A Study on the Psycho-Social and Economic Situation of Leprosy Patients in Ethiopia: The Case of Admitted Patients at Alert center

By
Yonas G/Mariam Burako

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This is to certify that the thesis prepared by Yonas G/Mariam Burako entitled "A review on the psycho-social and economic situation of leprosy patients in Ethiopia: the case of admitted patients of Alert center" submitted in partial fulfillment of the requirements for the Degree of Arts (school of social work) complies with the regulation of the university and meets the accepted standards with respect to originality and quality.

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_____	_____	_____
Examiner	Signature	Date
Haileom Banteyirgu (PhD.)	_____	_____
Principal Advisor	Signature	Date

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Abstract

A review on the psych-social and economic situation of leprosy patients is mainly conducted to see the psycho-social situations of leprosy affected people. Many studies have been done on the disease leprosy but little is done on the psycho-social aspect of the disease. This study also tried to give emphasis on the economic situations of leprosy patients. In conducting the research qualitative method was employed. The study area was selected purposively because of the long time experience of the service provision and has the largest number of leprosy patients. The respondents of the study were taken from both sexes and different background to get a variety of views about the issue. Data was obtained through in-depth interview, key informant interview, focus group discussion (FGD), and observation. Data found from different sources was collected and triangulated to assess the trustworthiness of the information and analysis was done. The findings show that, most leprosy patients come to the health facility after the disease damaged their body. It was also found out that, almost all of the participants were highly suffered from the psycho social and economic impact which the disease inflict on them. The study also shows that the social stigma attached to the disease was mentioned as a root cause for the psycho social and economic challenges which leprosy affected people are facing. This research answered how health care providers and social workers tried to play their role in improving the psycho-social and economic situations of affected people. Besides, the study tried to assess, how patients themselves perceive their situation. Thus attempt was made to look in to the holistic situation of leprosy patients. Finally, applying a biopsychic-social approach to health care can be recommended to mitigate the magnitude of the problem.

Acronyms

AALVRA -Addis Ababa Leprosy Victims Rehabilitation Association

ENAELP-Ethiopian National Association of Ex-Leprosy Patients

EU-European Union

GLRA- German Leprosy Rehabilitation Associations

MDT-Multi Drug Therapy

MOH-Ministry of Health

TB-Tuberculosis

TVET- Technical Vocational and Educational

WHO-World Health Organization

MOLSA- Ministry of Labor and Social Affairs

PWDs- Persons with Disabilities

CHAPTER ONE: INTRODUCTION

1.1 Background of the Study

Leprosy is one of the critical public health problems in developing countries; it affects every part of society the rich and the poor, the old and the young. Leprosy is one of the oldest diseases known to human kind (First, 2001). There is much speculation about where leprosy originated. Some writers suggest the upper Nile, other believe the river Indus valley or Israeli could be the cradle of leprosy. The earliest recorded occurrence of the diseases is seen in the skeleton of an Egyptian in the 2nd century B.C and mummified bodies of the 5thcentury A.D. (ENAELP, 2004).

According to WHO (2002), leprosy is now found in parts of Asia, Africa and central and South America. The distribution and prevalence of Leprosy is neither uniform nor random. In some parts of Africa more men than women are diagnosed with leprosy but there are some African countries where more women than men are affected (WHO, 2002).

Twenty million persons have been successfully treated for leprosy since the introduction of Multi Drug Therapy (MDT) in 1982. Roughly 800, 000 people, new cases detected each year are under treatment around the world at present time (Rafferty, 2005). Bekri (1998) stated that leprosy is caused by bacteria called Mycobacterium leprea, but the disease is closely interwoven with myths, superstitions and false conceptions. Hence, leprosy is widely thought to have natural and super natural causes. As a result, the majority think that leprosy is a punishment for something evil. In some areas it is related with witchcraft, the visitation of signs of past life, eating certain kinds of food or heredity (Raju&Koppatry, 2004).

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

According to ENAELP (2004), in addition to the physical and social consequences of the disease as it is stated above leprosy damages the whole economic life of those affected and results in poverty.

World Health Organizations (2000), states that 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, 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 and social health, but also can affect them physically. The shame associated with this disease can prevent people from seeking treatment until significant disability has occurred, while those who have been treated may never be cured in a truly holistic way nor be accepted back into society.

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 (non-compliance) because of fear of rejection by their community or a lack of acceptance of the condition. Non-compliance with treatment is a major problem. Even if patients are cured of their mycobacterium disease, the stigmatization can remain an insurmountable obstacle to the resumption of a normal life. Negative perceptions of leprosy still can be a barrier to the process of reintegration into their families, jobs and wider society. Complete cure requires that the barrier be overcome (Heinders, 2004).

Ethiopia is one of the least developed countries in the world, with vicious cycle of poverty from generation to generation. Access to modern education, health, infrastructures and other services are not available for the majority of Ethiopian population. Studies show that, for those with disabilities it is even worse (ENAELP, 2004). The disabled are the poorest of any given society in the country. Moreover, there is a misconception by the general public that persons with

disabilities are not feet or productive citizens; that the disabled are dependent up on the society and reliant on institutions and philanthropists. But the reality is that, disabled persons in general, and people disabled by leprosy in particular have joined together in regional and local associations and demonstrating that they can support each other and address issues of marginalization and stigma. In addition to this, people affected by leprosy are capable of earning their living, supporting their families and contributing to society. However, there are still many challenges that subsistence farming where there is only sufficient food to fed the family for part of the year means a move to the city to beg(ENAELP, 2004).

According to ENAELP (2004), self-employment activities in their own villages, such as petty trade, brewing local drink, and other economic activities are not profitable to the level of sustain their families as a result begging has become the major source of income for the majority of persons affected by leprosy, especially for those with severely damage hands, feet and faces. In addition to the physical and social problems, the consequent sufferings of the client from economic complications associated with leprosy are intense.

In Ethiopia the Ethiopian National Association of Ex-Leprosy patients (ENAELP) members are some of the most socially, economically and physically affected social group in the country. Most of them are illiterate and jobless living on begging. Almost all are isolated from the community due to leprosy stigma existing in the country. Consequently, the existence of rampant poverty in the country will be more sever among the disadvantaged ones like persons affected by leprosy, who are the members of ENAELP (ENAELP, 2004). The introduction of MDT in 1982 has been successfully in statistically controlling leprosy in relatively short period, at low cost, reduced relapsing rate, and minimized/ prevent deformity. Moreover, MDT is a cure rather than merely arresting the spread of the disease. Medically there is now no reason to regard leprosy as a special disease; this has led to the integration of leprosy treatment with other diseases. However, the social stigma handed down from generation to generation is more difficult to cure than the disease itself. Therefore, the biggest challenge to day is how to eliminate the age long deep rooted social stigma of leprosy and the socio economic problems it causes for those affected. In some countries, leprosy affected people have joined associations of people with other disabilities. However, where stigma is the core problem they are not accepted

as members of these associations. Hence, those affected by leprosy have formed their own associations in many countries including Ethiopia. The goal of such associations is to promote the truth about leprosy, minimize members medical and socioeconomic and advocate on behalf of leprosy affected people. For holistic care, we must never forget the impact leprosy can have on a patient's psychological and social well-being.

