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**Assessment of the Impacts of Stigma on Leprosy Affected People: The Case of Beneficiaries
in Ethiopian Catholic Church Medihn Social Center, Addis Ababa, Ethiopia**

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Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ALERT	All African Leprosy, Rehabilitation and Training Center
HIV	Human Immune –Deficiency Virus
MoH	Ministry of Health
GLRA	German Leprosy Relief Association
MDT	Multi-Drug Therapy
WHO	World Health Organization
ENAPAL	Ethiopian National Association of Persons Affected by Leprosy
ILEP	International Leprosy Association
FGD	Focus Group Discussion

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Abstract

Stigma related to the chronic health conditions such as HIV/AIDS, leprosy, tuberculosis, mental illness and epilepsy is a global phenomenon with a severe impact on individuals and their families, as well as on the effectiveness of public health programs. This study focuses on stigma related to one of these health conditions, i.e. leprosy. The study mainly explores the lived experience of leprosy affected people, with special emphasis on the impacts that leprosy stigma has on those people. The purpose of this study is to broaden our understanding of leprosy stigma, its impacts and dynamics, its extent or severity in our country. The study was done in the organization, Ethiopian Catholic Church Medihn Social Center. Qualitative data was gathered using in-depth interview, focus group discussion and key informant interview. Published and unpublished studies, electronic documents, and books have been broadly reviewed.

The finding of the study mainly indicates, even if there are some improvements on the awareness of the community towards leprosy affected people, people living with leprosy are victims of stigma throughout their life as well as in their current situation. Due to stigma, they are facing various problems. Their social, economic as well as psychological well beings are strongly affected. They do not have good relationship with their families, their neighbors, their friends. Their economic status is strongly affected as well. They have restricted participation in different community organizations. The study implies that these people need much attention from the government and the community. Based on this, the research recommends the need for a broader and multilevel intervention that will help to reduce leprosy stigma and its impacts which helps to enhance the well-being of leprosy affected people.

Chapter One

1. Introduction

1.1. Background

Leprosy or Hansen's disease is a chronic disease caused by the bacteria *Mycobacterium leprae* and *Mycobacterium lepromatosis*. *Mycobacterium leprae*, the causative agent of leprosy, was discovered by G. H. Armauer Hansen in 1873, making it the first bacterium to be identified as causing the disease in humans (WHO, 1995).

Leprosy mainly affects superficial tissues especially the skin and peripheral nerves. It affects nerves by causing inflammation that leads to loss of function. The number of individuals who have suffered its chronic course of incurable disfigurement and physical disabilities due to nerve damage can never be calculated. Cells become infected and unable to regenerate causing trauma and infection, which in turn lead to deformity. Patients develop nerve damage either before diagnosis, during treatment or after completion of treatment (Lockwood, 1998).

Despite great advances, leprosy is still a problem in many countries. It is estimated that between 11 and 12 million people living in the world today are suffering from leprosy. Two to three million people are estimated to be permanently disabled because of leprosy. Although most of that number will not now have active disease, for many the stigma of leprosy is still real and needs to be addressed. It is simply not enough for the medical profession and society to treat the disease and ignore the patient as a whole person. Many leprosy patients, despite their leprosy being dealt with, are still living a sub existence, mere shadows of their former selves and their true potentials (Link, 2001).

Ethiopia has suffered from a high incidence of leprosy since the time immemorial. Its existence is well documented in the rich travel literature all over the country. Due to the fact that

Ethiopia is one of the historical countries, it may also be a fact that it is one of the countries with the origin of the leprosy disease (Pankhurst, 1984).

With the introduction and expansion of Multi Drug Therapy (MDT), the prevalence of the disease has dramatically decreased in all endemic areas. However, the notification of new leprosy cases remains constant over the past ten years. There are three main regions where leprosy is still endemic: Oromiya, Amhara and Southern Nations Nationalities Peoples of Ethiopia (WHO, 1995).

Leprosy was identified as a major health problem in the country since the 1950's. Since then, the effort to control leprosy began by the establishment of a National Leprosy Office in the Ministry of Health (MoH) with the support of German Leprosy Relief Association (GLRA) (ENAPAL, 2007).

MoH has integrated the leprosy programme within the general health services. The integration service covers a wider geographical area and is closer to the community. This integration is believed to reduce the stigma associated with leprosy, and this again helps to divert the negative awareness and attitude that has existed for years and has been observed as a major social problem. However, there is still much to be done if the underlying menace of stigma is to be dealt with. Stigma is causing problems for the treatment of leprosy. To prevent discrimination, patients try to hide their disease by not immediately seeking medical help (WHO, 1995). According to Alemayehu (1993:3),

Leprosy is a social disease that has left behind terrifying images of mutilation, rejection and exclusion from the society. It leads to progressive physical, psychological and social disabilities because of the stigma associated with the disease. Many people in developing countries have difficulties in accepting the disease due to misconceptions, stigma and superstitions they have towards the disease. This makes leprosy affected people reluctant to go to clinics for examination even after being diagnosed.

Leprosy and stigma have been almost synonymous. For centuries, leprosy was a feared disease, the very word invoking shame and disgust. People with leprosy may lose their employment because of the stigma and the disabilities due to the disease. When this happens, they lose the means of supporting their families, and often the respect of their communities. This in turn leads to loss of self-esteem. Many patients are affected mentally, not because of only the disease, but because of the society's rejection, fear of rejection or lack of acceptance of the condition (Jopling, 1991).

The Ethiopian society seems traditionally unaware about the cause of leprosy. Most people regard it as inherited complaint. And they sought to cure it in numerous ways. They use prayers and amulets, traditional medicines for internal and external applications, medical vapor baths and immersion by thermal pools (Elizabeth, 2012).

In Ethiopia, living with leprosy has enormous social implications. Though it is not contagious, contracting the disease forces most people to a solitary life, or at best, into a leper community which are found throughout the country. Lepers in large measure are isolated from the rest of the population, but are permitted to beg around churches. In general, the affected people have high psychosocial problems (Elizabeth, 2012).

This study intends to assess the impacts of stigma on people affected by leprosy. Thus, it focuses on examining leprosy stigma and its socio-economic and psychological impacts.

1.2. Statement of the problem

Considering the impacts of the problem of leprosy in the society, the value of a research on this subject in yielding a modest understanding is undeniable. A number of studies regarding the problem of leprosy in Ethiopia have been carried out. For example, Mengistu (2000) has investigated the knowledge and attitude of health professionals towards the leprosy patients in

ALERT Hospital and showed how it affects the lives of patients. Rosalijn (2007), while interviewing women affected by leprosy in Addis Ababa, investigated how the disease affects all aspects of life of affected people, especially women. Anandaraj (2004) also touched four areas related to stigma and its impacts: “stigma on leprosy patients affects their family relationships, vocational conditions, social interaction, and self-esteem” (ENAPAL, 2007:13).

However, there are still few researches done regarding the socio-cultural and psychological aspects of leprosy and leprosy stigma. Addressing the disease in a broader context can improve the health outcomes of people with leprosy, while helping to curb stigma. In view of the visible gaps and information limitation of the community on the disease, it is prudent that this research sparks a timely enquiry by investigating the current situation and the level of stigma. Since leprosy stigma is fundamental and serious issue, bridging such knowledge gap on the disease is essential. Accordingly, this research attaches great importance in assessing the impact of leprosy stigma in the community. Thus, it answers the question, “what is the burden of stigma on people affected by leprosy?”

1.3. Objective of the study

1.3.1. General Objective

The general objective of this study is to assess the problem of stigma on leprosy affected people and its socio-economic and psychological impacts on them. In line with this general theme, the following are specific objectives of the study:

1.3.2. Specific Objectives

- To assess the stigma experience of leprosy affected people
- To analyze the current situation of leprosy stigma.
- To examine the impacts of stigma on leprosy affected people.

1.4. Significance of the study

Now a day, education and media campaigns counteract false beliefs about leprosy and raise awareness of new advances in the field. Leprosy care is increasingly provided in an integrated setting showing patients and their communities that leprosy is not a disease apart. Physical and socio-economic rehabilitation is worthwhile in restoring self-worth and status in the community and helps patients to find employment. Gradually, attitudes towards leprosy are changing. However, there is still much to be done if the underlying menace of stigma is to be dealt with. “Certainly more research is needed. Perhaps with effort, we will one day be able not only to treat the disease but also to cure the stigma of leprosy and make that road an easier one” (Joy, 2005:1).

This thesis accordingly, has a great importance in policy formulation with regard to development planning in general and surveillances to speculate factors to instigate outbreak of the stigma. Indicating how the communities participate on reducing stigma is also the benefit anticipated from this research.

This study also gives a worthwhile insight for further studies by investigating the current situation of leprosy affected people. As the subject of leprosy stigma is too broad, this small research perhaps may not adequately address the multi-dimensional aspects of the problem. Nevertheless, it could pin-down clues and identifies opportunities for further investigations with the purpose of designing more effective stigma reduction interventions. It is also useful to assess stigma in a compressive way which would enable to increase our understanding of the dynamics and effects of stigma, with the purpose of designing more effective stigma reduction intervention.

1.5. Limitation of the study

Although the research has reached its aim, there were some unavoidable limitations. First, although it is very important to look into different aspects of leprosy affected people's experience, this study focuses on the socio-economic and psychological effects of stigma. This is because of researcher's interest to the specific issue and also because of resource and time constraints to deal with other issues of leprosy.

The other limitation was that, since the informants of the study were selected from the beneficiaries of Medihn Social Center, this may result the selection bias, possibly resulting in exclusion of the most stigmatized patients who may not have reached this organization.

1.6. Definition of key terms

In order to have unambiguous understanding on key terms which are repeatedly stated throughout this research paper, definitions are highlighted below:

Health: according to WHO (2003), health is the state of complete physical, mental and social well-being of a person and not merely the absence of disease or infirmity.

Leprosy: Link and Phelan (2000:3) defined leprosy as "a chronic human disease with potentially debilitating neurological consequences, results from infection with *Mycobacterium leprae*." Leprosy is primarily a disease of the peripheral nerves and mucosa of the upper respiratory tract. Skin lesions are the primary external signs. Left untreated, leprosy can be progressive, causing permanent damage to the skin, nerves, limbs and eyes.

Stigma: According to Sabir (2010:1), stigma is a social process or related personal experience characterized by exclusion, personal blame or devaluation that result from experience or reasonable anticipation of an adverse social judgment about a person, or a group. It results unjustifiable different treatments given to different people or groups by the society. Stigma

impedes recovery by eroding individuals social status, social network and self-esteem, all of which contribute to poor outcomes including unemployment, isolation, delayed opportunities, lack of seeking treatment, and avoid social interaction. Goffman (1963:34) postulated:

Stigma occurs when the construction of categories is linked to stereotyped beliefs that label and distinguish people as different or unacceptable. He further defined stigma as the situation of individual disqualified from full social acceptance and it is an attribute that is deeply discrediting and that reduces the bearer from a whole and usual person to a tainted, discounted one.

Jopling (1991:34) further stated that, stigma can result from the perception of mental illness, physical disabilities, diseases such as leprosy, illegitimacy, gender identity, skin tone, education, nationality, ethnicity, religion, and criminality.

Leprosarium: are leper colonies or lazar houses, a place to quarantine people with leprosy (Saikawa, 1992)

Chapter Two

2. Review of Related Literature

2.1. Historical Background of Leprosy

The origin of leprosy is important epidemiologically and historically. Knowing the origin and spread of leprosy could help to understand human interactions as well as the biological and social reaction to the disease. The English word 'leprosy' comes from the Greek word '*lepros*', meaning scaly. Scholars argue that leprosy in the bible is not necessarily leprosy as it is known today. It was some form of skin disease that was considered 'unclean'. In Europe during the middle ages, leprosy and many other afflictions like syphilis were viewed as 'unclean' (Catalina, 2009).

Leprosy must be one of the worst diseases we cannot imagine. However, the reality of leprosy today can be very different, and many of these images are based on ancient prejudices. Understanding the history and origins of this disease and its antiquity may help us to understand the true causes of the stigma as well as to understand the relationship of the disease to its human host. In the bible, the term leprosy refers to a condition of moral uncleanness and ritual impurity. Early Christian commentators interpreted the passages in the bible relating to leprosy within a framework of sin and divine punishment, so that leprosy became an outward sign of inner evil and of sins like greed and lust (Lewis, 1987:3).

One of the earliest well-accepted textual descriptions of leprosy may come from texts found in the Chinese tomb of 'Shui-hu-ti' and dated between the fourth and third centuries. Legal and medical texts from 300 BC in India also described leprosy. However, there is no concrete evidence of leprosy in the Mediterranean countries until far later, which may indicate that it was not yet present. Writers of these ancient sources believed, in fact, that the origin of leprosy was in Egypt (Catalina, 2009).

According to Nick Anderson (2006:24), "leprosy is believed to have existed in Egypt as long ago as 4000 BC. Leprosy has affected humanity for over 4,000 years and was well

recognized in the civilization of ancient China, Egypt, and India.” Catalina (2009:11) further noted that leprosy is:

One of the oldest maladies and is well recognized in the oldest civilization of China, Egypt and India as a contagious, mutilating and incurable disease. The humans feared it because it resulted in disfigurement and physical disabilities, which are irreversible. Leprosy is also associated with a lot of stigma and in ancient times the community shunned people affected with leprosy into separate colonies.

Leprosy spread to the Mediterranean and Europe through the maritime slave trade, which brought slaves from India and Egypt around the 4th and 3rd centuries BC. Children, who were more susceptible to leprosy and who may have been sold precisely because of their disease or that of their parents, in confined conditions for prolonged periods of time or in prolonged contact during household work, would easily spread the disease. In Europe, there is evidence of leprosy in Germany by 450 to 680 BC, with more males than females affected, potentially indicating different exposure to the disease, and with a high proportion of the people living long after infection (Catalina, 2009).

