stigma. On the other hand, good and well planned leprosy eradication program and educating the public can help for minimizing the social stigma (Srikanth & Mishra, 2007).

2.6.3 Psychological Impact of Leprosy

Psychological impact is a mental process affecting or intended to affect the mind. It exists only in human mind without having a physical basis. Leprosy can make such problem in the milestone of lepers. Patients with chronic neuropathic pain together with a high psychological distress level had higher pain intensity and also low quality of life in all domains. Higher prevalence of psychological distress in people with leprosy with higher disability level (Grade 2) and the existence of disability seem to raise the risk of mental distress, probably because of disfigurement (Ruth, Elisabeth, & Atalay, 2005). People with leprosy are ignored by the local community and family members: they are enforced to stay in leprosy homes. As a consequence of these problems, people with leprosy are liable to a high risk of developing psychiatric
disorders. The prevalence of psychiatric disorders among these people is higher than that among the general population (Singh, 2012).

According to the finding by Peters, et al (2012), the physical impacts of people with leprosy challenged their life and influenced their emotions and social and economic situation. Sadness, dissatisfaction, loss of confidence, losing of capacity, stress and hopelessness were some of the emotions seen due to the leprosy. In the research article by Luka (2010), 74 leprosy patients were having one or other psychiatric disorders from a total of 133 patients. Once the diagnosis of Mycobacterium disease is made, usual feelings such as fear, shock, anger, shame, and guilt have been distinguished. These feelings may come in influence and will slowly subside over time; however, it may be advantageous to have the help of a psychosocial clinician to support in this process (Heru, 2012).

According to Heru (2012), the stress of having a chronic illness can be serious, leading to emotional distress. When our lives are significantly disrupted, we often experience several emotional troubles.

2.7 The Impact of Leprosy on the Family

Persons with stigmatizing situation experience challenges in their marriages or difficulties in getting married and in their employment. Their community relation is affected, such as social relationships and friendships. Their families may experience less educational opportunities, leading to further inequalities between those affected and those who are not. All of these negative effects come from poor society knowledge of the disease and the misunderstanding held about them (Luka, 2010). The psychosocial aspects that are usually related to stigma are people’s self-esteem, social status, job opportunities, job security, family relationships, and friendships.
People with leprosy have left their families, children and even spouses fearing the repercussions of the fact that they had leprosy (Singh, 2012).

2.8 The Social Relation of People with Leprosy

According to the finding by Singh, Sinha, Banerjee, and Jaswal (2009) in the Netherlands, 54.2% of people with leprosy had no significant participation restriction and only 3.67% had extreme participation restriction. However, people with leprosy, in the Netherlands, encounter in activities limitation and participation restrictions, which are linked to the cruelty of impairments (Slim, Vanschie, Keukenkamp, Faber, & Nollet, 2010).

In the Netherlands, care for people with leprosy at hospital focuses on the treatment of leprosy and the resulting impairments. To what level a person with leprosy also experiences limitations in activities and participation restrictions is not well recognized (Slim, Vanschie, Keukenkamp, Faber, & Nollet, 2010). People with leprosy not only face psychosocial problems but also physical impairments because of the prevalent social stigma. As result of such impairments, many people experience limitation of activities in daily living. As a result of such limitations, or because of visible impairments or because of the diagnosis of leprosy, many people are limited in their social participation. Long term restriction in social involvement results depression and social rejection of some of them (Kaur & Brakel, 2002).

2.9 Government Policy Statements in Ethiopia

In the past, there was no policy regarding the employability of the disabled. A proclamation concerning the rights of disabled persons to employment was declared for the first time in the country on 26th August 1994. The rights of disabled persons to employment proclamation No. 101/1994, page 476 takes important points in to consideration that there are many people within
the society suffering disabilities due to natural and man-made causes. It has also been realized that disabled persons have got less job opportunities, despite the fact that some of them have required the appropriate training and skills through their own efforts and the assistance of the government and humanitarian organizations. It has also become necessary to stop much discrimination and protect the rights of disabled persons to compete for and get employment on the basis of their qualifications (TGE, 1994).

2.10 Theoretical Framework: Impact of Stigma

Studies proved that stigma dominate the patients to protect themselves from social relations. ILEP (2011) described the effect of stigma on the lives of individuals who have health difficulties, such as leprosy. The recognized four issues in which stigma affects on the lives of people with leprosy are: emotions, belief, behavior and interaction. These issues are interrelated and marked themselves in diverse amount, at various moments, and in different situations.

The first domain contains emotions such as terror, unhappiness, sadness, disgrace, guiltiness, nervousness, low self-esteem, hopelessness and anger, or incapability to communicate these feelings. The second issue represents the impact on belief in particular the pessimistic and gloomy feelings and attitude about self, and the world. Emotions and belief manipulate the manner people reply and act and be able to result in lack of self-confidence, evasion, taking out from community, and self-isolation. These things are element of the third issue; behavior. To end with, the power of the people’s communal support system and the attitudes of people in the network are significant in the practice of stigma. The impact on the final issue, interaction, is described as rejection, enforced segregation and limited communal participation.
2.10.1 Social Stigma Theory

In Erving Goffman’s theory of social stigma, stigma is a characteristic, actions, which is communally being lower in a particular way: it causes a person to be emotionally classified by others in an undesirable, discarded, stereotype rather than in a conventional, normal one (Goffman, 1963).

2.11 Coping Mechanism of People with Leprosy

Chronic illnesses are severe stressors for most individuals. One’s life is profoundly disrupted in many ways: physically, socially, emotionally, and financially. Many feelings are usually expressed by patients with mycobacterium disease; each person experiences his or her illness in different ways that reflect one’s individual and cultural background (Heru, 2012).

There are coping mechanisms that many people with leprosy find useful. Each person will also have developed individual ways of dealing with stressful situations. Emotional support is another coping mechanism that is helpful to all people. Support comes from relatives, friends, families, medical staff, counselors, priests, and so on. Activity is another very helpful means in coping with illness. People with leprosy may sense weak and exhausted, while staying in bed often worsens the fatigue and weakness; it can also lead to deep feeling of boredom. Activities such as physical therapy and relaxation exercises are also important coping mechanisms. On the other hand, for some people humor is a very powerful way of coping but for others, religious faith provides comfort and hope. Even though most people with leprosy can eventually find ways to adequately cope, looking forward to a time of improved health (Heru, 2012).
Chapter Three

Research Methods

3.1 Research Design

Research designs are strategy and the steps for research that span the decisions from wide assumptions to in depth methods of data collection and analysis (Creswell, 2009). This study used descriptive research design to investigate the psychosocial challenges of people with leprosy in Addis Tesfa Hiwot. The researcher used this design to obtain information concerning the current status of the phenomena and to describe what exists with respect to conditions.

The researcher employed qualitative research since the issue needs comprehensive understanding rather than measurements and numerical figures. The researcher is interested in gaining rich and complex understanding of people’s experience and not in obtaining information which can be generalized to other larger groups. Besides, qualitative research method was used to allow participants to discuss their unique perspective. Furthermore, qualitative research method was chosen because it was found to be an appropriate research method to address the central question which tries to assess overall conditions of people with leprosy in Addis Tesfa Hiwot.