The study will be conducted at Alert Hospital which is a medical facility on the edge of Addis Ababa, specializing in Hansen's disease, also known as "leprosy". From the beginning, ALERT provided leprosy training for medical students from Addis Ababa University. Also at ALERT is the Armauer Hansen Research Institute, founded in 1970, specializing in leprosy research. There is currently a 240-bed teaching hospital, which includes dermatology, ophthalmology, and surgery departments, also an orthopedic workshop, and a rehabilitation program (peter, 2003).

Alert is the continuation and expansion of the leprosy hospital originally built by Dr. Thomas Lambie in 1922, which was later named the Princess zanabework Hospital. A memorandum to found ALERT was signed Dec. 11, 1965 by representatives of the Ministry of Health, Addis Ababa University, the International Society for the Rehabilitation of the Disabled, The Leprosy Mission, and Dr. Eugene Kellersberger of the American Leprosy Mission, who had had the vision for establishing such a multifaceted center and had been the main promoter of the project(Winifred, 1999).

1.2 Statement of the problem

Untreated or late detected leprosy causes nerve damage, which can result physical impairment and disfigurement, and in some cases, eye defects (Mesele, 2005). Moreover, the psycho social impacts of the disease become hazardous problem, which affects the economic and social life of the individuals.

In most cases, the physical deformity or impairment due to the disease provoked the stigmatized attitudes of the society towards persons affected by leprosy. This stigmatized attitude breaks the

social bond of the person within the society, and results in isolation and discrimination of the leprosy affected persons from the society. It doesn't mean that, only with disability due to the disease are stigmatized and excluded, but also people who are clinically cured and who have no clear manifestations of the disease suffered with the social consequence of the disease. Moreover, persons from leprosy affected family who have not totally infected by the disease became isolated, discriminated and excluded from the community (ENAELP, 2004).

The social exclusion is not only prohibiting individuals' relationships with the society, but also it affected the material and social assets of the affected persons. Moreover, it has also a significant impact on leprosy affected persons decision making and treatment success of the disease (White, 2007). It might be the case that the number of new detected cases of the disease remains constant over the last two decades (ENAELP, 2006).

Even though leprosy has psycho-social and economic impacts on the lives of the patients and their family, much of the work that has been done so far in Ethiopia concerns are medical detection and treatment. As the researcher discussed with experts and health workers at ALERT(All African Leprosy , TB Rehabilitation Training Center), and ENAELP (Ethiopian National Association of Ex-Leprosy Affected People), he recognized that there is a research limitation, in addressing the multidimensional psycho social impact of the disease in the country in general and in the study area in particular. Hence, the researcher believes that investigating such sensitive issue in such particular society is timely and helpful so as to understand the social impacts of the disease, and contributing to the psycho social and medical intervention. This research is therefore, anticipated to fill such research gaps.

1.3 Objectives of the study

1.3.1 General objective

The overall objective of the study is to assess the psycho-social and economic situation of leprosy patients and identify areas for social work intervention to improve the life of leprosy patients.

1.3.2 Specific objective of the study

- ✓ To assess the psycho-social situation of Leprosy patients in Alert center.
- ✓ To assess the economic situation of Leprosy patients in Alert center
- ✓ To understand the psycho-social and economic impact of the disease and draw social work implication

1.3.3 Basic research questions

- ✓ What do the social and economic conditions of people with leprosy look like?
- ✓ How do these impact their social, psychological wellbeing?
- ✓ What life style are leprosy patients forced to lead
- ✓ What coping mechanisms do leprosy patients use to deal with social, economic and other challenges they face?
- ✓ What social wok interventions could be put in place to improve the living conditions of people with leprosy?

1.4 Significance of the study

This study has explained about the psychosocial and Economic effect of leprosy. Besides, it can be is used as a source of information for Alert center to evaluate its intervention mechanisms and treatment condition of the patients.

The study may provide some insight and serves as a supplementary source of information for those people who deal with the psychosocial and economic effect of leprosy and who want to conduct detail study on the same topic and practitioners in the area as consideration of the holistic aspect of leprosy is neglected for long.

On the other hand, since the study primarily conducted to assess the psychosocial and economic effect of leprosy could be significant to enhance the awareness of the community about leprosy. It also helps to improve their attitude and knowledge toward the diseases and its psychosocial and economic effect on the lepers.

Moreover, the study might have a considerable contribution to researchers or other stake holders showing the gap both in terms of research and practice to necessitate further action and as well in

developing appropriate interventions by identifying factors that affect the psychosocial and economic wellbeing of the leprosy patients.

1.5 Limitation of the study

Owing to the social rejection they continuously face, and the inferiority complex that goes along with it, communication with the ex-lapers is understandably a difficult task. Therefore, to accomplish my assignment I had been in their places frequently to approach them as a friend. Because of the time limit of the study, it was difficult for me to spend so many hours in collecting the data in addition to other responsibilities I have.

The major limitations of this study is again due to time and financial constraints the sample which is taken as a case study is not considered as inference for the general population. Besides, some of the respondents were not willing to be recorded for their own reasons.

1.6 Definition of terms

Leprosy: is a chronic infectious disease which affects particularly the skin, mucus membrane and the nerves.

Social Exclusion: refers to the tendency of vulnerability of people to be excluded socially and economically due to the inability of society to treat with all groups' equality.

Stigma: is an attitude of identifying and labeling people, based on presumed thought to be un acceptable

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

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

CHAPTER TWO: LITERATURE REVIEW

2.1 Leprosy as a Disease

2.1.1 The nature of the Disease

According to Webster's Third New International Dictionary, leprosy is "a chronic disease caused by infection with an acid-fast bacillus (*Mycobacterium leprae*) and characterized by the formation of nodules on the surface of the body and especially on the face, or by the appearance of tuberculosis macules on the skin that enlarge and spread and are accompanied by the loss of sensation followed sooner or later in both types by the involvement of nerves with eventual paralysis, wasting of muscle, and production of deformities and mutilations".

2.1.2 The cause of the Disease

Leprosy is one of the earliest diseases to have been recorded: some of its clinical signs have been identified from descriptions given in the ancient literatures of Egypt, India and Israel. But it was not until 1873 that the Norwegian physician Dr G.H. Armauer Hansen discovered *Mycobacterium leprae*– the first bacterium to be identified as causing a major disease in man. Before (and even since) this discovery, many other theories were current about the cause of leprosy – that it was a curse from God or a punishment for one's own sins or the sins of others; that it was related to the law of karma or witchcraft; and that it was due to eating certain foods, hereditary disposition or even sudden changes of temperature (Frist, 2001)

2.1.3 Transmission of the Disease

Leprosy is a communicable disease, and the human being is the only known route through which other human beings can become infected. Although the process is not fully understood, it is thought that the bacillus is passed from one person to another through the skin and upper respiratory tract. People with untreated multibacillary types of the disease are the main sources of infection; the household contacts of these untreated multibacillary patients are the population most at risk (Frist, 2001).