Leprosy became an epidemic since early time of its spreading. WHO estimated, approximately 410,000 new cases of leprosy were detected worldwide during 2004. Between two and three million people were permanently disabled because of leprosy. In the past 20 years, 15 million people worldwide have been cured of leprosy (WHO, 1995).

Leprosy is also an endemic disease in some countries including China, India and Iran. The incidence rate of leprosy was one in thousand people in 23 countries in 1998. But the prevalence rate of 16 of these 23 countries is over than 3.9 in thousand. In India, more than 400,000 new cases are detected every year. Although, the mortality rate of the disease is not

high, the deformity and disability of leprosy patients is significant community health problem (WHO, 2003).

As WHO (2010) reports, recently leprosy affects a large populations in developing countries particularly in Africa, Asia and Latin America. So there are more than 249 thousand new leprosy patients mainly from Asia and Africa, but the number of cases had reduced from almost 5.4 million in 1985 to less than one million cases in 2002. Leprosy transmission is reduced slowly with a range of annual decline from 2 to 12%, using the eradication strategy. The main key factor of this achievement was early diagnosis and treatment. Also deformity rate of leprosy patients is reduced using early case diagnosis in screening method.

Even though recent reports of the World Health Organization present encouraging numbers on the prevalence of leprosy, in 1994 over 42 African countries were highly endemic. “Although the numbers are drastically declining, it is much more than a medical problem due to the complex and troubling nature of leprosy. However, the socio- cultural as well as psychological factors of the disease are neglected” (Rosalijin, 2006:1).

Effective treatment for leprosy appeared in the late 1930s with the introduction of the drug called ‘dappson’ and its derivatives. However, leprosy bacilli became resistant to dappson and due to the resistance, the disease became widespread. The disease was not diagnosed until the introduction of Multi Drug Therapy (MDT) in the early 1980s which treated the disease successfully in the community (Smith, 2008).

2.2. Leprosy in Ethiopia

Evidences suggest that leprosy has been prevalent in Ethiopia for Centuries. Those evidences are well documented in travel literatures. The Portuguese priest, Francisco Alvares, the first foreign observer to write a comprehensive account of the realm in the sixteenth century,

as cited in (Pankhurst, 1984:57) testified that, “it was inhabited by many leprosy affected persons.” The more numerous observers of the nineteenth and early twentieth century indicated that, little has changed in the intervening years. A British resident Nathaniel (1831) declared that, “in north of the country, infection was very common among lower classes and that there were thousands who had lost their fingers and toes and whose bodies were covered all over with large white spots” (Pankhurst, 1984: 57).

The history of leprosy in Ethiopia seems to have followed unique routes. Initially, people with leprosy were not segregated and their movement was not restricted. Helping people with leprosy was highly valued, and the church and rulers of Ethiopia tolerated leprosy affected people and provided them with charity. However, at the beginning of the 20th century, with the emergence of leprosaria and the spread of euro-centric explanations of leprosy, this positive attitude was challenged. The new leprosy discourse challenged the previous attitude of people as shaped by the Ethiopian Orthodox Church. Thereafter, Ethiopian rulers facilitated the emergence of leprosaria and the subsequent segregation of people with leprosy. This was exacerbated as the educated elite spread fear among the people by disseminating exaggerated information (Mesele, 2001). Next to the travel accounts,

The bible played a major role in spreading images about leprosy. Missionaries in Ethiopia had the bible translated to Geez at a very early stage. In the Geez and Amharic translations of the bible, leprosy is often referred to as lams. In other Ethiopian literature terms like ‘*qwesale sega*’¹ or ‘*sega dewe*’, ‘*qumtenna*’,² and ‘*tilik dawwe*’³ are frequently used as well (Rosalijin, 2006:17).

Regarding cures for illness, innumerable varieties of traditional medical cures were and still are in widespread use for leprosy in Ethiopia. “The national Ethiopian rural health survey

¹‘*qwesale sega*’(‘*sega dewe*’): wounded , impaired or diseased body

² ‘*qumtenna*’: Amharic word meaning to impaired body

³ ‘*tilik dawwe*’: Amharic word meaning to a big disease

from 1982-1983 revealed that more than half of all Ethiopian health seekers utilized traditional healers” (Rosalijin, 2006:20).

When we come to the modern treatment, during the period 1955-1961, a UNICEF supported program on leprosy started operating in Ethiopia. At this time, care of leprosy patients was carried out by the princess Zenebework Hospital, Shashemene Hospital, and 12 provincial clinics. In the late 1950’s, to expand treatment of leprosy, four leprosaria were established: Bisidimo in Hararghe region, Boru Meda in Wollo, Gambo in Arsi, and Gendeberet in Shoa region (Ashenafi, 2007).

In 1970 the Ministry of Health (MoH) approved a policy of leprosy control and integration service for the whole country. The main objective of the policy of leprosy control was to increase coverage and improve the quality of services offered to reduce the prevalence and incidence rates of the disease. And with the introduction of Multi Drug Therapy (MDT), in 1983, there achieved 100% coverage of registered cases and the prevalence of leprosy decreased (ENAPAL, 2007).

In 1994, the country’s Ministry of Health introduced the programme of “Combined Tuberculosis and Leprosy control.” The program objectives were: to interrupt transmission of the infection, to reduce morbidity, mortality, disability and to prevent emergence of drug resistance. In view of this, leprosy patients were diagnosed and treated in all health facilities together with other patients. This is a breakthrough in the abolition of stigmatization and specialization of vertical services (Elizabeth, 2012).

WHO reported that currently leprosy is not a major public health problem in Ethiopia, as the prevalence rate has gone down. Despite of this, the alarming note is constant, 14.8% new

patients with disability have been noted, which is very high. In addition, nerve impairment in Ethiopian leprosy patients is as high as 65.5% in patients (Lockwood, 1998).

Further ILEP (2013) reported that at the end of 2009 leprosy prevalence in Ethiopia is 4,942 (0.6 cases per 10,000 populations). And the following table shows the prevalence rate of leprosy in Ethiopia from year 2000-2009.

Table1. Ethiopian leprosy case notification: 2000-2009

Year	New cases
2000	4,732
2001	4,584
2002	4,940
2003	5,193
2004	4,787
2005	4,698
2006	4,092
2007	4,187
2008	4,414
2009	4,302

Source: ILEP (2013)

2.2.1. Popular attitude towards leprosy in Ethiopia

The biblical ideas found their way to influence Ethiopian society's beliefs and thoughts about leprosy. For instance, the miraculous healings become a major theme in Ethiopian literature. The Ethiopian belief in miraculous healing also partly explains the dominating tolerant attitude towards leprosy. According to Rosalijin (2006:18),

The Ethiopian Orthodox Church did not always copy the Old Testament traditions on leprosy. Instead, a tolerant social environment developed in Ethiopia that was significantly different from the rest, the Judeo-Christian world. A couple of factors can explain this. First, the Ethiopian church taught that leprosy was a test of faith. Those who have been suffering from illness in general are believed to be rewarded in the hereafter. Equally, others can also be rewarded in the hereafter based on their charity towards these people.

This attitude was very crucial on molding sympathetic social concern towards the patients. Christian charity became an important culture. Handicapped people, who in many African societies remained unseen in their villages, were led in Ethiopia to display their sufferings in order to benefit from Christian charity. This attitude also explains why people affected by leprosy were so often found near churches, in quest of alms and miraculous cures

The Fetha Nagast (the law of the kings), containing the traditional laws of Ethiopia, made another important contribution to the tolerant atmosphere in Ethiopia towards leprosy by taking a humanitarian view of the disabling disease. A good example of this is the statement made towards marriage. The code rejected the idea that leprosy was a disablement and affirmed that marriage to a person affected by leprosy was a decision entirely for the would-be-spouse. However, it seemed a different issue if the disease developed after marriage, in which case a man was allowed to separate from his wife, but only if he gave her a complete outfit and dowry (Rosalijin, 2006).

In addition to these, tolerant values and ideas, spread by the law and the Church, the people kept their own opinions about leprosy. This was partly due to the great amount of illiteracy and lack of knowledge about the disease. The people of Ethiopia held hundreds of ideas about the causes of leprosy, the main are: a blow from the devil, adultery by moonlight, intercourse during menstruation, spirit possession and heredity. Contagion was not seen as one of causes, and that was a huge contributor to the tolerant attitude of the time. Ideas about the contagious of leprosy changed during the 20th century, and together with that the attitude of the people changed. Until then leprosy patients were mostly regarded as objects of pity, even of sympathy among many Christians (Lewis, 1987).

2.2.2. The rise of leprosaria in Ethiopia

“Though there are no written records, there is evidence that leprosaria began forming in Europe by the 12th century, as out growths of earlier charitable enterprises by the church” (Walker, 2006:21).

Throughout the world, leprosy has been viewed as a mysterious and frightening disease for a long time. This was partly because leprosy was not fully clinically described until the

1840s. The discovery of mycobacterium leprae by Dr. Armauer Hansen in 1874 established leprosy as a bacterial disease. This had far-reaching consequences, as can be illustrated by the first International Leprosy Conference of 1897 which declared that isolation is the best means of preventing the spread of the disease. Leprosy was also officially declared virtually incurable. A policy of quarantine and segregation arose based on the fear that leprosy could not be contained and was about to become endemic. As a result, isolated leprosy villages and colonies were established (Rosalijin, 2006).

These ideas and practices found their way to the African continent through colonists. It took a long time before this happened in Ethiopia, partly because the country was never really colonized. However, two processes contributed to the rise of leprosy in Ethiopia and when taking a close look at them, it becomes clear that Western ideas played a major role in Ethiopia after all. First the media played an important role.

Melaku, a journalist at the Amharic Weekly (Brhanenna Salam, 1925-1936), took an active part in calling for segregation. As a former student of chemistry and medicine in the United States, he compared their segregation policy with the tolerant climate towards leprosy in his own country of Ethiopia. He condemned the Ethiopian traditional conceptions urging the seclusion of patients from society. He also declared that leprosy was an actively transmitted infectious disease stressing the need of an immediate segregation of the patients from the society as a solution to the problem (Rosalijin, 2006:22).

Another important contributing factor to the rise of leprosy in Ethiopia came from Emperor Haile Selassie I (1930- 1974). He immediately searched for possibilities of establishing a leprosarium near Addis Ababa. Missionaries also played a major role in the establishment of leprosy in Ethiopia, moved by a need to preach the gospel and Christian compassion to those affected by leprosy (Rosalijin, 2006).

The very first leprosarium in Ethiopia was St. Anthony's, founded at Harar in 1901, by Ras Makonnen. Despite its success, no other leprosy were set up for several decades. The

delay was mainly caused by the widespread Ethiopian belief that leprosy was a God-given, inherited disease that was not contagious (ENAPAL, 2006).

It took until the 1930s before the second leprosarium was established. This one was outside the capital of Addis Ababa and was officially inaugurated by Haile Selassie in 1933. Later on it was given the name princess Zenebework, after the daughter of the emperor. At first, only some 80 to 100 persons were admitted. This changed after the invasion of the Italians in 1935. At the princess Zenebework leprosarium, the number increased to more than 100 inmates. Commencement of modern treatment in the late 1950s again caused movement of people towards the leprosaria (ENAPAL, 2006).

As a result, the princess Zenebework leprosarium became a scene of humanitarian misery, which the government closed to the public and foreign visitors. Finally, the government had to give in and it asked for assistance from religious and humanitarian organizations to establish new leprosaria in the 1950s and 60s. Inhabitants from the princess Zenebework leprosarium and from St. Anthony's were then moved to the new leprosaria, due to the population pressure. This happened involuntarily and those who moved were capable of walking, tried to escape from their new homes (ENAPAL, 2006).

Things changed for the princess Zenebework leprosarium in the 1960s when three international organizations, International Society for Rehabilitation of the Disabled (ISRDI), the American Leprosy Mission (ALM), and Leprosy Mission London looked for a suitable area for a training center for teaching the social and clinical aspects of leprosy. Their aim was to establish a training and research center in Africa in which students from all over African countries shall be trained in treatment and rehabilitation of leprosy patients. As a result, ALERT (All African Leprosy, Tuberculosis Rehabilitation & Training Center) took full responsibility for running the

leprosarium in 1967, and constructed a new, larger hospital. Then in 2001 the Ethiopian government took over full responsibility on the hospital.

2.3. Overview of Leprosy Stigma

According to Anandaraj (1995:18), “Stigma is an attribute that is deeply discrediting, leading to a spoiled identity. In terms of human suffering, the consequences of stigma often outweigh the burden of physical afflictions.” Many people live happily with severe physical impairments, as long as they are accepted, respected, and loved by those around them and are able to function and participate meaningfully in the society in which they live. Hetherton (2000:3) further points out that:

Stigmatization is personally, interpersonally, and socially costly. It is a social construction that involves at least two fundamental components: firstly, the recognition of difference based on some distinguishing characteristic, and secondly, a consequent devaluation of the person. Stigmatized individuals are regarded as flawed, compromised and somehow less than fully human.

Stigma can take on different faces. Stigma is called enacted when the person actually faces the effects of stigma, such as discrimination, rejection, physical abuse, loss of employment, or divorce. Although enacted stigma against leprosy is now less common than before, it still affects countless people worldwide. Even people related to or working with those affected may experience such stigma (Andaraj, 1995)

‘Perceived’ or ‘felt’ stigma (‘self-stigma’) refers to the fear of enacted stigma. Perceived stigma is a very widespread phenomenon which may disrupt people’s lives even more than enacted stigma. Perceived stigma may cause emotional stress and anxiety, depression, attempted suicide, isolation, and problems in family relationships and friendships (Andaraj, 1995).

Health-related stigma is a common phenomenon worldwide. Many people suffering from a chronic health condition are stigmatized due to this condition. Not only does the condition has

an impact on the persons affected, but these persons are often more vulnerable to other health problems also. Stigmatized persons are frequently identified with other conditions and situations that are stigmatized, for example poverty, sexual preferences and ethnicity. Often, the stigma related to these health conditions is even more destructive to the affected person than the health conditions themselves. Stigma has impacts on marriage, employment, educational opportunities, friendship, and self-esteem and may result in a high burden of emotional stress and anxiety (ILEP, 2013).