3.2 Study Area

The study area of the research is Arsi zone. It is one of the zones of Oromia regions in Ethiopia. The study was conducted in Addis-Tesfa Hiwot which is found in Arsi zone Jiju woreda. The area was selected purposefully. The rationale for selecting this place was because it is one of the places where people with leprosy are living.
3.3 Population and Sampling Technique

The total population of this study was around 545. The participants of the study were 10 people with leprosy and 5 informants, who were not infected by leprosy. The factors which the researcher has taken into consideration were willingness to participate, resource and time availability. Purposive sampling technique was used in this study. It is also known as standard based sampling, because the sample criteria are prearranged (Ritchie, Lewis, & Elam, 2003). Purposive sample sizes are regularly used on the foundation of theoretical saturation (Mack, Cynthia, Macqueen, Guest & Namey, 2011). Thus, the respondents of this study were selected based on the willingness to participate in the study, people with leprosy who are living in Addis Tesfa Hiwot and people with leprosy who have children.

Besides, key informants thought of having contact with these people were selected using purposive sampling method. The researcher used these informants for the reason of their direct contacts with many of the studied groups so that better information can be acquired.

3.4 Data Collection Methods

In-depth interview was used to gather relevant data. It is an interview technique that is characterized by flexibility and interaction. In such interview, the researcher uses a range of probes and other techniques to obtain data in terms of penetration, investigation and justification (Legard, Keegan, & Ward, 2003). The researcher used open-ended questions as they allow participants to discuss their experiences, feelings in detail. Seventeen interview guide questions were prepared in line with literature and research questions. Using these questions, an attempt was made to assess the psychosocial challenges of people with leprosy in Addis Tesfa Hiwot.
The researcher also conducted the interview with five key informants who are not infected by leprosy. This was to triangulate the data obtained from people with leprosy.

3.5 Issues of Validity and Reliability

A pilot study was conducted after translating the interview into Amharic. It was translated from the belief that many of the respondents may have difficulties in understanding the English language used in developing interview questions. The translation was made by the researcher and edited by people from English language background. Besides this, items were also evaluated by one higher level teacher who has knowledge of the issue of the study.

Finally, the Amharic version was piloted on two persons who fulfilled the inclusion criteria. Accordingly, the responses of the respondents answered all the research questions of the study.

3.6 Data Collection Procedure

The first step in data collection was to go to the study area and meet the participants. The researcher got all the participants, with the support of the gatekeeper. The researcher communicated the purpose of the study to the participants. Then the semi-structured interview question, which is translated to Amharic, was arranged after the participant fulfilled the inclusion criteria. The researcher made appointment with each participant. In addition, the researcher prepared a tape recorder, notebook and other materials for the interview.

3.7 Data Analysis Technique

Analysis is a difficult but exhilarating phase of the qualitative research procedure. It needs a combine of inspiration and logical penetrating, a mix together of encouragement and attentive finding (Spencer, Ritchie, & O’Connor, 2003). The procedure of data analysis involve
manufacture intelligence out of text and likeness data, preparing the information for analysis, conducting diverse analysis, affecting deeper and deeper in to accepting of the data, on behalf of the data, and making an explanation of the bigger sense of data (Creswell, 2009). The procedures in the data analysis of this study were the following. The first was pre-coding the raw data. After data collection, the researcher transcribed the data from field notes into English language. In addition, the tape recorded interview was transcribed into text format, originally to Amharic and back to English. Teachers were invited to comment the translation in order to check its accuracy. Then, the researcher read and re-read the transcripts closely until understanding of the main points were achieved. Accordingly, the researcher underlined significant respondent quotes.

The coding process started after the interview was transcribed. Specific topics or words in the text were coded. The codes were transformed into categorical labels which contained related codes explored in the analysis of the data. The coded data were categorized depending on the similarity under different headings. In this study, themes were created from the categories by extracting common and significant linkages. Therefore, the researcher applied thematic data analysis technique and the collected data were analyzed under six major themes namely, participants’ background, leprosy and its causation, psychological challenges of leprosy, social challenges of leprosy, the impacts of parental leprosy on children’s social life and coping mechanisms.

3.8 Trustworthiness of the Data

To keep the credibility of participant information, participants of the study were carefully selected based on the criteria set. To get accurate and detail information, participants were interviewed in the appropriate place. Consequently, the researcher invited teachers to comment
and debrief on the prepared questions. In this study, trustworthiness was guaranteed by avoiding complex and long questions. Besides, efforts were made to avoid leading and emotional questions. To avoid respondent’s biases, the researcher tried to explain the purpose of the study.

In most cases, it is recommended that a pilot study be carried out prior to the main research using 10% of the actual sample size, this study is a qualitative study only two participants who met the selection criteria were used in the pilot study, which was used as training a researcher in interviewing process as well as to evaluate the interview questions.

The interview was tape recorded and listen the participant responses with probing and verbal reactions repeatedly. These early interviews were transcribed and reviewed. During the interview, attention was given to body language as well as the manner of asking questions.

3.9 Ethical Consideration

The ethical measures in this study included consent, confidentiality, anonymity, privacy, and the right to withdraw from the study. Obtaining informed consent was the first vital ethical prerequisite. All participants freely decided to participate in this study. They were informed about all necessary information regarding the research. They were informed that they can withdraw from the study at any time if they wish. Their rights were explained to them prior to engagement in the study. The researcher attempted to keep participants’ emotions when probing questions.

Conducting interview, application of tape recorder and other necessary instruments were done only after the researcher got consent of the participants. The researcher made the interview with participants who were voluntary to participate in the study. Moreover, issues of confidentiality, anonymity and privacy were communicated well. In this study, privacy was maintained by conducting the interview in appropriate place and time chosen by the participants. The researcher
informed the participants that results will be disseminated in the form of a research report. Anonymity was assured because the results will not mention the participants’ names.
Chapter Four

Findings of the Study

The data obtained from people with leprosy and informants were categorized under six thematic areas. These include participants’ background, leprosy and its causation, psychological challenges of leprosy, social challenges of leprosy, impacts of parental leprosy on their children social life and coping mechanisms.

4.1 Participants’ Background

With regard to their physical damages, seven of them had lost both their hands and legs. From seven of them, two of the respondents were using artificial legs. Besides, two respondents had lost their facial appearance. The other one respondent had only injured his thumb.