2.2 Psychosocial and Economic Impact of Leprosy

Effects of leprosy on community health and wellbeing of individuals and families, according to the Ethiopian TB/Leprosy guideline (2012), Leprosy is caused by Mycobacterium Leprae. It is a

disease affecting the skin, (where the signs of infection are often first discovered and other organ eye, upper respiratory tract and muscles), and the involvement of leprosy can be explained in terms of disease (biomedical perception), illness (self-perception) or sickness (social perception). Leprosy is experienced and shaped by cultural and social influences. It is perceived and named by society, mostly causes of social stigma. Leprosy, one of the major public health problems in some developing countries and well known for the strong stigma associated with it. Leprosy is associated with poverty.

Moreover, most people appear to be naturally immune to leprosy and do not develop disease manifestation under normal circumstance; only very small proportion (less than 5%)of all individuals who are infected by the leprosy bacilli will develop the disease during their lifetime. On the other hand Yawaldar (2002) stated that leprosy is more of social problems with extreme dimensions such as, ignorance fear and superstition surrounded the problem of leprosy. By definition, it is well known that leprosy is a social disease carrying a stigma which disadvantages the sufferer and his/her family in a society and which often leads to premature "social Death" .The disease causes its victims to be physically disabled, economically dependent on others and socially outcasts them from the community).

In the world of today one can find that between 11 and 12 million people have suffered from leprosy. Scott (2005) suggested that much research has been conducted on the medical aspects of leprosy, but there is a need in various parts of the world for specialized studies of the psychosocial aspects of leprosy.

Every year between two and three hundred thousand people are diagnosed with it and an estimated two to three million people around the world are disabled because of leprosy. Leprosy can affect people in many ways, not just physically. In some countries, largely due to myths and superstitions, there is a great deal of fear associated with leprosy – people diagnosed with the disease can be stigmatized, rejected by their families and communities, they may lose their jobs and end up without a home or source of income. The Leprosy Mission should cares for the whole person focusing on the physical, social, spiritual and psychological needs of leprosy-affected people (MOH, 2005). Besides, the psychosocial needs of leprosy patients are dissimilar. Their

needs appear to be three-fold: the need for self, societal and community acceptance. Self-stigmatization after diagnosis is not only true of leprosy sufferers, and is often of a permanent nature. Some leprosy sufferers never accept the disease. A special need of self-acceptance is required in a sufferer. Their families' reject many patients on account of the latter's fear of leprosy. They may even request the patient to leave home (Scott, 2005).

The word 'leper', like most labels, is offensive; people shouldn't be defined by their disease. But leprosy through the ages has provoked great fear in many societies, largely because of misunderstanding. This fear is still prevalent in some countries and stigma is an issue that leprosy-affected people have to face. For some it even means being rejected by their communities, or divorced from their spouse. It can be tough for people affected by leprosy to get the help they need (Aboon, 2006).

The social and cultural background of the patient determines many of the problems that may be encountered. The client may have difficulty in coming to terms with leprosy. The community may reject the patient's education, employment, and support from family, friends and doctor and plastic surgery to correct stigmatizing, deformity all have a role to play (Aboon, 2006).

The adverse effect of leprosy on both the victim and the society is very huge. Discrimination and stigma are central features of the social impact of leprosy in addition to the many problems that leprosy victims are facing even today. As stated by Kazeem&Adegun, (2011, pp. 104)social constructions of leprosy are commonly steered by cultural, traditional and religious beliefs or myths about disease and illness not only in low resource settings like Ethiopia and many African countries but also in Western. Leprosy patients may not be sympathetically treated in medical instances; in India, cases have been reported of doctors refusing to treat leprosy patients. Leprosy sufferers have a strong desire to be accepted in the community, especially in the labor market (Scott, 2005).

Patients who seem to suffer most psychological damage due to leprosy are educated adults, in particular, those who have held a prominent place in society, with a good career or job and those who have a family to support. Many fear ostracism by society and feel for their family members

who also may be rejected by an intolerant and ignorant community. Tragically, those in this group who psychologically suffer most of all are the ones disowned by their most intimate family loved ones. A husband may reject his patient wife or vice-versa. Sometimes, a leprosy patient with relatives who have a covetous attitude towards his property, sense that he is under their "death wish" and this, too, has a devastating psychological effect. Those patients from the more affluent, "higher" strata of the community, and particularly those with daughters, have been known to commit suicide because leprosy in the family makes a marriage arrangement difficult, if not impossible. So great can be the strain and trauma of facing such enormous problems that those unable to commit suicide often are affected mentally (Scott, 2006).

Scott (2006) cited that, in addition they become timid, withdrawn, and isolated and lose self-confidence and self-esteem. It is difficult to picture a socially created status more damaging to self-regard than that of leprosy. Ultimately the leprosy victim loses social status and becomes secluded from society family and friends. Frustration with employment, crippling deformities and social exclusion may finally force him or her in to alcoholism, begging and adoption of a hostile attitude towards society. This condition is known as Dehabilitation. Eventually, leprosy Patient may be forced to leave his or her home and settle in a rehabilitation home or leprosy colony with other leprosy patients. This final stage is known as destitution.

As cited in Kazeem&Adegun, (2011, pp.104), in general, the extensive and adverse impact of leprosy stigma leads to avoidance and delay of seeking healthcare services, deterioration of personal health and socio-economic status. Research in leprosy has been quite consistent in showing that stigma is a deterrent to leprosy elimination

2.3 Leprosy stigma and social exclusion

Leprosy is the oldest and "the gold standards stigmatized disease" which is known as social diseases (Ramakrishina and weiss 2001, P.3). According to Goffman's Social Theory, stigma is applied to any condition, attribute, trait or behavior that symbolically marked of the bearer as "culturally unacceptable" or "inferior" (Branaman and Lemert, 1997). The symbolic attachment with people involves 'normality', 'difference' and 'acceptability' (Jenk, 2003).

Hence unacceptability of leprosy- affected person often occurs due to the difference that an individual embodied or actualized in his or her life. The word "leper" has a mythical status that the community used to disregard patients (Duff, 2005). Teklehaymanot stated in subramansam (1999) that the name *'Kumtina'* was also given to leprosy in Ethiopia, denoting "state of amputation or mutilation".

There are two possible reasons for the cause of leprosy stigma. The first reason is related to the deformity and disability effect of leprosy (Barrett, 2005). Leprosy is a very chronic disease that exposed individuals to disability. People who have been defected are stigmatized since their deformities are visible to whole community (ENAELP, 2002, 2003; 2004 and Jenks, 2003). The physically damage of people due to the disease has a consequent effect to other parts of people life. Although the physical deformity or impairment that provokes stigma, other people who has direct or indirect relation with the affected person also victims of the society. People who are early treated and cured, and the non-leprosy persons from leprosy family – only their association with someone with the disease still suffer with social stigma (ENAELP, 2002; ENAELP 2003, Mesele, 2005).

The second reason is related to misconception and belief of the society about the cause and transmission of the disease (Mesele, 2005). It develops fear and prejudice, which in turn breaks the social fabric of individuals in their living area.