Diseases, such as HIV/AIDS, leprosy, epilepsy, and mental health conditions such as schizophrenia are frequently associated with high levels of stigmatization. When comparing the results of research regarding stigmatization across different health conditions, many similarities in the effects of stigma are evident. The consequences of health-related stigma are remarkably similar across the different health conditions, cultures and public health programs (Stevenson, 2011:2).

Society tends to have stereotypes that go with these health conditions, particular views of what such a person is like (very contagious, cursed, sinful, rejected or dangerous, unreliable and not able to take decisions in the case of mental illness).

People who have such health problems are reduced to the stereotype then tend to separate themselves by using expressions such as 'people like that', 'us' versus 'them'. This in turn often leads to loss of status of the stigmatized person and to the actual discrimination (ILEP, 2013:11).

When we come to leprosy stigma, throughout its history, leprosy has been feared and misunderstood. For a long time, leprosy was thought to be a hereditary disease, a curse, or a punishment from God.

Before and even after the discovery of its biological cause, leprosy patients were stigmatized and shunned. For example, in Europe during the middle ages, leprosy

sufferers had to wear special clothing, ring bells to warn others that they were close, and even walk on a particular side of the road, depending on the direction of the wind. Even in modern times, leprosy treatment has often occurred in separate hospitals and live-in colonies called leprosarium because of the stigma of the disease (Link 2000:22).

Leprosy is still a stigmatized disease despite the fact that it is curable and that MDT is available. Strong beliefs and fear still persists. It is those beliefs, attitudes and behaviors that need to be taken into account in order to address the struggle against stigma in leprosy. Studies of leprosy stigma indicted that stigma varies according to social context and access to effective therapy (WHO, 1995).

Despite effective treatment today, leprosy remains a cause of stigma and isolation. In India, where half of the world's leprosy patients live, even if cured of it, are subject to social sanctions. In this case, the "extreme poverty and demoralization" among people suffering from leprosy may in fact exacerbate problems associated with nerve damage and associated trauma. The stigma associated with leprosy is so great that people will avoid clinics and treatment to avoid being labeled leper, a label which makes marriage difficult if not impossible and forces segregation because of religious pollution taboos. Once patients have permanent disfigurements, they survive by reclusion or through begging (WHO, 1995).

People have left their families, and even spouses and children, fearing the repercussions of the fact they had leprosy. In addition, stigma may affect many aspects of leprosy control. People who fear the consequences of the diagnosis of leprosy may delay in presenting themselves to the health services, and thus have an increased risk of disability and continue to be a potential source of infection in the community. Fear of being found out and the possible consequences of that may lead to the patient discontinuing of treatment. Similarly, stigma may

lead to non-compliance with self-care routines and thus, worsening of impairments. Despite enormous cultural diversity, many areas of life affected by stigma are remarkably similar in different countries. They include mobility, interpersonal relationships, marriage, employment, leisure activities, and attendance at social and religious functions (Anandaraj, 1995).

Some patients diagnosed with leprosy may conceal their illness out of fear of rejection and exclusion from society. Others may stop their treatment prematurely out of fear for stigmatization because they experience drastic appearance changes due to side effects of treatment, e.g. uneven darkening of skin and facial swelling and weight gain. This has consequences for control efforts and not only that it will have financial consequences as well because the condition of the person affected may worsen and therefore people will need prolonged treatment and special care. Late reporting can have adverse consequences for the patients as they may suffer physical impairments and disabilities, which could have been prevented if they come earlier (Bainson, 1998).

WHO intended to wipe leprosy out by the year 2000, but so far the incidence of leprosy in those countries with the greatest proportion of cases has not decreased. WHO continuously changes treatment recommendations and diagnostic criteria, so that in the end patients do not receive what they truly need. Leprosy has a long shared history with humans and is a continuing presence in the lives of many, especially among the poor of developing countries, like India. Many of those with the disease today do not know that they can be treated or do not have access to the care they need. The deformities it may cause in advanced stages have led to stigma and the belief that those with leprosy suffer some kind of impurity, despite how easy it is to cure the disease nowadays (Ananadaraj, 1995).

Leprosy is considered by many as not merely a medical condition, but as a condition encompassing psychological, socioeconomic and spiritual dimensions. Leprosy, if untreated, leads to progressive physical, psychological and social disabilities and debilitations. Furthermore, because of the stigma associated with the disease, patients sometimes delay seeking proper care until they develop physical deformities (Jopling, 1991). According to Robinson (1990:12),

Leprosy can be explained in terms of disease (biomedical perception), illness (self-perception) or according to physical symptoms. The illness of leprosy is experienced by the person, and is shaped by cultural and social influences. The sickness of leprosy is the problem as perceived and named by the society, and it is this that reflects social stigma.

The quality of life of such persons declines rapidly. Leprosy patients used to be forced to leave home; somewhere admitted to asylums or sanatoriums. Today, however, they remain within their families, although they are often looked down, and may receive little or no support from their communities. In addition, stigma has indirect but strongly negative implications for public health efforts to combat the diseases concerned. Both personal effects and negative public health impacts are surprisingly similar for a wide range of chronic stigmatized conditions. Many people in developing countries have difficulties in accepting the disease due to misconceptions, stigma and superstitions they have towards the disease. This makes them reluctant to go to clinics for examination even after being diagnosed. In general, it affects the physical, psychological, quality of life, social relationship, and spiritual, as well as environmental makeup of the society (Alemayehu, 2001).

There are many factors contributing to the stigma on leprosy patients and these vary across continents and communities. In each community, there is a complex mix of reasons why leprosy is a feared and shameful disease. Some of the common reasons are beliefs about the causation of leprosy, disability and deformity, odor, and self-stigmatization (Mesele, 2000).

As stated previously, leprosy as a disease has wide reaching impacts beyond the medical impact, most notably stigma. In the last century, the understanding and management of leprosy

has advanced greatly. However, there is much more to a disease than just its pathological processes. Leprosy is a complex condition that affects patients not only physically but it has social and psychological implications that must be considered if cure is ever to be complete (Joy, 2005).

The wider issues involved in leprosy are ignored. As human beings, we need to understand what leprosy means to patients and their communities. For holistic care, we must never forget the impact leprosy can have on a patient's psychological and social well-being. More than any other disease, leprosy has a very negative image (Joy, 2005).

As much as disabilities can be a determinant of stigma, this is not always the case as it is not only the person suffering from leprosy who is affected by stigma, but people associated with the patient as well. These people do not have any signs of leprosy but are still stigmatized and the impact weighs heavily on their lives. The prospect of getting a job or getting married can be at stake (Nihon, 1920).

2.3.1. Types of stigma

Stigma is typically a social process, experienced or anticipated, characterized by exclusion, rejection, blame, or devaluation that result from experience, perception, or reasonable anticipation of an adverse social judgment about a person or group. Stigma refers to unfavorable attitudes and beliefs directed toward someone or something, which may be broadly grouped as

2.3.1.1. Felt stigma:

Refers in particular to the negative attitudes the community felt or perceived by those with a stigmatized condition. Internalized (or self) stigma refers the way people who are the sufferer feel themselves. This usually is due to reduced self esteem ("I am no good", "no one will want to marry a person affected by leprosy like myself"), feeling hopelessness ("I can no longer do anything") and feelings of guilt or self blame ("It is probably my own fault that I have developed

leprosy”). People with leprosy may become ashamed, possibly because of local attitudes and deformity, and may isolate themselves from the society. Thus, they perpetuate the idea that leprosy is something shameful to be hidden away. Patients may find it difficult to value them and to have a positive self-image. The self-loathing associated with leprosy can be permanent; persisting after the disease is cured. It can be hard for some patients to accept that they have leprosy. They may never be able to come to that point, refusing to believe it is true, while others may not believe they are actually cured after treatment (Joy, 2005).

2.3.1.2. Enacted stigma:

Denotes actual occurrences of discrimination (e.g. divorce, denying someone access to public transport) or negative behavior (e.g. gossiping)

2.3.1.3. Institutional stigma:

Is stigma or discrimination which is part of institutional arrangements or policies. This includes separate clinic arrangement for people affected by leprosy, insufficient arrangements for confidentiality, laws sanctioning divorce or social exclusion. Manmade barriers (e.g. buildings without elevators, sidewalks without ramps) may also be seen as part of the same category, as they exclude people with disability.

2.4. Factors causing leprosy stigma

Many factors contribute to the stigma of leprosy, and these vary across continents and communities. In each community, there is a complex mix of reasons why leprosy is a feared and shameful disease. Some of the commoner reasons are discussed below.

2.4.1. Beliefs about the causation

Beliefs about the causation of leprosy have differed over time and between places or communities. These beliefs affect how the disease is understood and those who have it are perceived. Some groups believe that leprosy is a judgment from God or for wrongdoings, either

now or in previous life. Those with leprosy are avoided as they are seen as sinful, and those around them do not themselves want to incur that wrath. Likewise, those with leprosy may be avoided in places where leprosy is viewed as a sexually transmitted disease, as something contracted by victims of witchcraft (Joy, 2000).

Stigma is not only associated with fear of catching the disease or a result of a person's strong feelings of dislike towards disabilities. Some traditional and religious beliefs also play a major role. For example, in many Hindu societies, persons affected by leprosy are blamed for their condition, which is thought to be a punishment for something they have done wrong in a previous life. In this case, stigma involves a moral judgment (Seddon, 2006).

More recently, in some areas, traditional beliefs about how the diseases are caused are giving way to a fear of infection by germs. Although there is no one common perceived cause of leprosy, all the beliefs described above are negative and usually imply that the sufferer has done wrong and brought the disease upon himself (Joy, 2005).

2.4.2. Fear of contagion

Behind the ostracism of those with leprosy lies the fear of infection. In the past, in certain epidemiological settings, leprosy ran in families to the extent that many authorities considered it an inherited rather than an infectious disease. So marriage into a leprosy family was forbidden. Once infection had been established as the cause, by Armauer Hansen in 1873, patients with leprosy were further shunned. Later, it became clear that contact with a person with leprosy, even if intimate and prolonged, was not essential to contracting the disease, although it did increase the risk (Alemayehu, 2000).

Despite extensive health education that leprosy cannot be caught through touching someone with leprosy or sharing utensils, in many societies this reality has yet to lead to

behavioral change. There are traditional and historical reasons for this fear of infection. In the past, those with leprosy were isolated from the rest of society to try to stop its spread. It is now accepted that enforced segregation is a violation of the patient's human rights, after a case won in 2001 by Japanese leprosy patients. Treating leprosy apart from other diseases in separate programme and hospitals unfortunately sent out the message that leprosy is somehow different and more infectious than other diseases. Many people still hold this belief and want those with leprosy to be treated away from their communities to avoid others getting the disease (Alemayehu, 2000).

2.4.3. Disability, deformity and odor

Another reason for the stigma associated with leprosy is the deformity and disability caused by the disease. There is a characteristic of facial appearance that marks out a patient as having the disease, as the skin becomes ridged and thick and the nose wider. There is also deformity on legs and arms. This means that at first glance other people can see that they have leprosy. The greater the disability is, the greater the level of stigma. Some patients with leprosy may have a distinctive odor caused by infected ulcers. As well as making them outcasts, bad odor can affect the patients' sense of worth and dignity (Alemayehu, 2000).

2.5. Leprosy stigma in various contexts and its impacts

Having a stigmatizing disease like leprosy severely affects aspects of life; its consequences have a negative effect on individuals, families and the wider community. Leprosy has been described as "a disease that destroys not only the body but the soul" (WHO, 1996:2). As stated by Jopling (1991:1), "The problem with leprosy is not what the disease is, but what the people believe it to be." Further, Weis and Ramakrishna (2010), as cited in Elizabeth (2010:96) described leprosy stigma:

The impact of leprosy stigma may be a greater source of suffering than symptoms and physical damage of the disease. Individuals with leprosy have emotional stress and anxiety, which may lead to psychological and psychiatric morbidity, as well as a decreased quality of life. They become isolated and lack motivation to continue treatment. Individuals may have decreased status in the community because of their conditions; they may become destitute and resort to begging as the only way of survival.

According to Tadele (1989), people affected by leprosy experience unsympathetic reactions, insults, hate and rejection from the society. Leprosy often afflicts individuals in their most productive stage of life and limit or prevents them from fulfilling their normal roles in the society. They may lose their economic independence as a result of losing their jobs, their physical independence as a result of disabilities, their self-esteem as a result of social isolation and generally live a lower quality of life

Researchers have shown that leprosy and its stigma have a pervading effect on a patient's life. It affects marriage, employment, interpersonal relationships, leisure activities and attendance at social and religious functions. For leprosy suffers to lose this is to lose a large part of who they are. People with leprosy may lose their employment because of their disease, the disabilities associated with it and negative attitudes of employers. When this happens, they lose the means of supporting their families and often the respect of their communities, with loss of self-esteem

(Joy, 2005). Jopling (1991:13) summarized effects of leprosy stigma as:

Stigma processes have a dramatic and probably under recognized effect on different aspects of life such as social, psychological, and economic. Leprosy stigma is not only produced by local beliefs about the disease. However, the wider social, political and economic contexts are also significant. In many previously colonized countries, government policies and laws on leprosy have lagged behind the scientific breakthroughs. Overall, the ways in which leprosy stigma is explicitly or secretly expressed are shaped by a range of social, cultural, political, and economic factors. Addressing these broader social and economic forces can improve the health outcomes of people with leprosy while helping to curb stigma.