Regarding to respondents’ educational level, two were grade ten complete. However, seven of the respondents were illiterate. Besides, one respondent was grade three but he could not write and read properly. Regarding informants, three had college diploma while one BA degree. There was only one informant who was twelve complete. In view of their sex, six of the respondents were males while the rest were females. Additionally, there were three male and two female informants. When considering their age ranges, the respondents’ age ranged from 60 to 87 while the informants’ age ranged from 38 to 57. Seven of the respondents told to have been married but two of them were widowed and one was widower. Besides this, four informants were married while one was single. With regard to religion, eight respondents and four informants were orthodox Christians while the rest were Protestants. Regarding their birth place, 3 were from Gojam, 2 from Gonder, 2 from Wello, 2 from Debube, 2 from Addis Tesfa Hiwot, 1 from Sheno, 1 from Asella, 1 from Semen Shewa and 1 from Wellega.
Table 1: Participants’ Background

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Sex</th>
<th>Marital status</th>
<th>Educational level</th>
<th>Place of birth</th>
<th>Religion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respondent -1</td>
<td>72</td>
<td>M</td>
<td>Married</td>
<td>Grade 3</td>
<td>Gojam</td>
<td>Orthodox</td>
</tr>
<tr>
<td>Respondent -2</td>
<td>87</td>
<td>M</td>
<td>Married</td>
<td>Illiterate</td>
<td>Gojam</td>
<td>Orthodox</td>
</tr>
<tr>
<td>Respondent -3</td>
<td>60</td>
<td>F</td>
<td>Married</td>
<td>Illiterate</td>
<td>Sheno</td>
<td>Orthodox</td>
</tr>
<tr>
<td>Respondent -4</td>
<td>70</td>
<td>M</td>
<td>Married</td>
<td>Grade 10</td>
<td>Debube</td>
<td>Protestant</td>
</tr>
<tr>
<td>Respondent -5</td>
<td>72</td>
<td>F</td>
<td>Married</td>
<td>Illiterate</td>
<td>Asella</td>
<td>Protestant</td>
</tr>
<tr>
<td>Respondent -6</td>
<td>65</td>
<td>M</td>
<td>Married</td>
<td>Grade 10</td>
<td>Wello</td>
<td>Orthodox</td>
</tr>
<tr>
<td>Respondent -7</td>
<td>65</td>
<td>F</td>
<td>Widowed</td>
<td>Illiterate</td>
<td>Wello</td>
<td>Orthodox</td>
</tr>
<tr>
<td>Respondent -8</td>
<td>74</td>
<td>F</td>
<td>Widowed</td>
<td>Illiterate</td>
<td>Gonder</td>
<td>Orthodox</td>
</tr>
<tr>
<td>Respondent -9</td>
<td>69</td>
<td>M</td>
<td>Widower</td>
<td>Illiterate</td>
<td>Gonder</td>
<td>Orthodox</td>
</tr>
<tr>
<td>Respondent -10</td>
<td>74</td>
<td>M</td>
<td>Married</td>
<td>Illiterate</td>
<td>Gojam</td>
<td>Orthodox</td>
</tr>
<tr>
<td>Informant -1</td>
<td>44</td>
<td>M</td>
<td>Married</td>
<td>Degree</td>
<td>Wellega</td>
<td>Orthodox</td>
</tr>
<tr>
<td>Informant -2</td>
<td>47</td>
<td>M</td>
<td>Married</td>
<td>12 complete</td>
<td>Addis Tesfa</td>
<td>Orthodox</td>
</tr>
<tr>
<td>Informant -3</td>
<td>38</td>
<td>M</td>
<td>Single</td>
<td>Diploma</td>
<td>Addis Tesfa</td>
<td>Orthodox</td>
</tr>
<tr>
<td>Informant -4</td>
<td>52</td>
<td>F</td>
<td>Married</td>
<td>Diploma</td>
<td>Semen</td>
<td>Orthodox</td>
</tr>
<tr>
<td>Informant -5</td>
<td>57</td>
<td>F</td>
<td>Married</td>
<td>Diploma</td>
<td>Debube</td>
<td>Protestant</td>
</tr>
</tbody>
</table>
4.2 Leprosy and its Causation

Leprosy is an infectious disease that causes severe, disfiguring skin sores and nerve damage in hands and legs. One of the finding of this study was about how people with leprosy became aware of their status. All of the respondents experienced different symptoms to the disease.

One of the respondents told the researcher,

I could be able to detect it after I found red spots on my body particularly on my back and thigh. As an additional symptom, the disease was found to be gradually spread to other parts of my body and changed the color of me.

Another female respondent added, “I saw skin fractures on my legs and hands. And I started to face hard breathing difficulty of free air passage through my noses. Lose of feeling on my legs and hillock on my ears alerted me that the disease may be leprosy”.

The other male respondent said,

I have medical information that white and red spots on a human body are the symptoms of leprosy. However, I got such spots on my hands and some body parts. I also confirmed that pinching of infected areas were not with feeling of pains. It was the way how I detected whether I am infected with leprosy.

The remaining respondents also shared the symptoms of the above respondents in one way or another.

Respondents were also asked about their perception of the disease and its causation. In this regard, one respondent stated, “I don’t know the causes of the disease, but in our country people
believe it as a wrongdoing but I don’t believe it. Although it is not my belief I hear as if the disease is traditionally called *kumetena* (*㻏㻏㻏㻏*) is hereditary”.

The other respondent told the researcher, “I specifically learnt from scholars about the causes of leprosy in previous time but I do not remember now. However, I used to hear as if the disease is caused by heredity, and contagious I don’t share this”. The other female respondent told the researcher that she doesn’t know the scientific knowledge about the disease. She still believes that the disease is brought by God’s bad grace. Contrary to the above respondents, another respondent told the researcher that he knows that leprosy is bacterial infection.

Additionally, one respondent said:

> I know what the disease is. As to me, I have been caught by the disease because of my poor livelihood. Because, I believe that my natural immunity has been weakened due to my poor standard of life. I am a technician in similar laboratories and I observed that many of the victims are from poor families. My families in rural areas have no idea of the disease. However, my wife and children know better about it.

Opposing the above respondent, one female respondent told the researcher, “I believe leprosy is caused by *lekefete* (*硃硃硃硃*). I also was infected due to similar situation. It was after I stood up on uncovered blood that my feet started to swell and got injured feet”.

Still another female respondent stated, “I believe leprosy is due to the punishment of God. The health workers thought me about the causes of leprosy but I didn’t accept them. My family also didn’t have awareness about this disease. They assumed leprosy as *yebet tata* (*硃硃硃硃*). The other two respondents support the above idea. Besides, one male respondent added, “Nothing I
know about the disease. I don’t know the causes of leprosy other than hearing some people cultural sayings like *meche* (*หมอ*) or *yedare wedeket* (*ยัดเรดีเคต*).

However, almost all informants had a similar understanding about the causes of the disease. They argued that leprosy is a disease caused by *mycobacterium leprae*. While one female informant stated, “I know leprosy is caused by bacteria. But in this place I saw more than two people in one family were affected by this disease.”

The other informant, a chairperson of Addis Tesfa Hiwot Victims Rehabilitation Association, told to the researcher,

> In my opinion leprosy is caused by bacteria. My parents were affected by this disease. People didn’t have awareness about the causes of the disease. Still they believe it related to culture that is god’s punishment. And also the society assumed leprosy as was transmitted from single person to person by hereditary. By the way, the disease is transmitted by contact for instance by sleeping together before treatment.