Different societies regarding their religious beliefs and cultures have different perceptions and belief on the causes of the disease. Some suppose that leprosy has been incurred as a punishment of God because people sin or are impure. For example, the Hindus in India consider deforming due to leprosy is a result of divine punishment. A similar view is shared in China where leprosy is considered as a punishment of 'moral lapse'. They believe that the disease has been transmitted during sexual intercourse with prostitutes (Ramakrishana and Weiss, 2001). More over in Ethiopia, the survey study in Gunichire Gurae Zone, southern region shows that among the leprosy affected, non-leprosy and non-leprosy family respondents 52.7% time were believed that leprosy is the result of curse and calamity, while only 13% of the respondents understands the causes of the disease correctly (ENAELP, 2003).

Still some other society considered leprosy as a hereditary disease (Mesele, 2005). The belief is also widely spread in India, Malaysia, China and Africa (Ramakrishana and Weiss 2001). It was also one of assumptions of the medical professionals before Hansen first identified "M. Leprae bacterium" is the causes of the disease in 1873 (Jenks, 2003). The belief is also deeply rooted in Ethiopian culture (Mesele, 2005).

2.4 The Dimensions of Social Exclusion

Social exclusion is a concept focuses on whole person who is "cut off" from different angle of the social bond that attached to the society. It is reflected in a combination of "a lack of normative integration and low degree of social participation, material deprivation, and insufficient access to social rights" (Gijisberg and Vrooman, 2007; 18; Sene, 2000). Thus the leprosy affected persons are the marginalized and stigmatized group that has multidimensional and interlinked problems. They are excluded from social and economic rights (Jenks, 2003).

2.4.1 Social Relationships

Leprosy breaks human relations geographically as well as socially. Since 20thc, structured type of disintegration on the leprosy affected person has been shown in Ethiopia (Mesele, 2005). Mesele confirm that leprosy affected person and their families were settled in a geographically isolate area, because of the intention of the emperor Haile selassie regime to limit the spread of the disease to only to the already infected people. As a result different colonies and settlement areas has been established in several areas of the country. For example, a number of leprosy sufferers have been raised in St. Anthony Colony near to Harar and prince Zannebawark colony at the edge of Addis Ababa, which was established in 1901 and in 1932 respectively. Since then, these areas are expanded and much known as leprosy villages (Mesele, 2005).

A number of leprosy sufferers specially the disabled still voluntarily migrated to these villages to get relief from stigma or for the intension of getting better medical treatment. This kind of condition, according to calcraft (2004. P.4) is called "dehabilation of leprosy affected people", which means that the physical displacement of people because of loss of their former social position. Hence, these people may face cultural shock since they are new to environment (Merill, 1961). More over some of these people are separated from their families as well as from their own children. They may suffer with their loneliness. According to the psychological therapist Dennis (1987), loneliness my expose persons to trauma consequently, he/she may get in post-

traumatic problem unless they get appropriate counseling and support. In addition due to either their loneliness or stigma attached to the disease, peoples with leprosy have high risk for exposing to mental health. The study under taken in all Africa leprosy Rehabilitation center (ALERT) on the mental illness of leprosy and non-leprosy patients shows that the number of leprosy patients who exposed to mental distress is seven times greater than the non-leprosy patients who are similarly treated in the hospital (Lekeassa, 2006).

Besides the displaced people, a number of people are preferred to live in their locality even if they are neglected and isolated from the community. It is reflected in different social and cultural human relations established in the society. Marriage is one of a significant aspect of humans integrated in the society. Research results showed that the stigma of leprosy does have an impact on marriage for leprosy-affected individuals and also on the marriage prospects of relatives (Mesele, 2005, Jenks, 2003, ENAELP, 2002, 2003). Either the society does not allow marriage with these people and their families due to the class strata and social order established between the leprosy affected and the community, or the social fear of contagion or being infected (Mesele, 2005). Hence the leprosy affected persons are obliged to look a spouse among the families of their 'own kind' (Jenks, 2003, Mesele, 2005). This sense of identification of classes according to Merrill (1961) is known as self-identification. Moreover, leprosy is also the main reason for divorce. Ato Negatu, he is a key informant interviewee under Meseles' study, said that 'when mother identified my disease, she said that me to divorce her child. We divorced crying'. It implies that divorce has done unwillingly with the influence of the parent (Mesele, 2001).

2.4.2 Social Participation

The other form of disintegration is lack of participation in different role of the society. Stigmatized people are not considered as capable to overcome the social function as others. Thus, they are isolated from participating in community based organizations, formal and non-formal community meeting and from cultural and religious festivals (Sen, 2000). The managing director of ENELAP during the exploratory interview said that there are no clear rules that isolated the affected persons, but the norm developed in the society protected them to participate in community based organizations. Thus persons grouped and established their own social clubs.

2.4.3 Income and Employment

The other dimension of exclusion is the material deprivation of the affected persons. Leprosy affected the income and livelihood of the sufferer in different ways. First, it is most likely related with the consequence of disability. According to clacraft (2004) and Jenks (2003), the chronic symptoms of untreated leprosy often afflict individuals in their most productive age of life and limit them from fulfilling their normal roles in society. It is mostly reflected on persons who engaged in physical-based employment. Thus, it is the main type employment in rural society (calcraft, 2004).

Second they may lose their independence because of un even distribution of resources, and utilization of services. The majority of leprosy affected person due to the stigma associated with the disease has leaved own home place and settled in a new area with similar groups. they left their land and resources in the former place without a replacement. They might not have adequate farming land in the new area. Regarding it the survey study undertaken in leprosy settlement area of Gunchere, Gurage Zone, Ethiopia shows the fact that the majority of the persons affected by leprosy have not have or have small plots of land than the non-leprosy in the new area (ENAELP, 2003). Hence, land is the indispensible resources for rural community, absence of land have a direct impact on those people whose livelihoods are based on agriculture.

Third, the leprosy affected people are excluded from their former employment mainly from service provision appointment because of employers losing their customers (calcraft, 2004). These people in developing countries like Ethiopia had not had social security from the government or from the agencies. Their life becomes getting worse. As a result, the majority has been migrated to urban area for getting their daily bread.

2.5 Social works in the Care and Management of Leprosy

In addressing such multifaceted problem of leprosy, social work has a tradition of service that focuses on basic dimensions of human being, encompassing direct clinical work, advocacy, education and case management. Given the above, social work is well suited in the realm of assessment, prevention, care/ rehabilitation and control of leprosy.

In the management of leprosy where social worker is a member of management team, Geraint &Zumla (1999) suggested that, the ideal management of leprosy patients in a community

involves multidisciplinary approach requiring the coordination of effort of medical personnel, social workers and traditional healers. Referring WHO (1988) Geraint &Zumla indicated the major roles in the management or care for leprosy involves administration of specific chemotherapy, prevention and treatment of deformity or disability and social as well as occupational rehabilitation.Verinda (2004) on the other hand, emphasized the importance of social welfare, rehabilitation and health education. He stated that, the rehabilitation of the patient (with leprosy) should start from the day of his/her diagnosis. Psychological rehabilitation of the patient is vital: systematic attitude and understanding of the patient is of considerable assistance of the patient and changes his attitude towards leprosy.

Arole (2002) also argued that, during the process of diagnosis, the importance of assisting the patient to maintain both his self-identity and social identity cannot be overemphasized. Nevertheless, scientific working group form WHO (2002) indicated the attitudes of the person making the diagnosis, of all medical and paramedical personnel who in any way deal with the patient, is equally important. Furthermore, the attitudes of his family in the first hours and days after diagnosis, may permanently affect the decisions to be made. Those decisions in turn will affect the success or failure of the patient's whole future course of treatment.