2.5.1. Social impact

Various writers have implicated historical events and social aspects in leprosy stigma. Firstly, biblical teachings perpetuated by missionaries associated leprosy with sin and uncleanness; and people with leprosy came to be considered outcasts as a consequence. Secondly, the related concepts of contagion and aesthetic features of leprosy induced fear. Finally, twentieth century Western policies advocating incarceration of people affected by leprosy at various leprosaria due to the social construction of the disease also induced fear and ultimately stigma (Modlin, 1994). Alemayehu (2000:17) stated:

The social constructions of leprosy are commonly guided by cultural, traditional and religious beliefs or myths about the disease and illness. Too often, leprosy infected people are thought of as cursed or victims of witchcraft, or as blameworthy (immoral), and their disease well deserved. The social constructs and myths of leprosy are knotted with high rates of illiteracy and misinformation about the disease.

Stigma restricts social participation in a wide range of areas. Through participation restriction the person affected will become more and more isolated and excluded from the society as she/he cannot fulfill the role which was expected of him or her. The social participation of persons affected by leprosy is much more distressing to them than their individual effects. It impairs their quality of life in various ways. Persons with stigmatizing conditions experience problems in their marriage or difficulties in getting married and in their employment or getting employed. Their community interaction such as social relationships and friendships is affected. Individuals may have decreased status in the community because of their conditions. Their families may experience low educational opportunities, leading to further inequities between those affected and those who are not. All of these negative effects result from knowledge of the disease, and the misconceptions held about them (Modlin, 1994).

2.5.2. Psychological impact

Stigma affects people's psychological wellbeing. It often lowers self-esteem and can cause or aggravate psychiatric morbidity. As Smith (2008:98) noted:

Measurement of self-esteem and depression is highly relevant to monitor the impact of stigma reduction interventions. The extent to which a stigmatized person is denied the good things in life and suffers more of the bad things has been posited as a source of chronic stress, with consequent negative effects on mental and physical health. Stress is also associated with the constant threat of being stigmatized.

Individuals with leprosy have emotional stress and anxiety, which may lead to psychological and psychiatric morbidity, as well as a decreased quality of life. They become isolated and lack motivation to continue treatment (Elizabeth, 2010).

According to Jopling (1991), Psychological changes occur in the patient due to impairments and disabilities that are perceived as negative by the patient, resulting in negative expectations of himself/herself with respect to life. A variety of emotions like fear, grief, confusion and anxiety may develop and could lead to depression, loss of self-esteem, withdrawal and mental problems. As a result of the disabilities, people affected by leprosy are more prone to be stigmatized. Visibility of wounds and ulcers can aggravate the fear of contagion. Bainson and Bourne (1998:2) described leprosy stigma as:

A set of affective dimensions that involve the emotional reactions that individuals, groups or communities develop towards leprosy patients. These emotions include pity, anger and fear. With leprosy, it is the element of fear that is most likely to lead stigma. According to them, stigma has a double perspective: does the stigmatized individual assume that his/her differentness is known already, or is evident on the spot, or does he/she assume it is neither known by those present, or immediately perceivable by them.

Sometimes, the stigma and ostracism of leprosy can affect the psychiatric state of the patient. Leprosy itself attacks the peripheral nerves, the brain and central nervous system. But mostly it doesn't damage it. Yet many patients are affected mentally, not because of the disease, but because of society's rejection of them. Negative attitudes towards people with leprosy act to

destroy the patient's psychological health. The shame associated with this disease often lowers self-esteem and can cause or aggravate psychiatric morbidity (Smith, 2008).

2.5.3. Economic Impacts

Negative perceptions of leprosy still can be a barrier to the process of affected people's reintegration into their families, jobs and the wider community. Of course physical impairments cause difficulties for a leprosy affected person in carrying out activities she/he could do well before. If these impairments have become permanent, the person may experience greater disadvantages, for example, losing job, not able to work well and because of that, unable to earn enough for living, denied going to school, loss of social status (Kaur, 2002).

Leprosy results in social instability which, in turn, curtails economic growth and impoverishes previously self-sufficient communities, and worsens conditions for those already poor. People with leprosy may be refused employment or lose their jobs because of their disease, and associated complications with consequent brutal financial burdens. Leprosy affected people live in conditions of extreme poverty with few opportunities of earning income, and may turn to begging as a last resort. A person's sense of well-being and the level, to which they see themselves as useful, is inextricably linked to their income generation, and ability to secure employment (Smith, 2008: 20).

Stigmatization results on leprosy affected people to be unable to work, they become dependent for care and financial support, leading to insecurity, shame, isolation and consequent economic loss. Many of those leprosy affected people are afraid of losing their work. The combination of leprosy, physical impairments and social stigma leads to loss of former place in society or social role. Many such people live in extreme poverty and have few opportunities to earn an income. They may be excluded from their former work place or denied access to their former market (Joy, 2005).

2.5.4. Effects on treatment and cure

In dealing with leprosy stigma, the impact on public health programmes and interventions also takes an important place. People with the stigmatizing conditions may conceal or deny their condition and delay seeking treatment which may result in the diseases getting worse and increase the risk of complications. In addition, it increases the transmission of the disease in the community which makes it difficult to trace contacts and those defaulted from treatment. Some patients may not adhere to treatment, when diagnosed especially for treatment that takes a long time (Smith, 2008).

Stigma causes problems for treatment of leprosy. Often, to prevent discrimination, patients try to hide their disease by not immediately seeking medical help on finding signs of leprosy. When they do, they may have significant disabilities and deformities. This, in turn, makes the stigma of leprosy worse and perpetuates the cycle. Once treatment for leprosy has commenced, patients may stop going to clinics or taking their medication because of fear of rejection by their community or a lack of acceptance of the condition. Even if patients are cured of their mycobacterium disease, the stigmatization can remain an insurmountable obstacle to the resumption of a normal life (Joy, 2005).

The above reviewed literature indicates the extent of the problem of stigma on leprosy affected people and the intensity of its damage, which raise the need of the research to examine the current situation of leprosy stigma and its impact on leprosy affected people. Therefore, this study will assess the impact of stigma on the lives of leprosy affected people by gathering primary data from the targeted population of the study

Chapter Three

3. Research Methodology

3.1. Study Design

The method of the study was qualitative case study approach. This design was chosen in order to obtain an in-depth and a compressive understanding of the stigma experiences of leprosy affected people and to assess the impact of leprosy stigma on them. According to Creswell (2007:40),

Qualitative study is best when the issue of concern at hand needs exploration, comprehensive understanding of the context and the phenomenon. It is also more appropriate in terms of documenting rich and detailed information. Qualitative design has flexible nature, helpful to understand real life context and allow the active involvement of the study participants.

Assessing leprosy stigma is a very wide issue which needs detail information and data. To do the assessment with those affected people, the researcher should hear them with passion and allow them to openly narrate their story. Thus, qualitative method was accurate to get detailed information by allowing participants freedom to express their live experience in relation to stigma. A detailed and careful study has been done so as to be able to address the research objectives.

As the aim of this study was obtaining rich information on the experience and situation of leprosy affected people related to leprosy stigma, case study design was used to conduct the study. As Yin (2003: 211) argued, “the evidence from more than one case are often considered to be stronger than evidences from a single case, among the different types of case studies”. Thus, in this research, the stigma experiences of different cases (people affected by leprosy), was assessed in depth.

3.2. Scope of the study

The study population is people affected by leprosy who are beneficiary of Medihn Social Center and who are above the age of 18. From the project areas of Medihn Social Center, the study was done on those leprosy affected people who live in Kolfe Keranio Sub-City, 'Woreda'⁴01, Addis Ababa. The study area was chosen because the area is one of the leprosaria sites in Ethiopia where most leprosy affected people live.

3.2.1. Location of the study area

The research was conducted in an organization named Ethiopian Catholic Church Medihn Social Center, a non-governmental organization which is located at Kolfe Keranio Sub-City, 'Woreda' 01 (Zenebework area), in Addis Ababa. Kolfe Kerano Sub-City is one of the 10 Sub-Cities found in Addis Ababa. It is located to the west of the city with the total population of 261,235 and land coverage of 63.25 km² and it consists of 10 'Woredas'

3.2.2. General description about Ethiopian Catholic Church Medihn Social Center

The idea to set up a social center grew from a small social work project within the Medico Social Unit of ALERT (the All African Leprosy, Rehabilitation and Training Center). The founder, Sister Senkenesh, started this journey in May 1982. She used to pay frequent visits to the homes of people affected by leprosy and discuss their problems with them. This enabled her to identify the needs and circumstances of the poor people that were living in the surrounding area of ALERT. This enkindled her commitment to provide basic services for these communities

⁴ 'Woreda': the smallest unit of local government.

and reached an agreement with the management of ALERT to establish a Social Center as a separate entity from ALERT (Melaku, 2012).

In June 1988, Medihn Social Centre was officially established. Thereafter, it began to be involved in the development of the community, social rehabilitation, social welfare development services of individuals and families as well as reconstruction of dilapidated houses in the project area. According to the latest restructuring of the 'Kebeles', Medihn Social Center's project area comprises five 'Woredas'. These are 'Woreda' 02 from Nefassilk- Lafto Sub -City and 'Woreda' 01,02,04,05 from Kolfe Keranio Sub-City. These 'Woredas' are characterized by concentration of very poor people (Melaku, 2012).

Largest concentration of people affected by leprosy in Addis Ababa is found in the project area of Medihn Social Center. This resulted from the prevailing stigmatization and availability of free medical service in ALERT Hospital found in this area. There is also a high concentration of people who earn their living by begging. The community also comprises of very old people as well as people with disabilities resulting from leprosy (Melaku, 2012).

The main objective of the organization is to see a society of equal opportunity, free from stigma and discrimination with the goal of reducing stigma and discrimination on leprosy patients. This prevents further deterioration in their social, emotional and material conditions through the provision of integrated programs that enable them to function effectively despite their illness, disability, old age or crisis in life. Building self-determination and self-confidence among leprosy patients is among the goals. Major beneficiaries of Medihn Social Center are people affected by leprosy and their families, people living with HIV/AIDS, orphans and

vulnerable children, elderly and poor people, people with disabilities, girls and youngsters from poor families (MSC bulletin, 2009).

According to Medihn Social Center bulletin (2009), the organization has four major programs: social services, non-formal education, social development, and income generation activities. Medihn Social Center's programs mainly focus on increasing the participation of people affected by leprosy in their own development, and facilitating the process of change within the community.

3.3. Sample size determination

The informants of the study were selected by using purposive sampling technique as the study used qualitative method of data collection. "Purposive sampling is done based on the inclusion criteria, enable to gain detailed understanding of the phenomena as well as to balance the gender composition of the study participants" (Ritchie, 2003:107). Thus, the study used purposive sampling technique with the purpose to gain detailed information about the issue under study by having all inclusive data.

There are 350 people affected by leprosy who are beneficiaries of Medihn Social Center. From this, 150s are from 'Woreda' 01, Kolfe Keranio Sub-City. Thus, the sample was taken from this 150 population. In order to select participants, different criteria based on the research objectives were utilized.

The first criterion was age. As the experience of leprosy stigma may vary within different age groups, it was convenient to involve young, adult and old age groups. This enabled the study to be comprehensive in terms of age. Even if it was important to assess the experience of those with the age under 18 (child age group), the ethical board of Medihn Social Center did not allow this. The second criterion was the health condition of respondents. From the review of secondary

sources, leprosy stigma differs based on the affected person's health situation. Accordingly, the study involves both the deformed/disabled people and those who are free from any physical deformity/ disability. The third criterion for selecting the sample was gender. Leprosy stigma is not the same between women and men, and from the literature review, women are more affected than men. Therefore, to have all-inclusive data, the sample contains both females and males. There are also other criteria such as, the place where they come from/ original residence/, year of stay in the organization /how long they benefited from Medihn Social Center.

Based on these criteria, a total of ten informants (people affected by leprosy) were taken for the in-depth interview and another six participants were taken for the focus group discussion (FGD). For the focus group discussion, in addition to the above criteria, the speaking skill/ ability to express idea/ was taken into consideration as a criteria to select participants.

In addition to leprosy affected people, three staff members of Medhin Social Center were selected for key informant interview. The key informants were taken from different projects of the organization that have direct link with leprosy affected people. Thus, key informants were selected from social work unit, counseling unit and from the treatment or nurses.

3.4. Data collection tools

Both primary and secondary data sources were utilized in the study.

3.4.1. Primary data collection

3.4.1.1. In-depth interview

Interview questions were designed to collect data from ten leprosy affected people. The questions were semi-structured which allow the informants to have more freedom to narrate their story and experience. This in turn, helps the researcher to obtain the general picture of their life trajectories. The informants were asked to share the stigma experiences they suffer from

throughout their life. During the in-depth interview, issues about the relationship with their families, neighbors, friends, their social participation, feelings and attitudes about their health condition, their economic wellbeing, and the challenges they face in working areas, their current situation, and others were assessed.

3.4.1.2. Focus group discussion

A focus group discussion was held with six leprosy patients who were not involved in the in-depth interview. This was done by discussing on guiding questions. The purpose to conduct the focus group discussion was to generate additional information on the stigma experiences of leprosy affected people, the current situation of stigma, and impacts of stigma. Further, participants were invited to suggest what they need to be done to reduce stigma and to improve their lives

As Maxwell (2005:93) explained, “gathering data from different sources can maximize the trustworthiness of the information and minimize the limitation.” Thus, FGD was done to widen the sources of information, and it contributed to crosscheck the data gathered from the in-depth interviews. As the in-depth interview, the FGD group contains young, adult and old people. Both females and males were included. In addition to these, both the deformed and non-deformed leprosy affected people attended the discussion. The participants were good in discussion, where they were able to raise new ideas which were not identified in individual’s interviews.

3.4.1.3. Key informant interview

Key informants were taken from Medihn Social Center staffs that have direct relations and services for leprosy affected people. Two of them are female staff, one is sociologist and

another social worker, works in social work team and one is nurse. Pseudo names were used and key informant Selam is organizer of the social work team, Abel is a nurse in the treatment team and key informant Meron is from the rehabilitation unit.