Another informant supported the above idea that, “Leprosy is not caused by hereditary or punishment of God for bad deeds but it is caused by bacteria. And it could be transmitted by body contact from untreated patients.”

The other female informant said, “I knew many things regarding leprosy after I came in this place. For instance, the disease could not transmit to other people from people with leprosy who had finished their medical treatment.”

From the above data it can be inferred that many of the respondents did not have awareness about the disease and its causation. Only two respondents had awareness about leprosy.
Respondents were living with leprosy but many of them did not have awareness about this disease and still believed traditionally whereas almost all informants had awareness about the disease and its causation.

4.3 Psychological Challenges of Leprosy

As far as its impact on the psychological wellbeing of people with leprosy is concerned, the result of the study revealed a feeling of sadness, unhappy, hopelessness and stress.

One of the respondents says,

I feel very bad, depress and unhappy when someone insult me. My family’s segregation in the community makes me unhappy. My family and my children abide by their locality because of the disease. I am alone here also. My father always insults my mother. He says that as we are not his children, that is why I and my brother are victims of the disease. My father insults my mother because of our disease.

Additionally, another respondent says,

I am a strongly harmed patient in this colony. I am not happy to meet people even people with leprosy nearby me. They are not impaired as much as I am. At least they can eat with their hands but I can’t do this. I separate myself. I face many difficulties other than the people do. I feel hopelessness and I prefer to die.

During the in-depth interview, one female respondent told the researcher, “I strongly feel depressed due to the incidence that my body parts are harmed by this disease. Besides, some of the others around our colony insult our children. They ignore and separate us. They make us to feel hopelessness.”
Furthermore, one respondent told the researcher,

I feel very unhappy because my legs and hands are already damaged by this disease. And also my families have no need of greet with me. After they knew that I am victim they never visit me. There is much devaluation in the society also. They undermine my children. It made me worried about my children. I bother what will happen to my children after I pass.

The other respondent told the researcher that she strongly feel stress, terrible and unhappy since she was told that her children relation to her family are blocked because of her status. When she remembered, it made her stress. The other one respondent also added similar idea he stated, “I am unhappy, stressed and worried. I thought if I was healthy, I didn’t come here and I lived together with my families at my birth place.” All the rest shared the feelings of the above respondent in one way or another.

Almost all the informants told the researcher that people with leprosy in Addis Tesfa Hiwot were living in terrible conditions. They have huge psychological challenges. One of the informants stated,

People with leprosy in this colony could be possible to classify in three levels as the worst, medium and better life condition. People with leprosy that got irrigation land from government were living in better life situation. While the other people with leprosy who are known as 20 birr pensioner, they were living in worst life situation. Many of them didn’t go out from their home.

The other informant also added, “Many people with leprosy made themselves stressed because they thought why God differentiate from other people.” The other one female informant also told
the researcher, “I saw this people when they felt shabby, stressed, sadness and unhappy. Even I saw many of this people went to wedding in the evening just not to be absent because during the day time there were many healthy people and guests from other neighboring place.”

One of the informants told the researcher her experiences. She said,

One day in winter I enjoyed with friends in my home. Two of them are people with leprosy. During that time there was heavy rain and cold. One of my friend said emotionally yeze bered komata yasekefele (የወድ እር፣ ወሰኝ ይርቅወ።). After she told, two of my friends went out from my home. When I remembered that really I shocked and still our relation with them was blocked.

From this what I understood was this people were immediately depressed and sad because of their status.

As it can be inferred from the above information, all of them faced huge emotional problems. Almost all of them felt unhappy, sadness, worried about their children, depressed and stressed. Even, one of the respondents reported that he lost hope and he wanted to die. This implies how seriously leprosy affected their psychological wellbeing.

4.4. The Social Challenges of Leprosy

The huge impacts of leprosy are social stigma, discrimination, and its social restriction. As per the data obtained from the participants, many of them did not go out from their home.

One of the respondents stated,

I am not happy to meet the people because of my disability to keep my personality. I need to talk and enjoy with others, but I cannot do that freely, I could not wash my clothes, I
could not bathe. I know that it was the right time to do such social relations, but it is impossible. It was not by old age to do so, but the only reason is I was infected with the disease why I was segregated and restricted. Most of the people who came from the villages like Tibella and other local places have wellbeing personality. It is abject sitting with them; they abnegate me when we meet at wedding places and in other social programs.

Two of the respondents told the researcher that they could not walk, talk and work with healthy people as they need.

Case

One of the respondents told the researcher that how she was socially hurt due to her situation. What she said is presented as follows. “At one day I went to the market which is somehow far from the place where I live to buy some wheat and other materials. The seller used jug for selling wheat then she added some jugs of wheat to my sack. Lastly, when I counted my money to pay her, she insulted me and then she returned her wheat from my sack. During that time I was ashamed of myself and cried about my status. After wards I never go to the market.

The other female respondent also stated,

My social relation with the society in addition to my brother, sister and other family members ceased to meet with me because of the disease. Sometimes I participated in some social activities with people surrounding me but I faced social negligence.

Almost all respondents argued that the social relation in their place was somehow good particularly to those people with leprosy. Also, they were abruptly participating in social
activities within healthy people who were living in leper colony of Addis Tesfa Hiwot. However, the social relation outside their place was very poor it is possible to say no relation. They did not go to birth place, market, wedding place and other social programs. Even, they were ashamed of when they saw guests in their place.

One of the respondents stated that

I didn’t go to healthy people but they came to me to get services. I am capable of doing everything; I am technician in health laboratory there are healthy people who need my support, why should I be ashamed of myself, why should I consider inferior to others. I was only worried for my children.

During the key informant interview session, the chairman of Addis Tesfa Hiwot Victims Rehabilitation Association told the researcher, “Because of the overlap problems many people with leprosy especially a 20 birr pensioner were not went out from their home. They faced many social challenges.”

The other informant also said, “In my point of view this people didn’t have social relation outside their place or colony”. Contrary to the above idea, one of the health workers stated that “people with leprosy in this colony shared their happiness and sadness. I didn’t see any problem in regarding social relation even though in this colony there were people who didn’t go out from their home.”

The other female informant said,

Many of this people went to wedding in the evening just not to be absent because at the day there were many healthy people and guests from other neighboring place. This
people worried at the wedding as well as in other program. I saw when they felt terrible in those places and also they worried when they picked food.

The other informant also added,

This people were not freely gone to social program even they participated in social activities in caution and blenched manner. The disease damaged their bodies due to this many of them tried to hide their damage body parts in wedding place as well as in other ceremony especially when they saw guests from other area.

All of the respondents argued that stigma in their colony were less as they compared to the outside. Even, some of the respondents told the researcher that they faced stigma even in their colony. Besides, all the respondents argued that their children denied calling their birth place because of stigma frightens.

One of the respondents said,

I excluded myself from any social participation. Most parts of my organs are damaged by the disease. I protect myself from any interaction with society. Once in transportation bus, people rumbled me and pointed their fingers at me. Some of them left the bus and some of them escaped beside me. It made me emotional and I insulted them also. It was a one what I faced and hurt on it.