Arole(2002) also stated the challenges facing organizations seeking to rehabilitate people affected by leprosy is to find a balanced approach, which is caring, yet encourages people to manage their own lives in the wider community. He identified three key principles for rehabilitation work in leprosy: Primarily, recognition of the broad impact of leprosy on the individual – physical, psychological, social and economic, Secondly, responsiveness to the concerns of individuals affected by leprosy, resulting in an approach that ensures their participation and restores dignity, thereby promoting empowerment and self-respect. Finally, responsiveness and involvement of the families and communities affected by leprosy is considered to be key principles of rehabilitation. This is due to the fact that members of the family and the community have an important role to play in the rehabilitation process.

Similarly, health education for survivor of leprosy is also equally important with the aim of developing rational attitude towards the disease, self-confidence and provision of skill for self-

management. With regard to health workers team, Verinda (2004) like Geraint &Zumla (1999) suggested the team should comprise of medical staff, paramedical staff and medical social worker. He also imparted the importance of ongoing training to deal effectively with the disease. Unlike both Verinda (2004) &Geraint &Zumla (1999), who are predominantly focusing on the medical model of treating only the individual case apart from the socio cultural context. Michael (2009) advocated the medical ecological approach to the problem of disease in general and leprosy in particular. He signified that health problem disrupt personal, family, and social life, intimate behavior, and self-image and place additional dimension on family and friends. Medical treatment can produce further disruptions and reduce patient's motivation and ability to comply, if it could not consider environmental and cultural context of the patient. Appropriate treatment planning, Michael added, requires an understanding of client's socio cultural environment.

In the team formation, his view agrees with Verinda & Geraint & Zumla. He argued that Medical anthropology, medicine, Trans-cultural nursing, public health, and social work address culture through similar approaches that involve cultural system model. Key issues in developing
Culturally responsive care and health service is an assessment of community health needs. These approaches incorporate communities in to health care planning, development, delivery and assessment.

The professional value of social work Dean, Ronald, & Glenda (2010), here signifies to restore dignity, reduce stigma, promote social integration and improve economic status, giving more attention to groups with special needs, specifically children, older people and women. However study conducted in Indonesia in the province of South Sulawesi community the scientific working group WHO (2002) quoted Elissen (2000) finding indicated the prevalence of lack of communication between patient and health worker. Another study by Mull (1989) cited by the Review report by the scientific working group also reported similar findings about the inadequacy of the communication between staff and patient in Pakistan. In resolve or narrowing such a gap, Barbara (2006) underlined the use of standardized measurements, which can enhance comprehensive biopsychosocial assessment and help practitioners' perception of their health
Status in the treatment process. Such tool allows social worker to be aware of the multilevel impact of leprosy from the patient perspective.

Referring to the work of Lim & Zebrack (2004) Barbara suggested that social worker role of assisting patient must include families in the treatment planning, not only as therapeutic allies, but also in regard to the multiple stresses that care giver experience. Dean, Ronald, & Glenda (2010) suggested as a component of social work value, social works have to commit to assisting client system to obtain needed resources. Social workers frequently pursue this goal by facilitating access to resource. They perform role of facilitators or enablers in carrying out: enhancing communication among family members, coordinate efforts of the health educator, assist patients troubled adjustment, helping group provide maximum support to their members; opening channel of communication between coworkers including patients or inmate in the government institutions; facilitating teamwork among members of different disciplines in hospital and health centers. Also provide for consumer into agency policymaking board.

2.6 Government policy

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

According to this article "a disabled person" means a person who is unable to see, hear, or speak or suffering from injuries to his limbs or from mental retardation, due to natural or manmade causes; provided, however, that the term does not include persons who are alcoholics, drug addicts and those with psychological problems due to socially deviant behaviors.

Regarding the protection of the rights of disabled persons:

1) A disabled person having the necessary qualifications shall, unless the nature or the work dictates otherwise, have the right to compete and to be selected for:
    a) A vacant post in any office or undertaking through recruitment, promotion, placement and transfer procedures
    b) A training program to be conducted either locally or abroad.
2) No selection criteria shall refer to the disabilities of a candidate unless the nature of the work dictates otherwise
3) Any disabled person shall have the right to get the salary and other benefits of the positions he occupies
4) A disabled person shall be provided, by his employer or the training institution as the case may be, with equipment and materials necessary to carry out his duties or persue his training.

According to this proclamation vacancies should be reserved for the disabled persons under such conditions:

1) Posts suitable for disabled persons shall be identified and reserved from the vacancies created in offices and undertakings.
2) A disabled worker cannot use disability as a defense in case of failure or fault in discharging his duties.

As to the implementation of the proclamation, the Ministry of Labor and Social Affairs (MOLSA) and the public servants administration commission have given powers to issue directives necessary for the proper implementation of this proclamation.

Finally, any disabled person whose rights are affected because of noncompliance with the provision of this proclamation and regulations and directives issued hereunder, may lodge his grievance to the organ empowered by law to hear disputes.

2.7 Theoretical Frame Work

2.7.1 Social Exclusion Theory

The concept of social exclusion was first developed in French in 1960's. It was built up in French school by Rene Lenoir based on the theories of Durkheim (1897) social cohesion and solidarity (sen, 2000; Gijisberg & vrooman, 2007). It was referred as lack of social support that described various categories of people left out of the state benefits and social security. Such groups of people in French were labeled as 'social problems' (ILO, 1996; Jowell & Lessof, 2000).

After the 1980's economic crisis of French, the definition of social exclusion became commonly employed (Gijisberg & vrooman, 2007).And widened to social disintegration and the risk associated with social alienation that included people who are un-employed for a long time and suffering with multiple deprivations in the worst affected places (Todman, 2006).similarly, from 1980's to the beginning of 1990's the level of unemployment were also increased in other European countries. Accordingly, social exclusion becomes an issue in the European Union (EU) social policy since 1990's (Todman, 2006).

The definition and application of social exclusion concept were debatable among the French school of thought and the Anglo American paradigm in the middle of the 1990s (De Hann, Maxwell, Wilkes, O'Braine, 2002).The former school of thought was focused on the relational breakdown of individuals from society because of their economic and socio-cultural problems. However, according to, Gijisberg & vrooman (2007, p13), this wider social and relational dimensions of social exclusion concept raised in French paradigm had little acceptance and attention by Anglo-American poverty and social exclusion research. The Anglo-American researchers were focusing the case of social exclusion to the economic dimension of "social inequality" and "relative deprivation" theory. Thus they define the concept of social exclusion as the outcome of unequal access to income, Basic goods, public services and citizen ship rights (Gijisberg & vrooman, 2007, p.13).

Nowadays, socio economic researchers agree on the multidimensionality (social and economic aspects) of social exclusion (De Hann, 2004; Gijisberg & vrooman, 2007, sen, 2000, Todler, 2006). Todler (2006) argued that relational concept is the primary and the causes for the multiple character of social exclusion. He said:

> "The existence of social disconnections among identity groups yields many types of disadvantages; hence social exclusion is multidimensional. Among the many dimensions individuals may excluded, the economic, political, civic, cultural, geographic, and judicial are some of the impactful" (Todler, 2006, p.4).