Interview questions were also designed for key informants. The interview questions were semi-structured, and basically generated data on the current situation of leprosy stigma and what are the challenges that leprosy patients have as a result of this.

3.4.2. Secondary data collection

Besides primary data collection tools, sources of secondary data were journals, books, published /unpublished reports and prior researches in relation to the topic under study.

3.5. Data collection procedures

After obtaining approval from Medihn Social Center and after selecting the informants of the study, communicating with the informants and collection of the data proceeded. First, the interview question for the in-depth interview, the guiding question for the focus group discussion and key informant interview was translated to the informant's local language, from English to Amharic.

In in-depth interview, audio-recording was used for four informants of in-depth interview who were willing to be recorded. However, six interviews were conducted with note taking because the informants were not willing to be audio recorded.

After conducting the in-depth interview, arranging suitable time and place for the focus group discussion continued. Focus group discussion (FGD) was conducted with six participants of people affected by leprosy.

There was also key informant interview with staff members of Medihn Social Center. To conduct this, communicating with departments who have direct services for leprosy affected

people was the first action. Then the interview began with three staffs. As done before with leprosy affected people, there was a brief introduction about the purpose of the interview. The audio record was used for all of three key informants.

3.6. Data analysis process

After completion of all the interviews and the focus group discussion, finalizing of data gathering and data transcription has followed. In order to analyze the primary data, tape recorded interviews were transferred to handwriting and the researcher read many times to get full familiarity with informant's idea.

Based on the objectives of the research, cods were identified. Then, the important phrases were extracted into the basic codes. The purpose of coding is "to get unstructured and messy ideas to structured ideas about what is going on in the data" (Morse & Richards, 2002: 111). Thus, it clearly identifies the main facts which allowed simplifying and focusing on some specific characteristics of the data. The interview questions and the literature review were served as important base for coding. In the next step every interrelated basic code was integrated to one category as sub-themes and finally integration of those themes was done. These themes were used to write a description of the context or setting that expressed how the informants experienced the phenomenon under study.

3.7. Ethical consideration

The study was done in conformity with the ethical guidelines of social work profession. By explaining the objective of the study and its significance, permission was secured from concerned authorities. First, having the letter of recognition from the School of Social Work and permission to get ethical clearance from Ethiopian Catholic Church Medihn Social Center was done.

With informants, verbal and written consent was obtained to their participation in the study. Furthermore, the researcher has informed that their participation in the study is voluntary and that they will not be obliged to respond to any questions with which they are uncomfortable. They were told that they are free to withdraw from the interview and focus group discussion any time they want and assured that their names will not be written on the questionnaire format as well as in the thesis; instead the researcher used pseudo names. And they have completed the interviews separately to keep anonymity and to make them comfortable in giving honest responses. In addition to that, tape recordings were conducted only when the informants' consent was ensured in order to ensure confidentiality of the information.

Chapter Four

4. Finding of the study

Under this section, the data gathered from the in-depth interviews, focus group discussion and key informant interviews are presented and discussed. For this purpose, the following themes were developed: the socio demographic profiles and the general information about informants/leprosy affected people, the stigma experiences of leprosy affected people, the different impacts of leprosy stigma on leprosy affected people. All of the thematic areas were developed in accordance with the objectives outlined at the beginning of the study.

4.1. Socio-demographic profile of informants of the in-depth interview

Considering the gender composition, both females and males were included, of which four were females and the rest six were males. The age of the informants ranges from 24 to 66, and consists of youth, adult and old people which help to identify the stigma experiences on different age groups. Most of the informants /nine are originally from rural areas of Ethiopia, outside of Addis in which they change their former residence due to leprosy. All of the informants are followers of Orthodox Christianity. In terms of marital status, four are married, four are unmarried and the remaining two are divorced. Five informants are uneducated and others educational status ranges from basic education to 10th grade. The livelihood of most informants of the study is dependent on begging. From the observation and explanation of informants, eight out of ten have deformity on their body, their hands, legs, noses as well as their eyes are septic due to leprosy, whereas, two of them have no any physical debility.

Table2: Summary of socio- demographic profile of interviewees

Informants	Sex	Age	Marital status	Religion	Place of origin	Educational status	Livelihood	Health status
Almaz	F	25	Divorced	Orthodox	Wollo	Uneducated	Selling of goods(vegetables)	deformed
Solomon	M	55	Married	Orthodox	Gondar	Uneducated	begging	deformed
Abeba	F	50	Married	Orthodox	Gojjam	Uneducated	begging	Non deformed
Sewinet	M	41	Married	Orthodox	Arsi	10 th grade	coin changing	deformed
Kebede	M	66	Married	Orthodox	Semen Shewa	5 th grade	begging	deformed
Alemu	M	45	Unmarried	Orthodox	Holleta	2th grade	begging	deformed
Tigist	F	24	Unmarried	Orthodox	Gondar	Uneducated.	begging	deformed
Tena	M	34	Unmarried	Orthodox	Wollo	8 th grade	guard	deformed
Zinash	F	33	Unmarried	Orthodox	Zenebworq /A.A	Uneducated	daily laborer	Non deformed
Assefa	M	47	Divorced	Orthodox	Gojjam	4 th grade	begging	deformed

4.2. Socio-demographic profile of the focus group participants

Table3: Summary of Socio-Demographic information of focus group participants

Participant	Tirunesh	Getachew	Hawa	Tadesse	Abebaw	Addis
Sex	F	M	F	M	M	F
Age	27	40	45	38	62	38
Religion	Orthodox	Orthodox	Muslim	Orthodox	Orthodox	Orthodox
Marital status	Married	Unmarried	Married	Married	Divorced	Divorced
Educational status	5 th grade	Uneducated	Uneducated	4 th grade	Uneducated	Uneducated
Place of birth	Addis Ababa	Woliso	Gojjam	Gondar	Wollo	Gondar
Livelihood	labor work	labor work	begging	non	begging	non
Health status	non deformed	deformed	deformed	Non deformed	deformed	deformed

4.3. General information about the informants / leprosy affected people

To know about leprosy affected people's background, in-depth interview informants and FGD participants were asked different questions. From the explanations of informants of in-depth interview and FGD participants, most of them began to see the symptoms of the disease when they were a child, but still they are able to remember all of the coincidence. As they explained, first the signs like rashes, nodules had appeared on their body.

During the in-depth interview, informants have shared their original situation in detail. As explained by eight informants, in the beginning, they were noticing a small patch then expanding to their body. Their families did not take it seriously and they simply treated them by giving

different traditional remedies, like 'Tsebel'⁵ where it did not work, and they stay for long time without going to hospitals and taking modern medicines. Then their situation was going to be worse and they got physically damaged. Whereas, two informants were aware of some aspects of the disease because there were some people around who know about leprosy disease and advised them to go to hospital. Thus, as they recognize the symptoms, they immediately went to the nearest health services. As a result, they were able to get the treatment and they became free of any disability. Informant⁶, for example, narrated her condition when she began to see signs and symptoms of leprosy.

I was first infected by leprosy around the age of 12 or 13. Since I was a child, I did not know anything about the disease. What I can remember is, first some sort of white scratch appeared on my legs. Then, my legs became wounded and later on the wound over my legs became erupted. Despite this, I and my family did nothing to solve the problem. As I lost both of my parents since I was a little kid, there was no one who was beside me and concerned about my sickness. As time went by, the problem became more severe. Hence, the infection had extended further to my hands.

Even if most of the informants both in the interview and the FGD were late to go to hospitals, they heard about leprosy then and began to think about the cure of their sickness. In the words of informant:⁷

After time had passed, a man who lived in the village saw and advised me to go to hospital for medical treatment. As he was educated, he advised me very well. Based on his advice, I went to the nearby hospital in Dessie. There, I was told that I should go to Addis Ababa for better medication. In line with this, with the referral of the physicians, I came to Addis Ababa and I had started taking medicine. However, after some time, I became afraid of going to hospital and I stopped taking medicine. This was because I was afraid of the stigma from my neighbors and friends. Even after the reoccurrence of the infection, I did not go back to the hospital. As a result, I lost part of my body and the infection has extended to the rest of my body.

⁵ 'Tsebel': a holy water used for cure disease

⁶ Interview with Almaz, age25, April 15, at Medhin Social Center

⁷ Interview with Almaz

As can be learned from the above and key informant ⁸ explanation, the cause of the deformity was not only being late to seek treatment, but there are some patients who drop the medicine after taking it for some time.

From the informant's explanations, at the time of diagnosing symptoms of the disease, they generally were living in rural villages where there were no health facilities, extensive society isolation and neglecting. In addition to these hardships, they were suffering from poverty which aggravated the problem.

Data from all informants of the in-depth interviews and focus group discussion participants indicated that informants had fairly inaccurate knowledge about leprosy. This has its own consequence on them to consider themselves as being unequal and as sinful person. Before they were diagnosed as having leprosy, most of them did not have the awareness about the disease. They did not know the signs, causes, transmission and treatment of leprosy. Seven informants from the interview explained that they did not ever hear about leprosy before. Informant ⁹ and informant¹⁰, for example, explained that they did not ever hear about leprosy before their sickness.

Whereas the rest three participants explained as they heard about leprosy even before they were infected. As was described by informant¹¹,

Before I was infected by leprosy, I saw a number of people with leprosy around our residence who lost their hands and legs. The residents called them '*qomata*'¹² and most of them were begging sitting around the churches.

⁸ Interview with Abel, age,32,Nurse,April18, at Medhin Social Center

⁹ Interview with Solomon,age,55, April 15, at Medhin Social Center

¹⁰ Interview with Sewinet, age, 41, April15, at Medhin Social Center

¹¹ Interview with Tigist, age, 24, April 15, at Medhin Social Center

¹² '*qomata*': an Amharic word meaning a person who lost part of his/her body due to leprosy disease

In general, participants noted that at the time when they were first infected by leprosy, they were very young as well as the place where they used to live had been remote and rural area. There were no any health facilities where they could get information and awareness about such issues.

This aggravated the problem and has made it worse. Informant¹³, from the interview group said:

I thought that it was such a simple injury when it began. Later on, when my fingers became seriously injured, I lost hope. Except my sickness, I did not know anything about the disease. When I heard the roamer of my friends as I was infected by leprosy and I saw some people with similar cases in the village, I gave attention for the disease. Generally, I had to live in rural village far from the city where there is lack of health facilities, poverty as well as neglected by my parents which led my disease symptoms evident. During a few years my face was deformed to current shape of destroyed nose cartilage, flat-swelling face, losing eyebrows.

Currently, however, most of the informants explained that they have better knowledge about leprosy. Male Informants¹⁴, from the interview group clarified about the cause of the disease as it is not their fault or not because of their family sin, but as all other diseases it is caused by bacteria and as its not only hereditary. The same sentiment was reflected during the FGD and an informant¹⁵ said:

What I know about leprosy is that it affects the skin, joints, and eyes. Its signs are rashes and nodules on the body. Hands and feet can be damaged. It causes body damage or shows as rashes and nodules, some weep and some do not. If I see somebody with these signs, I will tell him/her to go to ALERT Hospital to seek help. There, they will get drugs free of charge.

Surprisingly, all participants except one attested that there is no one in their family who is leprosy infected. Thus, they have a belief that leprosy is not hereditary disease rather they believe that the disease can appear on a person who has no leprosy infected family background. An informant¹⁶ proved this,

¹³ Interview with Tena, age, 34, April 15, at Medhin Social Center

¹⁴ Interview with Solomon, Tena, kebede, age, 66, and Alemu, age 45, April, 15, at Medhin Social Center

¹⁵ FGD, Trunesh, age 27, April 20, at Medhin Social Center

¹⁶ Interview with Zinash, age, 33, April 15, at Medhin Social Center

Except me, no one in my family has leprosy. It is only me who is unlucky and I believe that the disease is not only transmitted through heredity but there are other reasons for the cause.

However, informant¹⁷ from the interview explained that there is a member of her family who is infected by leprosy.

My father was suffering from leprosy. I also got the disease. The first time, the symptoms of the disease appeared on me was when I gave birth for my first baby. As soon as I saw the symptoms, I went to the nearby hospital in Debre Markos. As I started taking medicine immediately after the appearance of the disease, my body was spared from being injured, and my child has not been infected.

All informants and FGD participants except two were originally from rural areas. They came here in Addis Ababa because of leprosy disease. Some left their residence for the purpose of medication and others to escape from the challenges they faced due to leprosy stigma.

4.4. Stigma experiences

All informants and FGD participants of the study indicated that they are suffering from leprosy stigma in different aspects of their life world. The stigma is manifested on their family and social interactions, psychological wellbeing as well as on the economic aspects of their life.

The most common stigma experiences revealed by the study are: devaluation, distancing, hatred, rejection, and exclusion by family, friends, colleagues and the community. As explained by the informants of the study, fear is often found to be the root of these negative attitudes, e.g. fear of exposure to the disease, fear of being infected. These negative attitudes were more prevalent when they are out of their villages (*'Zenebwoq'*). Participants¹⁸ in FGD when they were discussing about their experiences said:

¹⁷ Interview with Abeba, age 50, April 15, at Medhin Social Center

¹⁸ FGD with Trunesh, Getachew, age,40 and Tadesse, age 38, April 20, at Medhin Social Center

The stigma came from our family, friends, neighbors, and the society. Our life dimensions are negatively affected in most situations. The health, family and economic situations of us are highly discriminated and our life experiences have been touched a lot.

As explained by key informants, leprosy affected people are also stigmatized by some professionals like health professionals. In this respect, when key informants were asked about their feeling and attitudes about leprosy patients, they have different views. As they were first employed in Medhin Social Center, it was difficult to adapt the environment and to integrate themselves with the beneficiaries. Their prior attitude on leprosy made difficulties to work with leprosy affected people. As key informant¹⁹ explained,

When I first come to Medihn Social Center, I had some problem to communicate with patients. I was a little bit frightened of the diseases, to sit with them, touch them....Even if I am a social worker and I learned how to work with such people, it was difficult for me to apply my professional disciplines immediately I had started a work. Since they have odor and some of them had a wound, you have to have patience.