The other female respondent told the researcher,

All my families dismembered me including my son and his wife disgusted me. Once up on a time, I went to my sister who lives in Debrezeit to ask and know what she thinks about me. She didn’t accept me sisterly. I felt bad and came back. I decided never to go
to her. I am highly disgusted by my families and also highly discriminated by the society even by kebele officials many times.

Also the other respondent stated,

Here in Addis Tesfa Hiwot, there are complicated attitudes. Some people hate us; some people also treat us in many cases. I don’t care anything what I saw because this place is our colony. Even my father left me in Shashemene before. He hurt me strongly at that moment which is unforgettable. I didn’t go there when I heard his death. I won’t go there to be hurt again.

The other female respondent stressed the issue, “I faced many difficulties when I was in my home land. I didn’t go to there by fear of stigma. I haven’t faced such huge stigma in this place. However, I got such problems out of this compound. They called me by the name of disease komata (��ｵﾖ㎖).”

One respondent had tried to see the issue of social stigma from a different point of view. He says,

I didn’t face stigma directly. But I saw many people with leprosy in this problem. May be for requiring my services they came to me. I don’t meet some people those came from the towns. I think they do not be happy to greet me. So, I am not happy to greet them. I know this stigma made by myself. People didn’t talk their feelings in most cases, but I think they are not happy to greet us freely. I know it by their facial expressions.

Supporting the above idea, one respondent also said, “I am not much impaired, I didn’t face many challenges and social difficulties. Even though, I saw the problems on the others. Many
people didn’t think that we can do any duty.” Generally, almost all respondent argued that stigma dominated free interaction in between family members and to other society.

One of the informants stated about stigma like this,

Leprosy affected the legs, hands, faces…etc; other people didn’t perceive this people as human being. And this people were living still in segregated place. However, this place now days filled by many healthy people because of this people were living in blenched manner. In previous time, this people met together in certain place and made enjoyments but now many people with leprosy couldn’t go out from their home. This informant also stated the issue in different perspective; he said that, stigma is caused by over lapping problems of people with leprosy. Wealthy disable people not stigmatized. I believed this people face stigma not only by disease but also by their poverty.

The other one informant also stated, “Addis Tesfa Hiwot is the specific place for people with leprosy. So, the stigma in this place is less but this people faced huge stigma outside their colony.” Contrary to the above data, one female informant told the researcher, “In Addis Tesfa Hiwot there was stigma. Many healthy people in this area including me not ate together with this people in one dish. All this inferred stigma. Not only this but also this people discriminate from other.” While the other informant opposes the above idea; he told the researcher, “I didn’t see any people with leprosy that stigmatized by other people. But few people who didn’t have awareness about the disease saw them in different manner.”
4.5 The Impacts of Parental Leprosy on Children’s Social Life

One of the finding of this study was about the experiences of people with leprosy on their children social life. Almost all respondents indicated that their children faced huge psychosocial challenges.

One of the respondents stated,

Our children can do their works, jobs, can learn with others properly, but people insulted them by saying yekomata leje (\textit{yekomata leje}) after it known they were born here in Addis Tesfa Hiwot. Most of the time, our children didn’t tell Addis Tesfa Hiwot as their birth place because they know that many of other children born in this colony faced many social difficulties. They tell Doni or Merti is their birth village. For example, my daughter lives in Addis Ababa do not tell her friends Addis Tesa Hiwot is her birth village. She tells Adama is her birth place. This is the fear of stigma.

The other female respondent told the researcher, “My son didn’t visit me for long time. Because he got married with girl whose families are free from this disease. Due to this disease there was stigma and discrimination yet in marriage established relationships. He is not happy to get together us.”

Case

One of the respondents told the researcher that how his son was psychologically and socially hurt due to leprosy. What he said is presented as follows, last year my son was married to a girl whose families are free from leprosy. Before he married her, he told her about leprosy and our status. During that time she was accepted. However, after she
came to this place and saw us everything was changed. She immediately divorced my son.

Not only had this she also insulted him.

The other male respondent stated “My children are living in Addis Ababa because of their job but I didn’t visit them at their home even when I go to Addis Ababa for treatment”.

The other one respondent told the researcher that his children were living at urban but he didn’t go to there because his children saw that many of other children faced many social difficulties after it known they born here in Addiss Tesfa Hiwot. Due to this he didn’t know his son-in-law and their children. His daughter was living in terrible condition. If her husband knows about him, his daughter marriage will be in danger.

Still the other respondent told the researcher, “My son got married with a girl whose families are free from leprosy. My relation with them is blocked. People were insulting her by offending as her husband is son of people with leprosy.” All the rest are support the above data in one way or in another. While one female respondent told the researcher differently, “My children insulted due to my status. However, my son married a girl whose families are free from leprosy. I advised him to tell her. He told and she came and visited us soon. My husband is also healthy. We are living together without any problem. We have children.”

One of the informants said, “Leprosy had huge impact on their children. Their children denied their birth place when they far apart from this colony because Addis Tesfa Hiwot was known by many people as a camp of people with leprosy”. The other informant was support the above idea and also added, “Children of this people denied their birth place to cope from many challenges. Even some of them were not support their parents due to stigma frighten.”

The other female informant told the researcher,
I was so sad for their children about their social relation with other. For instance, the first wedding criteria for many children of this people are checking whether or not their spouse families affected by this disease. If the spouse families free from leprosy, the relation is stopped.

Also the other female informant stressed by saying,

Even my children faced challenges, when they went to urban for learning, people insulted them by saying yekomata leje (የዕመታል እጅ) because the place itself stigmatized. But I am not infected person while I was working here for many years and my children were born here.

4.6 Coping Mechanisms

The other finding of this study was about how this people cope with the challenges. Four of the respondents are used praying to God as coping mechanism. In addition to this two of the respondents are used working in their garden for long time. The other one respondent stated: “When I faced difficulties for that matter, I get together with my families and friends”.

The other female respondent told the researcher differently about her coping mechanism, “I cover my legs and other infected parts of my body when I go to the town, and I am living by tolerating every challenge.’’

The other one respondent also told the researcher his coping mechanism, “I don’t go to the town most of the time that is why to don’t be depressed and to keep the other’s feeling.”

Opposing to the above coping mechanism, one of the respondents told the researcher, “I don’t be offensive for some psychosocial domination. I keep myself well; I can do whatever works as
much as any”. And also the other one respondent added, “I pass many difficulties as I didn’t hear. I preserve calmly many things.”
Chapter Five

Discussion

This chapter presents the discussion of the findings under different sub-themes in line with research objectives, research questions and the related literatures. The major themes which the researcher discusses in relation to different literatures encompasses: leprosy and its causation, the psychological challenges of leprosy, the social challenges of leprosy, the impacts of parental leprosy on children’s social life and coping mechanisms.

5.1 Leprosy and its Causation

Based on the finding of the study, all informants talked about the causes of the disease when they were asked about leprosy. All the informants were familiar with what leprosy meant and the causes of the disease. However, the researcher found out that there is much confusion among those people with leprosy.