Similarly, the Netherlands institute for Social research (SCP) denoted the social exclusion concept by merging both social and economic dimensions. It indicated, "economic structural exclusion, which refers to distributional dimensions in line with the Anglo-American approach, and socio-cultural exclusion, which refers to the relational dimension that is emphasized in the French school" Gijisberg & vrooman (2007, p16). This approach recognized that the concept of social exclusion is the disconnection of social and symbolic bonds that attach an individual to the society. These bonds are economic, relational, and institutional aspects of the human society (calcraft, 2004).

This is one of the theories which guides the study, since leprosy affected people are among those section of the society who are socially economically, and even psychologically disconnected from the general public.

2.7.2 Biopsychosocial Approach to Health Care

Increasingly, the recommended approach for health-care service delivery today is *biopsychosocial.* Proposed by Engel in 1977, the bio psychosocial model addresses the biological, social, environmental, psychological, and behavioral aspects of illness. This expands the traditional medical model of health care that focuses primarily on the biological causes of disease. The biopsychosocial model considers the non-medical determinants of disease in collaboration with the purely biological components. For example, a biopsychosocial model of health service takes into account a patient's ability to purchase recommended medicine for diabetes when creating a treatment plan for the patient rather than focusing only on one's laboratory results and physical status, as a medical-model approach would do. Lindau, Laumann, Levinson, and Waite's (2003) interactive biopsychosocial model expands Engel's model to include general health status rather than illness alone and consideration of the important role of social networks and cultural contexts in health. The term *biopsychosocial*is used to indicate an approach to health service delivery that addresses the psychological and social aspects of health and treatment that includes behavioral and environmental factors. Intervention that considers

biopsychosocial issues related to health requires the use of an interdisciplinary team of professionals to address medical problems and concerns in a variety of settings. In addition to social workers, professionals may include physicians, physician assistants, and residents; nurses and nurse practitioners; dietitians; psychologists; patient care technicians; nurse and home health aides; physical, occupational, and speech therapists; administrators; chaplains; and pharmacists.

Prior to the introduction of Engel's biopsychosocial model, Nason and Delbanco (1976) recommended that providers of medical services attend to patients' psychosocial issues and advocated for the inclusion of social workers on health care teams. Health social workers directly address the social, behavioral, and emotional concerns of individuals and their social support network as well as develop and administer policies and programs and conduct research that are attuned to the psychosocial needs of individuals.

On an individual level, people may not be able to understand illness and recommended treatment due to developmental disabilities; low literacy levels; or language, hearing, or vision barriers. Many medical conditions and treatments are very complex, and social workers may be required to explain these issues to patients and their families. Socioeconomic disadvantage can greatly impact a patient's ability to receive medical care. If she lacks adequate health insurance, transportation to medical appointments, prescription coverage, or money to buy nutritional supplements and special dietary products, one's health may be compromised. Patients may need myriad services from a number of agencies, such as meal delivery, homemaker services, or physical therapy. Arranging and coordinating community services can be confusing or overwhelming for patients, especially for those with additional social, psychological, or medical burdens. Environmental factors also directly impact individuals' social functioning and health status. Emotional problems can be caused by and result from health problems.

A person who is depressed may be less motivated to follow up with medical appointments. If he is not coping well with his diagnosis and treatment regimen, he may do less well physically (Livneh, 2000). Effective coping, enhanced self-efficacy, and optimism have been associated with enhanced quality of life in the chronically ill (Rose, Fliege, Hildebrandt, Schirop, &Klapp, 2002). Patients' social support networks can influence their health status significantly. Families

can provide important support and assistance during times of health crisis, or they can also represent barriers to optimal care. Family structure and the availability of social support impacts the health of patients across their life course (Thompson, Auslander, & White, 2001).

Conversely, illness may exacerbate existing psychosocial problems; for example, a woman in a troubled marriage who becomes ill may lose her primary social support when her partner leaves because he cannot cope with the stress of her illness and its treatment. This may leave her with no transportation to medical appointments in addition to coping with issues related to role adjustment and loss, both of which can negatively impact her health.

Psychosocial issues like these, which occur outside hospitals and doctors' offices, greatly influence individuals' abilities to maintain their health. Many individuals who seek medical care also have what Rehr (1982) refers to as "social illnesses and problems." These illnesses and problems are psychosocial rather than biological in nature such as child or elder abuse, violence (including sexual assault and family violence), substance use, other harmful behaviors such as "cutting" or bulimia, and suicide attempts. All are factors that require social work attention and intervention to improve biopsychosocial status and, consequentially, health status.

2.7.3 Rehabilitation and Biopsychosocial Models

The field of rehabilitation medicine evolved in the mid-1900s and adopted a multidisciplinary team approach to the treatment of people with disabilities with physical therapists, occupational therapists, speech pathologists, social workers, vocational counselors, and psychologists joining physicians and nurses to treat people with disabilities (Albrecht, 1992). Rehabilitation professionals realized that the medical model did not necessarily fit the needs of their patients and began to ask if "in chronic illness and disability, is it the professional who treats the illness or is it the patient (or the patient and his family) who actually carries out the routine treatment day after day?" (Anderson, 1975, p. 19). The rehabilitation model of treatment acknowledges that the patient is not a passive recipient of care but an active member of his or her treatment team and that the goal of rehabilitation is not cure but restoration of the best possible physical and psychological functioning. Furthermore, in rehabilitation medicine there was a distinctshift from focusing solely on the individual with a disability to focusing on the individual, the family, and the community in which that individual resided. Rehabilitation in this sense embraced the