Key informants²⁰ however said that:

I have a positive feeling and attitude about leprosy patients. Of course there might be some hardship to work with them. They have some psychological problems. They always think that all people do not have a respect for them, they have lower self-esteem. So when I communicate with them, I should apply my professional disciplines. I have to pay attention for their feelings and needs. So I am close with them, I am doing my job with passion.

Another key informant²¹ also expressed similar idea:

Working with leprosy patients is somehow difficult because as they have lower self-esteem, they feel that everybody stigmatize them. So we have to be systematic to talk with them. And we have to know their inner feelings and based on that we should make our approach good.

4.4.1 Stigma from the family

The majority of the study informants challenges of stigma starts from their family. As most of them came from the family background who have no enough knowledge about the

¹⁹ Key informant Selam, age, 26, Social Worker, April18, at Medhin Social Center

²⁰ Key informant Abel

²¹ Key informant Meron, age24, April18, at Medhin Social Center

transmission and causes of leprosy, they were stigmatized by their own family members. Members of their family look down on them as they bring embarrassment for that family. All informants in the in-depth interview explained that until recently, they were abandoned by their sisters, brothers and their parents. They are receiving lifelong treatment or care in institutions like Medihn Social Center. As explained by an informant²²,

Since the beginning of the disease, my sisters and brothers were not happy to be with me. As the disease caused a bad sniff, they did not want to be with me. Except asking me why it happened, they were not interested to help me. Later on, as part of my body became seriously injured, they began to hide me not to go out of home. When somebody came to our home to visit us, they told me to be at the backside of the house. Due to such reason, I was forced to drop my education.

This finding is supported by the findings as isolation from domestic roles develops among informants a self- image of being a less valued member of the family. Most informants have lost their employment because of their disease, the disabilities associated with it and negative attitudes of employers. When this happens, they have lost the means of supporting their families and often the respect of their communities, with loss of self-esteem. Their families do not involve them in decision making. An informant²³ from the interview group said:

People should know that we are human beings and we have the right to live. We have our case like a harvest that is on fire, that we ourselves have plenty of miserable problems as we have been disabled. We suffered not only from the society's isolation but also from inability to do our roles in the family.

From the findings, most families do not understand the needs of leprosy affected people during the crises rather they became another problem. Such patients had helplessness feeling. In the interview, an informant²⁴ said,

²² Interview with Solomon

²³ Interview with Assefa, age, 47, April 15, at Medhin Social Center

²⁴ Interview with Sewinet

My family never understands me. They never support me. They left me alone with huge problems. It is only my mother who visits me still now. I do not want to go to visit my family because I know that they will not accept me. If I go, they will kill me immediately.

Another informant²⁵ added:

It is not only the society that stigmatizes me. Even in my family, they did not want to see me. My brothers were trying to kill me; they tried to burn me when I was asleep. They disliked me because I became a source of shame and embarrassment for them. They thought that if I am alive, I become a trouble for them to have a marriage with a person they want to marry. It had been long time that I left my original residence. I always miss my relatives but I cannot go there because I know that they will not accept me.

Further, families do not let other people to know that there is a family member who is leprosy infected. Rather, they hide the patients from their neighbors and even from their relatives. An informant²⁶ said in an in interview,

When I was sick, my relatives do not want to see me. They do not want to visit me. In rare occasions when they come to see me, they will hide themselves from other people and come to see me from a distance and worry about me. When my relatives look at me in such a way, I sometimes blame my Lord in a sense of ‘why did not he give me a healthy life like my family members’

Majority of informants lost their loved ones due to leprosy stigma. They are separated from their mothers, spouses and other family members. Informant²⁷ described her situation,

I divorced my first husband because I am infected by leprosy. Before we got married, he did not found out that I am leprosy affected since there was no deformity on my body. When he heard rumors about me from our neighbors, he immediately left me and my child without any thing. This made my life complicated.

4.4.2. Stigma from the society

Throughout their life, informants were stigmatized by the society, their friends, colleagues and neighbors. Some of the ways through which stigma exhibited on them are marriage, friendship, working areas, social and religious ceremonies. Relatives and spouses of informants

²⁵ Interview with Alemu

²⁶ Interview with Sewinet

²⁷ Interview with Abeba

also faced stigma and exclusion. Even though the participants appreciate the changes in the attitude of the community, they reported that they are still facing the problem starting from the time of knowing that they have the disease. As explained by an informant²⁸,

I have suffered my whole life from leprosy stigma. Primarily, my own families themselves hated me. Their reason was fear of stigma emanating from the society. My brothers and sisters openly told me that 'because of you, we cannot get married with a person we want to marry. Because of you the family got dishonor'. That is why I was forced to leave my home town. In our village, people having similar problem are called 'qomata'. Thus, the society discriminate them. As a result, they live around churches and engaged in begging. Like others who are suffering from the disease, I was also discriminated. Now I live here in Zenebework. Even if there are many leprosy patients who live in Zenebework and the stigma is expected to be less, we are still facing stigma from the people who are not affected by leprosy.

When participants explained the current situation of stigma from the society, there are some improvements. However, they are offended by the society in their day-to-day lives. Two FGD participants²⁹ shared their experience in this way:

Some people think that if they sit beside a person affected by leprosy, the disease will jump on them. They will not want to sit closer to us. If we stop a taxi/a vehicle and we enter, they will withdraw from us. You could be stigmatized against whether you have disability or not. You could also be discriminated against if they know that you have leprosy. Some people shun you because they think leprosy is contagious. Some others have no real reason for shunning people affected by leprosy. We are treated as dirty, irritable and repulsive. Thus, people do not want to associate with us.

Key informants also have similar thought. As key informant³⁰ said:

Stigma makes leprosy affected people restricted to live only in leprosarium areas. It prohibits them not to have a full social participation as other people have. In addition to this, they are not actively participated in developmental activities. They are not getting equal opportunities in education, employment. Generally, I can say that leprosy victims are ignored people. When they come to us/Medhin Social Center, they feel relief. This is because we treat them morally and support them by giving different services. What I understand from this is the stigma makes them to isolate themselves from the society.

²⁸ Interview with Solomon

²⁹ FGD participant Tadesse, age,38 and Hawa, age 45, April20, at Medhin Social center

³⁰ Key informant Meron

Key informant³¹ also has a similar view.

Even though there is a change in the belief and attitude of the society on leprosy, there is still strong stigma from the society. Leprosy affected people are victims of different harms coming as a result of the physical debilities and from the stigma. They have different needs of treatments as well as needs to reduce stigma.

However, some informants explained that currently, there is a positive change in people's attitude. FGD Participant³² during the discussion said:

In the time past, if you were called '*a qomata*', nobody would want to come close to you except when necessary. Anywhere you go, no one cared about you. But with enlightenment, many people are now interacting with us. For example, I married a woman who is free from leprosy disease and we have healthy children.

Informants both in the interview and FGD also explained that the stigma relatively is less in leprosarium, like '*Zeneborq*' area because many people who live there have similar cases. They are leprosy affected people. However, still there is stigma from other people, especially when they go to different organizations like '*kebeles*', clinics, markets to obtain some services. "*Kebele*' staffs undermine us; they do not have a positive attitude for us, they do not serve us properly."³³

From the finding of the focus group discussion, the community sees their sickness as a curse or a justified punishment for those who have committed sins and is misperceived as highly infectious and transmitted through touch or contamination of common goods like water or food.

We are prevented from accessing community resources or marrying healthy individuals. And we are excluded from wedding ceremonies, religious ceremonies, and employment. It is still commonly believed that touch is the main cause of transmission. And other beliefs deem that transmission occurs through food, water, and air. ³⁴

³¹ Key informant Abel

³² FGD, Tadesse

³³ FGD participant Tadesse and Getachew

³⁴ FGD participant Abebaw, age 62, April 20, at Medhin Social Center

As one informant³⁵ during the interview described:

Usually when the people see me, they put their hands at the back; they do not like to give greeting by touching my hand. This is because they think that if they touch me, the diseases would be transmitted to them. Most people think that leprosy is very infectious disease which could be transmitted through contact, through air, by eating together, and sitting together.

Another informant³⁶ told how his work colleagues stigmatized him when he was working in one organization as a guard.

Before three years I was working in private school as a guard. I was performing my job in a good manner. However, my colleagues began to stigmatize me. They thought that the disease would be transmitted to them through air and through contact with me. They obviously told me, 'if you work with us we could get this disease.' later on, I left my job due to this pressure.

4.4.3. Self-stigmatization

"The issues surrounding leprosy stigma are grounded in the attitudes and emotional reactions of both the people affected by leprosy and the people with whom they come into contact."(Tadele, 1989: 105) To assess self-stigmatization among the informants, different questions were asked. Questions like whether they consider leprosy like other diseases, their attitudes and feelings about themselves. Only some informants felt that leprosy is like other diseases. Male informant³⁷ has this to say:

I always feel that my sickness is unique from other disease. Even if I know that there are many other diseases, such as cancer which have no any medication, I prefer that to leprosy. Even I prefer HIV/AIDS to being infected by leprosy. I feel leprosy is my whole life disease; no cure, no death. I always consider myself as unlucky person.

As informants described, the main reason for stigmatizing themselves is their pre-expectation that the society do not like them and consider them as they do not deserve equal respect. In

³⁵ Interview with Tena

³⁶ Interview with Sewinet

³⁷ Interview with Kebede

addition to this, even if there are improvements, informants of the study noted as they have less knowledge, inaccurate attitude and feeling about the disease.

From the finding, leprosy patients isolated themselves from their friends and their family, not only because of a fear of infecting others, but because of fear of discrimination. To assess the attitude and knowledge of informants about leprosy, different questions were asked and different views were reflected from each of them. The first question was about their thought about causation. Seven informants of the interview reported, what they knew about leprosy was that they were destined by God to have it, and God also made provision for its treatment. They did not believe on scientific explanation of its cause. Though there is some improvement on this wrong belief, some of the informants still have a feeling that their disease is a gift from God for their and their family's wrong doings. The erroneous belief that leprosy is the gift of God is still held by most informants from the interview and participants from the FGD. Such beliefs, in part, contribute to the misconception that leprosy is incurable and the negative attitudes towards themselves. An informant³⁸ from the interview shared his experience as follows:

I never look myself as an equal person with other people who are not infected by leprosy. My physical appearance is very bad with injured legs. What I feel is, other people dislike me, and they do not want to be with me. Thus, I lost my self-confidence to participate in social relationship, to get a job. I prefer to be alone at home.

However majority informants noted that their thinking is changing from time to time. A participant³⁹ in the FGD states:

Now there is a modern medicine, when given to somebody with the disease, with God's help it becomes alright. We have to be strong and respect ourselves, if we do not have self-respect, other people will not accept us. We should have self-confidence.

³⁸ Interview with Sewinet

³⁹ FGD participant Tadesse

Furthermore, there is also a feeling of blaming themselves as they did something wrong. As explained by one of the informants⁴⁰, he still blames himself as the disease is his fault.

I think there is something which caused the disease to me. When I was a child, I used to love swimming very much. Once, when I was swimming, something like a man pushes my head inside the water. Then, after a long attempt, I was able to get out of the river. When I got out of the river, my body was sweating a lot. The following day, I became sick. Thus, I consider as it happened to me because I was alone at that time and assume as I have a bad sprit. Most of the time, I have a feeling of inferiority and I do not want to have a contact with other people.

Another informant⁴¹ from the interview has also similar feeling of blaming herself:

I guess a moment in my childhood might be the cause for the problem. In our tradition, it is believed that it is not good to go out on the sun immediately after painting hands with '*Ensoella*'⁴². But I did not keep the tradition. I was exposed to the sun immediately after painting. The following day, my hands and legs became wounded. Thus, I had been considering this as the main reason for the problem. Now, I regret with what I thought in the past... Of course, the doctors say that the reason is totally different from what I believed. But still, I condemn myself. Moreover, I usually blame my God, telling him that he made me unique among others, I always cry. I used to consider myself as a sinful person. Even now, I sometimes think in such a way.

Informant⁴³ further expressed his feeling:

I was fifteen when I saw rashes on my legs, and then my hands became injured. I always ask myself 'am I sinful? felt that my condition is my fault. I considered myself as a unique person. Since there was no body in my family with leprosy, I thought that God chose me because I was sinful even if I do not know what wrong things I did. Because of this, I expect other people disliking me and considering me as a horrible. Still my option is to be alone or to be with people who have similar cases.

In general, from the findings of the study, most informants are faced the challenges of self-stigmatization throughout their life. Some participants also have the feeling that they are

⁴⁰ Interview with Sewinet

⁴¹ Interview with Tigist

⁴² '*Ensoella*': Amharic word meaning a plant like red root used for ornament hands and legs

⁴³ Interview with Assefa

unwanted persons for marriage. One informant⁴⁴, for example, explained as he does not want to marry because of his health condition.

What is the use of marriage for me...? I am not a complete person to marry someone. I do not have a good looking and I am not in a good health status. What I know is nobody wants to marry me.

Another issue raised to analyze the informant's attitude was whether or not they need their case to be known by other people. In the beginning they were diagnosed, most of them did not have an interest to tell for someone about their disease. But as time went by, their body became damaged; they began to share about what happened on them. Contrary to this, those who have no physical deformity do not want to tell somebody as they are leprosy infected. Two informants⁴⁵ of the interview said that they want to keep their condition from knowing by others, since they have no disability and deformity. Other people cannot recognize them as having leprosy. They want to keep silent due to fear of stigma.

4.5. Impacts of leprosy stigma

All leprosy patients' life dimensions are negatively affected in most situations. The health, family and economic situations of them are highly discriminated and their burden been more serious. The informants showed that the impacts of the stigma can be explained as a core concept including: health, family, social, psychological, and economic experiences.