Regarding the cause of leprosy, a lot of myths and beliefs have been involved. Many of the respondents were still believed traditionally about the causes of leprosy. Some of them used to believe that leprosy is linked with sin and punishment. Others also linked it with traditionally thinking as yebet tata (የቤት ይታ). In addition, some of them did not know about the causes of leprosy other than hearing some people’s cultural sayings. Even though, two respondents and all informants of this study knew the scientific causes of the disease. They believed leprosy is caused by mycobacterium and some of them believed leprosy is transmitted by contact from untreated patients. According to Lata and Rebecca (2006), the bacterium that cause for leprosy is a rod-shaped bacterium called mycobacterium leprae.
With regard to how people with leprosy became aware of their status during that time, the findings show that all of the respondents saw symptoms of the disease. For example, they saw red or white spot, fractures and lose of sensation on their body parts. These findings were consistent with the literature. For example, Lata and Rebecca (2006) stated that the loss of sensation in the fingers and toes raise the risk of damage. The infection of the disease is distinguished by unusual changes of the skin. These abnormal changes, called lesions, are at initial flat and red. Up on extension, they have rough shapes and a typical appearance. The lesions are usually darker in color around the ends because the bacilli grow best at lower temperatures.

Similarly, the findings of this study showed that almost all respondents had damaged body parts because of this disease. Many of them had injuries on their legs and hands even two of them were using artificial legs. And the other two respondents lost the appearance of their face. According to MOH (2008), in Grade two disability, visible deformity and damage has been identified. This includes wounds and ulcers. So, according to MOH almost all respondents of this study were graded as grade 2 disability.

From the above discussion, the researcher understood that many of the respondents still had no awareness about the causes of leprosy. However, the informants had awareness in understanding about the disease, how it is caused and transmitted. So, much should be done in making the public aware.

5.2 Psychological Challenges of Leprosy

Based on the findings, all respondents reported that they developed emotional problems. As it was shown in the findings, some of the emotional problems that people with leprosy feels were
unhappiness, depression, stress, hopelessness, and even they worried about their children. These findings are consistent with several literatures. According to the finding by Peters, et al (2012), the physical impacts of people with leprosy challenged their life and influenced their emotions and social and economic situation. Sadness, dissatisfaction, loss of confidence, losing of capacity, stress and hopelessness were some of the emotions seen due to the leprosy.

As it was indicated in the findings, all the respondents faced many kinds of psychological challenges. Besides, almost all the informants reported that people with leprosy were living in blenchd manner and they had huge psychological problems especially people with leprosy who are 20 birr per month pensioner. According to Singh (2012), persons with leprosy are excluded by the native communal and family; they are enforced to live in leprosy households. As a consequence of these difficulties persons with leprosy are related with a high danger of evolving psychiatric sicknesses. The occurrence of psychiatric sicknesses amongst those individuals with leprosy is greater than among the broad population.

The finding of this study also showed stress as a major psychological problem which people with leprosy encounter. As most of the respondents stated, the major reason for such a feeling to develop was the huge impacts of leprosy on their children. They worried about their future life. Secondly, this people were mostly separated from their families and living in a specific segregated place. According to Heru (2012), the stress of having a chronic illness can be serious, leading to emotional distress. When our lives are significantly disrupted, we often experience several emotional troubles.
According to Ruth, Elisabeth, & Atalay (2005) stated that higher prevalence of psychological distress in people with leprosy with higher disability level (Grade 2) and the existence of disability seem to raise the risk of mental distress, probably because of disfigurement. One of the respondents stated that he was strongly harmed person in Addis Tesfa Hiwot. He was not happy to meet people even people with leprosy nearby him because they were not impaired as much as he was. He separated himself. He confronted many difficulties more than others since he was the most harmed one. He felt hopelessness and he wanted to die. As it was indicated in the findings, many of the respondents of this study reported that their legs and hands were severely damaged by this disease and two of them lost the appearance of the face. Structural change from normal or deformity in leprosy is also main problem causing severe socio-economic and psychological consequences to the people with leprosy and their families. It is stated that the proportion of families having patients with deformities facing problems was ten times higher than those having patients with no deformities (Kopparty, Kurup, & Sivaram, 1995).

From the above discussion, the researcher understood that more disable people because of this disease faced huge psychological challenges which was developed by themselves because of frightens and the wrong attitude of the societies. So, it needs a lot of awareness on sensitizing the public in general and people with leprosy in particular to reduce the psychological impacts of the disease.

5.3 Social Challenges of Leprosy

Kuar and Brakel (2002) stated that people with leprosy due to bodily impairments practice restrictions, or due to observable damages or merely as a result of the diagnosis of leprosy, many people are restricted in their social participation. Long term limit in social contribution reasons
social rejection. Community upholds negative emotional state to individuals with leprosy. For example, difficulty of divorce, joblessness and dislocation from region of habitation are communal in people with leprosy (Singh, 2012).

The study which was conducted in Netherland supports the above. People with leprosy in the Netherlands come across restrictions in actions and involvement limitations which are associated to harshness of injuries (Slim, Vanschie, Keukenkamp, Faber, & Nollet, 2010). Contrary to the above the study which was conducted in Netherland stated that 54.2% of people with leprosy had no significant participation restriction and only 3.67% had great participation restriction (Singh, Sinha, Banerjee, & Jaswal, 2009).

Regarding the stigma attached to the disease and societal segregation, the finding of this study showed that all of the respondents argued that stigma in their colony were less as compared to the outside. Even though, some of the respondents told the researcher that they faced stigma within their colony. One of the informants stated that there was stigma in Addiss Tesfa Hiwot. Many healthy people in this area did not eat together with these people in one dish while she and other healthy people ate together in one dish. She said that this indicated still there is revulsion. As it was indicated in the finding Addis Tesfa Hiwot is one of a leper colony. Hence, these people did not go to the market, birth place and other social programs outside this colony because of stigma. According to them, there were so many healthy people were living together with them. Many of them stated that they did not go out from their home because of fear of stigma of healthy people within their colony and outside societies. This also argued by some of the informants. Leprosy stigma is a global phenomenon, occurring in both endemic and non-endemic countries. The effect of stigma may sort from psychosocial dysfunction to segregation, refusal and participation restriction (Adhikari, et al., 2013).
The finding of the study showed that almost all respondents did not go to their birth place as well as did not participate in social activities outside their compound. One of them stated that she faced many difficulties when she was in her birth place. She did not go there because of fear of stigma. She also faced such problems outside her compound. They called her komata (комата). As she told the researcher, she felt sad when heard such derogatory words. The societal misconception appeared in various ways, people have a wrong perception about leprosy, they consider the disease as the worst of all disabilities as seen in the expression tiliku besheta (тилику бешета). This is aggravated by a number of saying that despise people with leprosy, for instance, yezariews bered komata yasakfal (эязариев беред комата ясакфа) meaning today’s chill forces you to hag a leper. The above idea was verified by the finding of the study, as it was stated by the respondents, people with leprosy used to be nick named using derogatory terms such as komata (комата). As was depicted in the study the respondents have stated that they suffered from these societal prejudice and nicknaming.