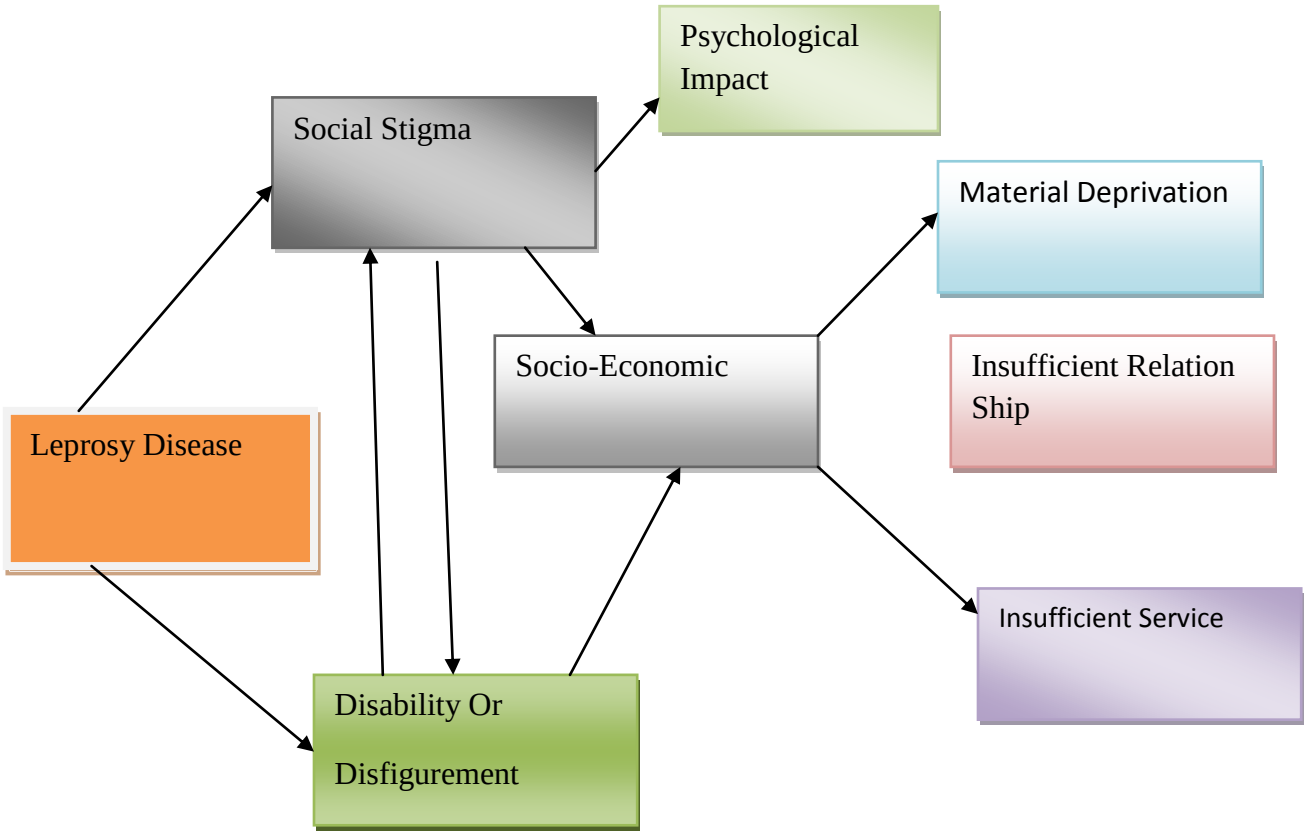
biopsychosocial model of health care (Engel, 1977). The biopsychosocial model expanded thinking beyond the narrow confines of bodily pathology and greatly shifted the focus to psychological and family issues. However, this shift in focus sometimes led to a tendency to pathologies patients' psychological make-up along with their bodies. It is not difficult to find literature that promotes the belief that physical disability invariably inflicts horribly disruptive and negative psychological consequences and leads to a whole host of personality disorders. A review of the literature, for example, reveals that patients with arthritis: have been said to have weak egos, to repress hostility, to be compliant and subservient, to be potentially psychotic, to be depressed, dependent, conscientious, masochistic, emotionally labile, compulsive, introverted, conservative, perfectionist, moody, nervous, worried, tense, over concerned about personal appearance, and prone to express psycho-pathology in physical symptoms. (Shontz, 1970, p. 112) The mind-set among many mental health professionals for years seemed to be that pathological bodies led to pathological personalities and they set out to analyze the "disabled personality" in spite of having limited research data to back up their assumptions. Far from freeing patients from the stigma of labels, early applications of the biopsychosocial model may have added to the stigma of disability by labeling patients first physically and then psychologically. Relatives particularly mothers of individuals with disabilities also found themselves being labeled and diagnosed as the focus of treatment widened to encompass the entire family system. The biopsychosocial model leads one to think about the interactions between the person with a disability and person's family, community, and social system. It highlights the connection between biological and psychological functioning. It also challenges some underlying principles of traditional medical thinking, allowing people with disabilities to be seen as active participants in their care and to have legitimate goals and needs even in the absence of a cure. It suggests that people with disabilities are much more than their functional limitations but it remains at heart a medical paradigm—one that is prone to misinterpretation and not completely free from the dangers of labeling.

2.8 Conceptual Frame Work

Every research activity is conceptualized and will be carried out with in some contextual frame work. This contextual frame work is in part conceptual, in part valuational,and in part practical or operational and all of these factors must typically be considered. The framework is a research

tool intended to assist a researcher to develop awareness and understanding of the situation under scrutiny and to communicate this.

One of the perspectives utilized by this research was the social exclusion theoretical perspective. The researcher here adopts the conceptual model, which was developed by the Netherlands institute for social research for structuring the study. (Gijisberg & Jehoel, 2004). The researcher believed that this model is so crucial to look at the multi dimensionality and processual aspects in terms of socio-cultural, psychological and economic dimensions. Specifically it incorporates the characteristics of exclusion in terms of rights, resources, income, participation and relationships. It also analyze in which leprosy affected people encounter. Besides, it enables to analyze the relationships that exist between the attitudes, beliefs and practices of the leprosy affected persons on the one hand and the general public.



Source: adopted from Jehoel&Gijisberg (2004)

CHAPTER THREE: RESEARCH METHODS

3.1 Study Design

Burns and Grove (2003, P. 195) define a research design as "a blueprint for conducting a study with maximum control over factor that may interfere with the validity of the findings". This research is qualitative in its nature aimed to assess the psycho-social and economic situation of leprosy patients admitted at Alert center.

3.1.1 Qualitative Research

Qualitative research is mostly associated with words, language and experiences rather than measurements, statistics and numerical figures. Consequently, this research used qualitative method because the focus is on the assessment of the psycho social and economic aspects of leprosy patients. As many scholars explained it, qualitative researchers study things in their natural settings, attempting to make sense of interpret, and phenomena in terms of the meanings people bring to them (Denzin & Lincoln, 2005, P.3). Similarly, Berg added qualitative techniques allow researchers to share in the understandings and perceptions of others and to explore how people structure and give meaning to their daily lives. Researchers using qualitative techniques examine how people learn about and make sense of themselves and others (Berg, 2001).A qualitative design will be used to conduct the study. Qualitative study is best when the issue of concern at hand needs exploration, comprehensive understanding of the context and the phenomenon (Creswell, 2007).Besides a qualitative approach enables the researcher to get an in-depth understanding of the issue and allow research participants to express their views broadly. It also more appropriate in terms of documenting rich and detailed information (Snap & Spencer, 2003).so the researcher will employ a qualitative design since the issue at hand needs a comprehensive understanding.

3.1.2 Case Study Approach

In this study the researcher believes that, case study is appropriate study approach for that it gives a wide opportunity to explore the distinctive and multifaceted experience of the targeted population of this study. As Yin (2003) point out that, case study allows investigator to retain the holistic and meaningful characteristics of contemporary phenomena and real life event desire to understand complex social phenomenon (Yin, 2003, P. 88). In addition, case study can provide

robust and important information about the issue by using various information sources (Padgett, 2003) Therefore, the study was aimed at obtaining rich information about the psycho-social and economic aspects of leprosy patients in Alert center.

3.2 Study area

As Creswell (2007) puts, in case of qualitative research, for the purpose of deep understanding of the subject matter under study or research question, it is up to the researcher to make a decision on the research participants, sites and even the material to use. The study area of the research was Addis Ababa. Addis Ababa has been serving as the capital city of Ethiopia and the seat of many international and continental organizations ever since its establishment in 1886. Addis Ababa is now growing and expanding rapidly in terms of its area and population size.