4.5.1. Social impacts

From the discussion with FGD participants, it was revealed that the disease become a serious situation that results on their live being complicated. It made endless injuries on their family interaction; separate them from their beloved family members, their mothers and fathers,

⁴⁴ Interview with Alemu

⁴⁵ Interview with Abeba and Zinash

and their spouses. “Even if our families did evil on us, we still miss them and want to meet them.”⁴⁶ Regarding the social interaction, issues like invitation to social functions and attendance in such functions were analyzed. Weeding alliance, how food is served to them, interaction with colleagues at work and their initiative in local affairs were also analyzed. As the FGD participants explained, in different holydays and ceremonies like weddings, food is served on separate plates for persons affected by leprosy. Most of them do not participate in social associations like ‘*Idir*’,⁴⁷ ‘*Iqub*’,⁴⁸ and others. Stigma results on them and their family members to move out of their original place of residence after the diagnosis of leprosy. They were allowed to use only a specific area. Due to fear of stigma, informants explained that they still do not want to go outside their area of living, the leprosarium, ‘*Zenebworqe*’. They cannot go anywhere they want. As explained by informant⁴⁹, she has suffered from social problems due to stigma.

I wish that God kills me as soon as possible to get me off from this painful life. For many years, I have been alone, no one sit next to me and talk to me for even a few moments. Some informants remained unmarried, sidelined and isolated. They said, they do not have even friends to share their feelings and ideas. A participant⁵⁰ in FGD explained, his first wife left him when she found out he had the disease, in fear that she would be attached to the stigma or contract the disease herself. This makes him to be alone and to be hopeless. Stigma also interrupts the relationship that informants have with their family member. For example, one FGD participant⁵¹ expressed the impacts of stigma on his family relationship:

⁴⁶ FGD participant Abebaw

⁴⁷ ‘*Idir*’: an association of people that have the objective of social and economic insurance for the members in the events of death, accident, damages to property, among others

⁴⁸ ‘*Iqub*’: an association of people having common objectives of mobilizing resources, especially finance, and distributing it to members on rotating basis.

⁴⁹ Interview with Almaz

⁵⁰ FGD participant Abebaw

⁵¹ FGD participant Addis, age,38, April 20, at Medhin Social Center

When my family found out that I have leprosy, the immediate reaction was they stopped me from entering into the house and they wanted me to stay away from them. They thought if I am around, I can transmit the disease to them. They became anxious to see the wound. They said that this disease would infect them. Seeing the wound, they started to hate me.

Another aspect of the social interaction examined in the study was the accessibility of the local services such as haircut in the village, local tea shop and local clinics and government organizations. When we see the impact of stigma on the use of different community services, only some of the informants took initiatives to meet government officials regarding local problems. Even if the accessibility of these services is improving from time to time, these places become another sources of stigma. “When we go to local services like clinics, they do not serve us equally as other healthy people.”⁵²

4.5.2. Economic impacts

From the finding, the loss of income is one part of the overall leprosy related stigma issue, and is itself governed by the attitude of the employers. As key informant⁵³ explained,

In the majority of cases, a lack of knowledge and understanding of the facts about leprosy leads to the assumption that leprosy will be easily caught by anyone coming into contact with an affected person. In the work place, this is obviously going to be a highly unwelcomed problem, leading to the stigmatization of the leprosy affected employee. Colleagues refuse to work with the person; customers may refuse to be served, or will stop business altogether. This is all amplified by the appearance of visible deformity.

From the interview held with informants, it is clear that the main source of losing job/ income is not only the debilitating physical effects of leprosy. In the majority of cases, there is a physical problem of some degree, but in most cases there is stigma related income loss.

Interviews highlighted several incidences of income loss of leprosy-affected people due to stigma. Most commonly a physical effect of leprosy diminishes income generating capacity,

⁵² FGD participant Trunesh and Getachew

⁵³ Key informant Abel

which then works alongside stigma. A female FGD participant⁵⁴ had been working in restaurant as a cleaner. She recalled the following situation when she was diagnosed as having leprosy:

Before the time that I was infected by the disease, I had worked in a number of places. I was healthy and I could do anything I wanted. When I began to see the symptoms, I started to be worried about it. My colleagues began to stigmatize me and said that they do not want to work with me. Then my employers told me that I do not fit the job and I have to search another job.

Poverty and low socioeconomic status is another issue where participants suffered from.

The patients who lost their job have not any income. One informant⁵⁵ said that

No one accepts me as a worker even if I am ready to work. Most employers told me as I am unable to work. I used to beg for years in the past and I had no job, no income. I am disappointed.

Begging is a common result of stigma. As pointed out by another informant⁵⁶

I had been employed as a school guard for two years, and I was enjoying the work. But after two years they fired me. When I ask the reason for losing my job, they told me that I am not an appropriate person to be a guard. To be fired for having leprosy is a common occurrence in my life which makes me sad.

Another case of stigma related to income loss was made by an FGD participant⁵⁷, age 40 and he said:

I had tried every work, including manual, farming, digging and any other works; I was able to do any work. However, due to my health condition, no one wants to employ me and to work with me. When employers see my body and my face, they respond me as I cannot do that work. Now as I am being an old person and I become hopeless I have one option which is going to church and beg.

This man developed visible signs of leprosy wounds on his hands and feet, and as a result of this he was unable to get work. His income suffered as a result of the stigma from both his potential

⁵⁴ FGD participant Addis

⁵⁵ Interview with Sewinet

⁵⁶ Interview with Alemu

⁵⁷ FGD participant Getachew

employers and colleagues. And he obviously felt that he was still physically able to carry out the work. Another informant⁵⁸ also has similar experience:

After I got a serious wound, usually employers did not want to offer me to work. But sometimes they offered me work when no other laborers were available there. Because there were wounds in my hand and feet, they usually told me that I had to work separately, not with other workers. Other laborers usually told me that if I went to anywhere for work they did not want to go there with me.

A similar case is found with FGD participant⁵⁹ who prior to leprosy, had been worked as a daily laborer. A female participant said her situation changed with the onset of the disease, and the associated stigma.

In the beginning I was not accepted to work with other laborers. So, I could not earn at that time. I had to take a loan to meet day-to-day expenditures. Because people wouldn't like to work with me, I had less job opportunity.

Another clear example of stigma affecting income generation was made by an informant⁶⁰ He was required to work on a farm due to an unpaid loan of his father.

My father had died when I was a small boy. I survived in my mother's sister's house and I had to pay some loan which was borrowed by my father. To pay that loan I became a servant of the lender. During that period he did not give me any salary, just food. With the onset of leprosy and the appearance of the visible signs of the disease, I had encountered stigma leading to a loss of income generation. After I developed the wound my owner refused to give me that work, so I lost my job, then I came to Addis Ababa.

Some study participants have a belief that they can work equally as healthy persons. However, an informant⁶¹ made a reference to some negative effects of the medicine taken. "My work efficiency has considerably deteriorated after this disease. The medicine creates weakness."

⁵⁸ Interview with Assefa

⁵⁹ FGD participant Hawa

⁶⁰ Interview with Kebede

⁶¹ Interview with Zinash

For some of the informants, the physical effects of leprosy prevent the continuance of physically based employment, which is the main type of employment for uneducated and poor people.

I am unable to work because I have deformity on my hand and leg. I stopped working when I got this disease because I am weak, have no power to work. Before that, I used to do all kinds of work, household and working in the field. Then I got a wound, I stopped working.⁶²

For other study participants, the physical effects are less inhibiting of their work activities, and will simply restrict the amount or type of work that they can carry out. The thing that inhibits them to work is the stigma from the society. The following examples highlight this point.

I don't feel any difficulty in doing work. I soak and scrub my hands and feet every day to remove dead skin and after that I apply oil, and that keeps me fit⁶³

Interviews highlighted several incidences of income loss of leprosy-affected people, due to stigma. The level of visible deformity, as mentioned previously, is also play a large role in the life of participants, the more visible the leprosy, the greater the likelihood of stigma and income loss.

4.5.3. Psychological impacts

As a result of stigma, people affected by leprosy often experience a loss of self-esteem, dignity and feel fear, shame, hopelessness and guilt. As informants clarified, they are experiencing stigma at home, in the community and in the work place. This has a number of psychological consequences. The common effects are an overriding sense of disappointment, anger and sadness. As explained by an informant⁶⁴,

When I know that I was infected by the disease, I was old enough. It was in 1990 EC. Before that, I used to be sick though I did not know the reason behind. I did not go to the hospital immediately after the problem. After coming to ALERT Hospital, I felt partially

⁶² interview with Alemu

⁶³ Interview with Sewinet

⁶⁴ Interview with Solomon

happy as the problem is known but partially, I was sad. The reason why I felt happy was that it is better to attend medication than the disease remains unknown.

Key informant⁶⁵ also described that:

Stigma impacts the lives of leprosy affected people in many ways. Due to stigma, leprosy victims have feelings of fear, grief, depression, shame, guilt, anxiety, low self-esteem, hopelessness and anger. Mostly they have negative thoughts and beliefs about them, the world and the future. For example, 'I am nobody'. These feelings therefore lead them to be isolated and to have restricted social participation.

Informants further described their initial feelings at the time they were diagnosed, as very stressful, miserable, challenging and difficult to accept. One of the informants⁶⁶ said that.

I was a student of 4th or 5th grade, at the time the doctors announced me that I have leprosy ('*Tiliku beshita*'⁶⁷). I was trying to suicide myself for three times but God saves my life, because he wants me to be alive to teach others. Still I always crying closing my home and I want to become alone. I lost the meaning of life on earth, I had the interest to continue my education but I am forced to drop it. With the help of God I have been able to reach 10th grade.

Another informant⁶⁸ expressed her feeling as:

I was fifteen when I saw rashes on my legs then my hands became damaged. And I asked myself 'am I sinful?', felt that my condition is my fault. I considered myself as a unique person. Since there was no body in my family with leprosy, I thought that God choose me because I am sinful even if I do not know what wrong things I did.

Some informants expressed their feeling as they had bad feeling but some relief as their sickness been recognized, because they had a hope of getting treatment before their body become deformed. One informant⁶⁹ said that

Before I know the cause of my sickness, I was worried, fearing of losing my legs or hands even fear of death. However, as I know the cause of my sickness, I was both terrified and had some hope of getting treatment. If my illness was not identified, I could

⁶⁵ Key informant Meron

⁶⁶ Interview with Sewinet

⁶⁷ '*Tiliku beshita*': the Amharic word meaning a big disease

⁶⁸ Interview with Tigist

⁶⁹ Interview with Assefa

lose my body, since I am able to get drugs I can survive without any disability. But still I am always unhappy, stressed.

This was also the feeling of Zinash. There was again a mix of emotions and attitudes among informants towards their health condition. Some informants seem to accept their condition, and are confident in their ability to convince people of their cured status. Others are less confident and are greatly troubled by the anticipated stigma problems that have been experienced/ have already been encountered. The extreme examples of this condition are seen in most informants.

4.5.4. Impacts on health

As the informants explained, fear of stigma and discrimination prevents people with leprosy from seeking medical help; if they do seek help they can face discrimination from health workers themselves.

The result of the findings shows that leprosy affected people encounter with numerous inevitable leprosy complications which reflect reality of their life and make them vulnerable groups. Informants believed that they are never asked about their problems, needs and demands and their remarks have not been considered in health care planning. This belief emanated from the discrimination and stigma from the society. As explained by an informant⁷⁰,

After I came to ALERT Hospital and started taking the drug, I was not strong to overcome the stigma that I was facing from my neighbors, since they know that I took the medicine. They were asking me about it. This forced me not to go for treatment because of fear of stigma. As a result I discontinued the medication which made me to lose part of my body. Now, I think that I would be in better condition if I had gone for treatment then.

As explained by key informant Abel, another reason why leprosy patients stop taking the medicine is due to some side effects of the drug.

Some patients may develop some side effects like weight gain, darkness on the skin color. Thus, this makes patients to hate taking of medicine. They think that other people may notice their physical change which in turn leads to stigmatization. Nevertheless, the

⁷⁰ Interview with Almaz

main reason for not seeking the treatment is a lack of awareness and fear of stigma. Most patients do not want going to ALERT. This is because they have fear of being known by other people as they are infected by leprosy.

Chapter Five

5. Conclusion and Recommendation

5.1. Conclusion

The results of the study indicate a dimensional picture and deep description of life experiences of leprosy affected people who are suffering from different problems. In all study participants, the description of daily living story is full of miserable experiences and negative feelings. The health, family, social, and economic situations are negatively affected by leprosy stigma. This study indicates a clear picture and deep recognition of life experiences and impacts of stigma in the group of patients/informants/, and it can help us in a better understanding of all aspects of patients' lived experiences.

From the assessment of participant's experience, today, leprosy is clinically cured relatively easily. However, it is still a stigmatizing condition and can lead to the person affected being rejected and excluded from the society. Stigma itself is a complex issue, with the capacity to affect all aspects of a leprosy affected person's life.

The finding shows that, in several cases, people affected by leprosy are separated from their family. In many cases, they are ostracized by their family. This has a profound effect on the well-being them, as to be cut-off from one's family is unthinkable. For a family to be willing to act in this way towards a close relative, shows the degree to which leprosy is feared in the local culture. It overrides the importance of family ties and duties.

The question of whether leprosy stigma has an impact on economy for the person affected by leprosy was addressed in the study. As described previously in literature review, there were several cases in the study where stigma did indeed account for a decreased income. Although this was not true in all cases, sufficient evidence was discovered to show that this is a

current problem faced by people affected by leprosy. Where a stigma related problem was present, the economic consequences for the person affected by leprosy were extremely high.

The general pattern of the situation for a person affected by leprosy, as determined through this study, is subsequent disclosure to the family and community, losing employment and feeling of sad. This is manifested in several ways. Verbal abuse, ostracism from social functions, enforced isolation and separation from the family, and also the loss of income generation and a decreased standard of living. When this aspect of stigma happens, the person may be forced into destitution.