These findings are consistent with several literatures. For instance, people with leprosy shared feeling of being sad, confused, negative comments from other because of their different appearance, feeling of pessimism and lack of motivation, and social exclusion due to dishonor (Lusli, et al., 2015). In a similar way, Birke (2004), the chairperson of ENAELP, reported that individuals have been deprived of their right to live at their residence, the right to learn, the right to get work…etc. The rejection of their rights has escalated mostly from the communal discrimination and emotional effect on those people with leprosy.

As it was demonstrated in the finding of the study, most people with leprosy were stigmatized by the society especially outside their colony even some of them were stigmatized by their family’s
According to ILEP (2011), a denounced individual can sense ashamed, which can result to worry and downheartedness. As a result of this, or of expected dishonor, they may no extend in any social activity. This in chance consequence in financial problem for the people with leprosy their households and thus cause poverty. The study found out that in Addis Tesfa Hiwot there were people with leprosy they did not go out of their home due to of self-stigma and expected stigma.

One of the respondents told the researcher that once up on a time, she went to her sister who lives in Debrezeit. Her sister did not treat sisterly because of her status and she felt bad and came back. According to ILEP (2011), experienced dishonor means an actual judgment or actions practiced by societies with leprosy. The other one respondent stated that he excluded himself from any social participation because most parts of his organs are damaged by this disease. ILEP (2011) also stated that perceived stigma refers to the development of fear with in people with leprosy where the fear may arise out of potential discrimination from family members, friends or society. As a consequence of both experienced and perceived stigma, person over a long period of time may believe that others think and say about him, resulting to the loss of self-esteem and dignity which is referred to be a self- stigma. Stigma affects the psychosocial wellbeing of people with leprosy.

The study found that most of the respondents were illiterate. The study which was conducted in western Nepal stated that the advanced supposed stigma mark was originating in uneducated leprosy patients (Adhikari, Kachler, Chapman, Raut, & Roche, 2014).

The introduction to the universal declaration of human rights, adopted in 1948, recognizes the intrinsic self-esteem and the equivalent and in alienable rights of the human being as the basis for
liberty, fairness and friendship in the world (Arega, 2004). As it was indicated in the finding of
the study, almost all respondents argued that the social relation in their place was somehow good
particularly to those people with leprosy. However, the social relation outside their compound
was too poor or it is possible to say no relationship. They did not go to their birth place, market
and other social program outside the place. The findings are consistent with several studies.

5.4 Impacts of Parental Leprosy on their Children Social Life

As it is indicated in the finding of the study, all respondents were indicated that their children
were facing huge psychosocial challenges and also the informants argued with the above idea.
Their children faced many challenges in regarding marriages, employment and education. One of
the respondents stated that her son did not visit her for long time. Because he got married to a
girl whose families are free from this disease. She said due to this disease, there was stigma and
discrimination yet in marriage established relationships. The other respondent also stated that
their children can do their works, jobs, can learn with other freely, but there was stigma after it
known they born there in Addis Tesfa Hiwot. According to him, most of the time, their children
did not tell their birth village because they knew that many children faced difficulties. In similar
ways, many of the respondent and informants shared the above findings. One informant told the
researcher that she was so sad for their children marriage. According to her, the first wedding
criteria for many children of this people were checking whether or not their spouse families are
infected by leprosy. Persons with denouncing circumstances practice challenges in their marriage
or problems in get married and in their work or being working. Their public relationship is
exaggerated, such as communal relationships and friendships. Their relatives may practice less
educational opportunities, leading to further inequalities between those affected and those who
are not (Luka, 2010).
According to Arega (2004), People of all ages whose lives have been affected by leprosy have had their most critical human rights deprived of by virtually every culture and major religion throughout time. Some of the basic rights denied include: The right to liberty of movement; the right to relations; the right to education; the right to work and the right to freedom from humiliating treatment.

5.5 Coping Mechanisms

The study showed that the various mechanisms of people with leprosy, in Addis Tesfa Hiwot, used to cope with difficulties. For instance, four of the respondents used to pray to God and the other one used humor as coping mechanism and also the other two respondents used working in their garden as a method. The rest of them also used different mechanisms as it was indicated in the finding. In a similar way, Heru (2012) stated that coping mechanisms that many people with leprosy find useful. Each person will also have developed individual ways of dealing with stressful situations. Emotional support is another coping mechanism that is helpful to all people. Support comes from relatives, friends, families, medical staff, counselors, priests, and so on. Activity is another very helpful means in coping with illness. People with leprosy may sense weak and exhausted, while staying in bed often worsens the fatigue and weakness; it can also lead to deep feeling of boredom. Activities such as physical therapy and relaxation exercises are also important coping mechanisms. On the other hand, for some people humor is a very powerful way of coping but for others, religious faith provides comfort and hope. Even though most people with leprosy can eventually find ways to adequately cope, looking forward to a time of improved health.
Chapter Six

Conclusion and Recommendation

6.1 Conclusion

In the study, it was found that a great number of respondents did not have awareness about the cause of leprosy. Still, many of them assumed leprosy as punishment of God, *yebete tata* (*mynm ኦ البعيد*), and *lekefete* (*አክፈተ*). This indicates such people did not have awareness about the cause of the disease even though they lived in leper colony for many years while all the informants of this study had awareness about leprosy.

Almost all the respondents developed low self-confidence, felt stress and sadness, and worried for their children. Besides, a great number of the respondents were stigmatized by outside societies even some of the respondents were also stigmatized within their colony. People with leprosy viewed their life and the way in which they conceptualized the disease was the major factor for their psychological and social challenges.

The psychosocial challenge of leprosy had upsetting effects on the wellbeing of people with leprosy and was much higher degree than its physical impacts. The challenges were worsened by social problems with extreme dimensions such as ignorance, fear, and stigma. Because of fear and stigma many of the respondents blocked their social relation especially outside their colony even many of them didn’t go out from their home.

Many of people with leprosy in Addis Tesfa Hiwot lived in terrible condition. They did not go freely to the market, birth place, and other social programs. Their social relation was in danger especially outside their colony. Thus, this people lead their life with difficulties as it is indicated above.
Many of the respondents told the researcher that their children faced huge psychosocial challenges because of them. The study indicated even their children hide their birth place when they go to urban for job and education and developed low self confidence and fear because of their parents’ status.

They were coping their life by farming in a small plot of land, discussing with their peer groups and particularly praying when they faced difficulties.

In general, psychological and social problems were the main challenges in Addis Tesfa Hiwot leper colony. Most of the people in this colony need governmental, nongovernmental and any other social supports.

6.2 Recommendation and Implications

The finding of this study indicated that there was a misconception regarding the cause of leprosy. So, the researcher believes that it is necessary to give awareness about leprosy for the public in general and people with leprosy in particular by education, training, media and workshops.

Since the study also showed that many of people with leprosy in Addis Tesfa Hiwot did not go out from their home because of anticipated stigma, self stigma and economical problems. Therefore, the government and nongovernmental organizations should take action in the plighting such elderly people from their overlapping problems.