In majority participant's case, going forward for treatment is left too late to avoid deformity. This is due to lack of knowledge of the symptoms of leprosy (i.e. the person does not recognize that he/she could have leprosy), and due to fear of stigma. Once leprosy has been diagnosed, then it is only a matter of time to stigma begins. If treatment is not received soon enough, deformities will develop, most commonly of the hands and feet. As a result of this, the act of avoiding stigma by not going forward for treatment is taken as an option.

From the study, we can conclude that even though there is some improvements in current situations, stigma on leprosy victims is evident. However, when we see the interventions and campaigns to change public attitude, it is very less as comparing to the problem. The issue of stigma is not getting attention from the government and the concerned bodies.

5.2. Recommendations

Based on the findings, the study has recommendations for programs and intervention planning on leprosy. Recommendations are proposed on how socio-economic dimensions may be incorporated into leprosy control programs to reduce stigma and fear on leprosy patients and to increase community acceptance of leprosy patients. To look at leprosy patient's story may help

health care provider and social policy maker to better understanding of all aspects of such patients' lived experiences

As explained by the study participants, they need a comprehensive health care program. The public enlightenment is necessary for changing public attitudes. Therefore, the study recommends that policy makers and other sectors who work on leprosy should cooperate to improve the existing interventions.

In order to achieve success in implementing a community care for leprosy patients, it should not left for the health workers only. Thus, the study recommends that everybody has responsibility to reduce the stigma on leprosy affected people. This begins from leprosy patients themselves. As the study participants suggested, in order to change public attitude, it is necessary that first they should take good care of their wounds, wear clean clothes and bath regularly. As they put forward, in past time, when leprosy patients were sighted, they were so ill; they did not look good at all...They were looked down upon. Thus if they do good self-care, no one dislikes them anymore.

Another thing that the study implies is that understanding the situation of people affected by leprosy in a given area should be part of the health care programs on leprosy, rehabilitation or health education as well as in advocacy work. Data on stigma strengthen the advocacy on behalf of those stigmatized. Such data awaken the interest of the public to the plight of those affected by the stigma.

The study further recommends that interventions on leprosy stigma should also consider the intensity of stigma between different people groups and communities, and try to discover factors that increase the risk of stigmatization.

There should be much work to enhance community ownership of all the interventions and services rendered by government and non-governmental organizations through giving continuous training to community leaders who have direct contact with the community. Because, these community leaders play an important role in changing people's wrong assumptions, perceptions and attitudes towards people living with leprosy.

Much work has to be done to educate people about leprosy and decrease the false beliefs that underlie its associated stigma. Teaching patients and the community is vital to improve the community's attitude. Teaching those with leprosy about their disease enables them to be empowered in their treatment and to have the confidence and knowledge to counteract opposition they may face from others. This can help acceptance of their condition and decrease their feeling of shame. It is not enough to educate only patients. The community needs to be educated as well. One way of changing perceptions of leprosy may be using of the media. All components of the media should be targeted, including radio, TV, music, billboards, and wall posters.

People affected by leprosy should also gain counseling to help them cope with their disease and avoid self-stigmatization and empower them to face discrimination.

Another recommendation of this study is, as the attitudes of health professional's influence how patients and communities perceive leprosy, it has to be done on health professionals to have a positive attitude to leprosy patients.

5.2.1. Recommendation for Social work Implications

From the findings of the study, the problem of stigma on leprosy affected people is not getting much attention from the community and the government. To prevent and reduce stigma, and to help the affected people, efforts from the government, religious institutions and helping

professions are crucial. Therefore, the roles of social workers in connecting the community, awareness raising and advocacy are needed in many ways to reduce stigma and its negative consequence on the lives of the victims and their family. Social workers should also engage in advocacy programs aimed at bringing the better conditions for affected people so as to help them overcome the major challenges identified by informants of the study.

This research further affirms the necessity of strength-based approaches to interventions dealing with stigma reduction. This helps to explore and develop the strengths perceived and explained by informants of the study to create better lives and create the awareness of the community and policy-makers. The more that the community and its leaders recognize the scope of the problem, understand its implication and the severity of its economical, social and psychosocial consequences, the more likely a consensus to take action will develop.

In addition, social workers should participate in programs like community conversation that encourage communities to share feelings previously kept secret and to facilitate self discovery, positive subjective interpretation, and acceptance of different health conditions. In addition, there is a need for programs that treat leprosy affected people with equal attention, economically, psycho-socially, culturally, spiritually as well as politically.

Moreover, social workers may develop mechanisms like community-based literacy programs or short term trainings and workshops on issues of leprosy, stereotyping etc; are important in reducing stigma. This is important because it can particularly help leprosy victims to develop their self-esteem, and confidence needed to improve their well-being. For doing this, utilization of community-based institutions would be a mechanism to deal with the issues.

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Appendix 1: Informed Consent Form

(For leprosy affected people)

Good morning/afternoon.

My name is Meaza Tadele. I am a student in Addis Ababa University School of Graduate studies, School of Social Work. I'm undertaking a research for the partial fulfillment of Masters Degree in Social Work. The main focus of the study is to assess the impacts of leprosy stigma on leprosy affected people. The purpose of this study is to gather information that will help me to understand the existing situation of leprosy patients, and generate valid recommendations. I am conducting interviews with key people, like you, to achieve the goal of my study. I would like to get your permission to interview you and discuss with you about your experiences related to this health condition.

Furthermore, I would like to assure you that everything you say will be kept confidential. Your name will not be used in any reports. In addition, it is up to you if you wish to take part in the interview and to answer any or all of my questions. The interview would take no longer than an hour, but can be stopped by you at any point.

If you have any questions about the purpose of the interview, or any other questions, you can raise.

If you agree to participate, please sign two copies of this form, one for you to keep and one for me.

Participant's signature _____

Interviewer's signature _____

Date _____

If you have any further queries regarding issues discussed during your interview, please contact Meaza Tadele (Researcher) at (telephone number) 0912152035

Appendix 2: In-depth interview guide

(For leprosy affected people)

A. Demographic information

1. Sex
2. Age
3. Religion
4. Marital status
5. Educational status
6. Place of origin
-current address
7. Livelihood
8. Health status

B. Background information of participants

1. When and how do you know that you are infected by leprosy?
-where did you live when you began to see the signs and symptoms?
2. What was your feeling as you know that you have leprosy or at the time of sign and symptoms appeared?
3. What measurements did you or your family take?
-Did you go to the hospital to take a treatment? If yes, where do you get treatment?
- Did you and your family tried to treat you by any other means rather than going to hospitals? If yes what was that?
4. How long you been infected by leprosy?
5. Is there any other member of your family who has this health condition?

C.knowledge, feelings, perception, and self-stigma

1. Have you ever heard about the disease before you know that you have it?

- If yes, what was your perception about it?

2. What do you think is the cause of the leprosy disease you have?

- do you feel that your condition is your fault (have you blame yourself? Or God's willing?)

3. What do you know about the transmission and treatment of leprosy?

-Do you think that contact with you might have any bad effects on others around you even after you have been treated?

- have you tried to avoid hugging and kissing other people out of your fear of contagion?

- How do you develop your knowledge or what situation helped you to know about the illness, its cause and treatment?

4. Do you think that you should keep the condition from knowing by others, if possible?

- If yes, Why? From whom?

-Have you discussed this problem with the person you consider closest to you?

5. Do you feel embarrassed or ashamed of that you have leprosy? If yes why?

- How good or bad do you feel because of you have this health condition?

-Do you disappointed in yourself for having leprosy?

-How often do you feel happy even though you have this condition?

6. Do you feel that you are different from others because of your health condition?

- Do you feel inferior to others who don't have leprosy?

- Has it reduced your pride or self-respect?

7. Do you think that having leprosy has spoiled your life?

-Do you feel that you will always been sick?

D. Stigma experiences

➤ Family and marriage relationship

1. Has the condition affects your family relation? If yes, how?
 - Is there any difference in your relationship before and after the sickness?
2. Have you get enough treatment from your family at the time of sickness?
3. Have you felt that your family are proud of you?
 - if no, what is the effect on you?
4. Have you tried to use household utensils separately from other family members fearing of transmission?
 - Have your family members avoided sharing household utensils with you?
5. Do you feel that leprosy makes it difficult for you or someone else in your family to marry? If yes, Why?
 - Have you or your family member been forced to dissolve marriage plans because of the condition?
 - Have you experienced divorce because of the condition?
 - Have you avoided marriage to an unaffected person fearing mistreatment after marriage?
 - Have you feared that marriage with an unaffected person may end in divorce?

➤ Community, social, and civic life

1. In your community, does leprosy cause shame or embarrassment? If yes, how it affects you
2. Are you socially active as your peers are? (E.g. in religious/community affairs)

-Do you take part in major festivals and rituals as other people do? (E.g. weddings, funerals, religious festivals)

- Do you take as much part in casual recreational / social activities as do your peers? (E.g. sports, chat, meetings) If sometimes or no, how big a problem is it to you?

3. Is there an example where you have been treated in isolation at a social event?

4. Have you continued seeing and spending time with your (unaffected) friends?

-Have your friends been visiting you less or spending less time with you because of your condition?

5. Has anyone in your neighborhood deterred you from taking part in group activities?

- Have you decided on your own to stay away from the social group? If yes, why?

-Have you avoided asking neighbors for help, or to borrow items because of your condition?

6. Do you have the same respect in the community as other people?

-If sometimes or no how big a problem is it to you? And what you think about the reason?

-Would people in your community think less of your family?

7. Do you make visits outside your village / neighborhood as much as your peers do? (Except for treatment) e.g. bazaars, markets

- Have you felt able to move around the community freely (without being stared at, pointed at or people noticing you?)

-Is there an example where you have been stared or pointed at when attending a social event?

- Have you avoided visiting public places like church, school or market?

8. Would some people refuse to visit your home because of this condition, even after you have been treated?

9. Have you ever change your residence? If yes, Why? Where is the former residence?

10. Have you received insults from others regarding your body damage?

11. Do you have equal opportunity to take care of yourself (appearance, nutrition, health, etc.) as your peers?

12. Have people ignored you, talked over you or told you to be quiet because of your condition?

-Have you or another person you know been welcomed (by unaffected people) while attending church, school or other community meeting places?

-Is there an example where you have not been invited to appear at public places?

13. Do you think that your condition deprives you from playing a leadership role in the community?

- Is there an example where you have been denied the chance of a leadership role due to the disease?

-Is there a situation where you have been denied the chance to make decisions in community matters?

-Is there an example where you have not been invited to appear at public places?

14. Do you participate in political issues as other people? (E.g. in election

➤ **Working conditions**

1. How often do you feel that your condition keeps you from doing things you like to do?

If yes or sometimes, what are the reasons?

2. Have you avoided any invitation to be employed for wage labor /job fearing stigma in the work place?

- Is there an example where you have been denied a job opportunity because of the condition?

3. Have you been mistreated at your work place due to the condition?

4. Have you been forced to leave a job because of the condition?

5. Have you feared unaffected individuals may feel uncomfortable working with you because of your health condition?

6. Have you avoided taking part in labour or other activities which require group involvement with unaffected people?

7. Do the people dislike buying food from you or from a person affected by leprosy?

8. Do leprosy cause difficulty for you to find work? If yes, why?

9. Do you work as hard as your peers do? (Same hours, type of work etc.)

If sometimes or no how big a problem is it to you?

10. Do you contribute to the household economically in a similar way as other persons who have no leprosy?

If yes or sometime, what is the reason? How big a problem is to you?

Appendix: 3

Focus group discussion guide

A. demographic information

1. Sex
2. Age
3. Religion
4. Marital status
5. Educational status
6. Place of origin
 - current address
7. Livelihood
8. Health status

B. stigma experience and impacts

1. How you explained your relation with your family?
 - have you faced stigma from your family? If yes what was the effect on you?
 - what is your current situation with your family and your relatives?
2. Does leprosy make difficulty on you to marry someone who you want?
 - have you experienced divorce because you are leprosy affected?
3. How do you explain your personal relationship?
 - with your friends
 - with your neighbors
4. Are you active in social activities?

- do you participate in social activities like *Idir, Iqub, Mahiber*?
 - do you have equal participation in religious, community affairs?
5. Do you think there is an improvement in level of stigma as the time passing?
- explain the current situation of stigma comparing with before
6. How do you explain stigma within your village and outside your village
- do you have equal respect as other people free of leprosy when you go outside your village?
7. Have you experienced stigma relating with your work?
- have you equally treated to get a new job as other people?
 - have you got fired from your job because you are leprosy affected person?
 - do you think that if you were a healthy person, you can have better income than you have now?
8. Do you feel you have been unhappy because of leprosy?
- Do you take your sickness like any other disease? If no what is the reason?
9. Have you fear to go to hospital to take treatment? If yes what is the reason?
- have you stopped taking of drugs because of fearing of stigma?
10. What you have to recommend to reduce the stigma that you are facing?

Appendix: 4

Key informants checklist

(For staffs)

1. Demographic information

-Sex

-Age

2. Work position

3. Work experience

4. How do you explain leprosy affected people?

5. Are they close to you? If yes how do you bring that closeness?

-are they willing to share their problem without any fear?

6. How do you explain about the status of leprosy affected people in the community? Are they still facing stigma?

- How is their social participation?

- How is their economic wellbeing?


7. What do you know about their family members, their children? Are they a victim of stigma, even they are healthy?

8. How do you think about stigma in working environment?

9. Can you suggest any solution to reduce the stigma and its effects of them?

I declare that the thesis entitled '*Assessment of the Impacts of Stigma on Leprosy Affected People: The Case of Beneficiaries in Ethiopian Catholic Church Medihn Social Center, Addis Ababa, Ethiopia*' is my original work. All relevant sources of materials used for this thesis have been duly indicated and amply acknowledged. I solemnly pronounce that this thesis was not submitted to any other institution anywhere and anytime for the award of any academic credential whether it is Master's Degree or Bachelor Degree or Diploma or Certificate.

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