In order to alleviate the psychological and social impact of the disease, people with leprosy, their children, Ethiopian National Association of Ex-Leprosy Patients and the general public have to combat negative stereotypes about leprosy and also strongly cooperate to decrease the effects of the disease.
This study found that the major challenges of people with leprosy and their children is the social stigma. The researcher recommends that their association, Ethiopian National Association Ex-Leprosy Patients, should perform a lot to build up self confidence of people with leprosy and their children by cooperating with several stakeholders and NGO’s.

In general, social psychologist should involve rehabilitating people with leprosy by breaking their cultural, social, psychological problems by creating awareness among the society of the misconception and fear of people with leprosy. The researcher believes that it is essential to conduct a research on the psychosocial challenges of people with leprosy. Because the findings are used as in put for intervention plan and policy implement.

Besides, the study focused in one segregate leper colony. Therefore, a macro level study that incorporates in many areas of people with leprosy would help to arrive at various results that might help to introduce better strategies to reduce the psychosocial challenges of people with leprosy.

Hence, the main challenge of leprosy is social stigma and its consequences. Many strategies have to be exerted at policy level. Therefore, the government, Ethiopian National Association of Ex-Leprosy Patients and nongovernmental organizations have to implement stigma reduction programs and give more attention for elder people with leprosy. Here social psychologist should play the role in changing the misconception of the societies about leprosy and in turning the wellbeing of people with leprosy through continues treatments.
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**Appendix E Informed consent**
Addis Ababa University

School of Graduate Studies

College of Educational and Behavioral Studies

School of Psychology

Date ..........................

Place ........................

Time ........................

Consent Statements

You are being invited to participate voluntarily in the study entitled the psychosocial challenges of people with leprosy in Addis Tesfa Hiwot. My name is Banchiamlak Biyadeglen. I am a master’s student at Addis Ababa University School of psychology.

The purpose of this study is to gather information on how your experience is on the psychosocial situation. You will be asked to discuss your experiences and feeling regarding the psychosocial challenges of leprosy. You know that your interview will be recorded. The interview will take approximately 45 minutes to 1 hour of your time. First of all you will be asked some personal questions including your age, marital status, religion, level of education and place of origin. The interview will take place in a convenient place. You can stop the interview at any time and can end your participation in this study if you wish. You are free to ask questions and receive answers at any time throughout the study.

The risks related to this study are possible emotional trouble during sharing your experiences. If you become emotionally trouble for the period of interview, you can stop the interview and begin again the interview at later time.
The information from this study may help to understand the psychosocial challenges of such people and to indicate directions to the government and nongovernmental organizations. There is no any benefit to you for participation.

The information you will share, will be kept in secret. The finding of this study will be presented and reported to Addis Ababa University of the school of psychology. When the findings are reported you will not be identified. You will be assigned with a pseudonym to protect your confidentiality.

So, are you voluntary to participate in this study? If yes, please your signature.

Participant’s signature ……………… Date………………

Thank you so much for your participation!

Appendix A Interview guide for respondents (English version)

Addis Ababa University

School of Graduate Studies
In-Depth Interview Guide for People with Leprosy

Part One: Personal Information

Age……………..

Sex…………………..

Marital status…………………….

Educational level…………………….

Place of origin………………………

Religion…………………………..

Part Two: Leprosy as a Disease

1. How do you know you have leprosy? Was there any symptom that led you to go to hospital for a test?

2. Which part of your body was affected?

3. Where and how did you get the diagnosis and treatment during that time?

4. What do you know about leprosy? What are the causes for it? Do your families know about leprosy?

Part Three: Leprosy and its Psychological Challenges

5. How do you feel about the psychological influence of leprosy?

6. Have you ever felt different conditions because of leprosy and its consequences? Like stress, depression, anxiety, sadness… etc.

7. How does your condition affect your personal relation with the family, community and society? Does it bring behavioral change on you? If there is any, can you tell us?
Part Four: Leprosy and its Social Challenges

8. What are the major social problems you face? How would you explain your social experiences?

9. Have you or your family experienced any benefit loss from social services because of leprosy? Can you explain some of those experiences?

10. Did you face any kind of discrimination and stigmatization for being affected by leprosy? If yes, can you explain your experiences?

11. Do you think these social stigma and discrimination restrict your social relationships?

12. How do you explain your experiences regarding to your child marriage, education and job opportunities?

13. Do you think social stigma and discrimination affect your family? If yes, how? Can you explain it?

14. How do family members respond to your condition? How about neighbors & the community?

15. What are the major problems in integrating yourself with the community?

16. What coping mechanisms did you use to overcome these problems?

17. What do you suggest for improving the psychosocial situation of people with leprosy?

Appendix C Interview guide for informants (English version)

Addis Ababa University
School of Graduate Studies
College of Educational and Behavioral Studies

School of Psychology

Interview Guide for Key Informants

Part One: Personal Information

Age-----------------

Sex…………………..

Marital status …………………..

Educational level…………………..

Place of origin………………………..

Religion………………………………

Part Two: Questions Regarding Psychosocial Challenges of People with Leprosy

1. What do you know about leprosy? What are the causes for it?

2. What are the major psychosocial challenges faced by people with leprosy?

3. How do you express the social relationships of people with leprosy?

4. What is your experience on leprosy related social stigma and discrimination?

5. What do you suggest for improving the psychosocial situation of people with leprosy?

Appendix B Interview guide for respondents (Amharic version)
 Challengers of People with Leprosy

1. Name: __________

2. __________

3. __________

4. __________

5. __________

6. __________

7. __________

2. How many people are affected by leprosy? and why? (in terms of disease, illness, or similar)

3. How are people living with leprosy treated?

4. How are people living with leprosy identified?

5. How are people living with leprosy identified?

6. How are people living with leprosy identified?

7. How are people living with leprosy identified?
Appendix D Interview guide for informants (Amharic version)
迦 ха: ይጠቅረ ከፋዳ

ስበር ከላይ ጥር ይህን ይህ ምስ ያለበት

ስስ ፋ ርል በላይ የተሰረተውን ያሉ ወለት

ፋት ስም

ፋት በታ ስም

ፋት በታ ሲሆን

ፋት በታ ሲሆን

ስስ ፋ ርል ከላይ የተሰረተውን ይህ ወለት

1. ከል የሚገሩ ህስታዊ ሦት ይህ የቃል ይሱ?
2. የተነጋገር የሚገሩ የለው ከላይ ይህን ያስታወቃል ይህ የሚገሩ ይህ የቃል ያቅርብ ይሱ?
3. ይህንን ከላይ ከላይ የተሰረተውን ያረ ይህን ያስታወቃል ይሱ የሚገሩ ይህ የቃል ያቅርብ ይሱ?
4. ከስጋ ህስታዊ የለው ከላይ ያስታወቃል ያስታወቃል ይህን ያስታወቃል ይሱ?
5. ከስጋ ህስታዊ ያስታወቃል ያስታወቃል የሚገሩ ያስታወቃል ያስታወቃል ያስታወቃል ይሱ?