This study was conducted in Alert center which is found in Nifas silk /Lafto/ Sub-city around Ayertena in Addis Ababa. The rationale for selecting this research field from others is because it is the pioneer hospital to start treatment for leprosy patients. It also has a long term experience of working with leprosy patients. Besides this hospital currently has large number of admitted leprosy patients.

The study was done with leprosy affected people considering the study site, with relatively high concentration of leprosy patients or leprosy affected people on the basis of preliminary assessment. It was thus before the onset of the data collection that the location was visited and potential site is identified. In many cases site characteristics and availability of leprosy patients are appeared to be the basis for selection of the site.

This site is selected purposively based on the preliminary assessment. During the preliminary assessment the researcher observed that many leprosy patients and leprosy affected people were there in the center and many more are lead their life in the slum near to the center. Besides, there were a number of NGO;s and local associations in the surrounding of the center. Since these NGO's and associations are working for long in issues related to leprosy, the researcher found out that it could be an asset for the success of the study. Moreover, the site is selected to get participants who are illegible for the study.

Alert is a medical facility on the edge of Addis Ababa, specializing in Hansen's disease, also known as "leprosy". It was originally the All Africa Leprosy Rehabilitation and Training Center

(hence the acronym), but the official name is now expanded to include tuberculosis: All Africa Leprosy, Tuberculosis and Rehabilitation Training Centre (peter, 2003).

Alert's activities focus on its hospital, rehabilitation of leprosy patients, training programs for leprosy personnel from around the world, and leprosy control (administration of the Ethiopian Ministry of Health's regional leprosy control program).

3.3 Participants

The participants of this study proposed to be seven leprosy patients, a physicians and two social workers, two nurses, and two other key informants from Addis Ababa Leprosy Victims Rehabilitation Association (AALVRA)and the general manager of Medhin Social Center, an NGO closely working with leprosy affected people. The primary rationally for selecting this much number of participants was depend on data saturation. Other factors which the researcher has taken in to in to consideration included: willingness to participate, resource and time availability.

3.4 Sampling method

The target population of this study were admitted Leprosy patients at Alert center , health care providers of Leprosy patients at Alert center and other key informants (officials)working in relation to leprosy. According to Merriam (1988), sampling in qualitative study tends to be small number of people nested in their context and studies in-depth unlike quantitative studies, which aim for large number of context of stripped cases and seek statistical significance. Purposive sampling will be employed to select the research participants. In order to make sure that research participants are drawn from different social strata gender, age, marital status, religion and educational status will be taken in to consideration as the inclusion criteria

3.5 Eligibility Criteria

Burns and Grove (2003, p. 234) define eligibility criteria as "a list of characteristics that are required for the membership in the target population." Participants who satisfied the following criteria were included in the study.

The participants of this study were seven leprosy patients admitted in Alert center, one physician, two social workers, and two nurses working there at the time of data collection process. Besides, to enrich the data gained from admitted leprosy patients three key informants were used.

The participants of the study were recruited based on the following inclusion criteria.

- ✓ Willingness to participate on the study.
- ✓ Work experience of more than three years, with the exception of the social workers since there is a high turnover.
- ✓ Leprosy patients who have been there for at least six months.

The inclusion criteria will be used for selection of study participants for in-depth interview.

3.6 Data Collection Procedure

The first step was to go to the study area and meet my potential participants. After getting the social worker or a health care provider then, the researcher has got all the participants with the support of the social workers or health care professionals purposively. Initially, the researcher and the participants were strangers to each other. Participants tend to be uncertain and overly critical. To avoid this problem I have established a good rapport and clearly communicate the purpose of the study with my participants. As first impression is the last impression, this phase determines whether a person will agree to an interview or not. Then, the date for data collection was arranged after the potential participant fulfills the inclusion criteria and the participants decided to go through the interview. I made an appointment with each participant at a time. Place which suited them and a quiet place conducive to conversation were arranged with the participants. In addition I prepared a tape recorder, note book and other necessary materials for the interview. Unfortunately, some of the participants were not willing to be recorded.

Before each interviewing, I thank the participant for the time and willingness to be part of the study, reminded the participants about the agreement, explained that the interview will be unstructured with probing questions and I asked a permission to record the interview.

During the interview, efforts were exerted to make the discussion open, free, no domination and unreserved. Interview will be initiated with a general question. The researcher was the main data collection instrument in this study. As the initiator of the interview, the researcher played an active role in making certain decision about the progress of the interview. The researcher showed sensitivity to the uniqueness of each participant and approached with empathetic understanding. I tried to be a good listener, friendly and non-judgmental throughout the interview process. Not to make boring and tiresome the interview, it runs from forty five minutes to an hour.

3.7 Source of data

Both primary and secondary source of information were used in order to undertake the study. Primary data was collected through in-depth interview with admitted leprosy patients, health care providers, social workers, and other key informants and through observation, focus group discussion was also conducted. While, secondary data was obtained from published and unpublished materials including books, magazines, journal articles, electronic materials and progress reports.

3.7.1 In-depth Interview

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

Efforts will be made to include probing questions from the main stem items. These interview guiding items are developed in line with concepts assessed in literature section and research questions. These questions are attempted to assess the psycho-social and economic situation of leprosy patients in Alert center, Addis Ababa.

3.7.2 Key informant interview

The researcher made the interview with eight key informants, among whom five of them were health care providers working at the Alert center, two of them were from Addis Ababa Leprosy Victims Rehabilitation Association and one of them was from Medhin social center. Both Associations and the NGO are still closely working with leprosy affected people. un structured questions were used as a tool of data collection to assess the psycho-social and economic situation of leprosy patients and about how social work intervention could be put in place to overcome those challenges. This help the researcher to triangulate data obtained through in-depth interview with leprosy patients.

3.7.3 Focus group discussions

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

3.7.4Non-participatory observation

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

3.8 Data Analysis Technique

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

The first step in data analysis is pre-coding the raw data. I conducted the entire interview with Amharic language. After data collection I transcribed the data from field notes in to English language every day. In addition, tape recorded interview of participants are transcribed in to text

format originally to Amharic and back translated to English. Then, I read and re-read the transcripts closely until understanding of the main points are achieved. According to Boyatzis (1998) pre-coding is done by circling, highlighting, bolding, underlining, or coloring rich or significant participant quotes or passages that strike the researcher (as cited in Saldana 2008, p. 16). Accordingly, I underlined significant participant quotes that impressed me. Pen with different colors were used to underline these statements.

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

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

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

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

3.9 Trustworthiness of the Data

Different techniques were used to increase the trustworthiness of this study. To maintain the credibility of participant information, participants of the study were carefully selected based on the set criteria. To get accurate and detail information without any fear, participants were interviewed in the appropriate place. Padgett (2008) explained that, researcher biases emerge when observations and interpretations are clouded by preconceptions and personal opinions of the researcher (p.184). Consequently, the researcher invited Peers and teachers to comment and debrief on the prepared questions and part of the research work for constructivist criticism. A colleague, with experience in qualitative research methods reviewed all coding of data to confirm the categories and themes that were emerged from the data. In this study for the interview guiding items trustworthiness were assured by avoiding double barreled, long and complex questions. In addition, efforts were exerted to avoid leading and emotional questions.

According to Padgett (2008) the other threat to trustworthiness is respondent biases. Respondents may withhold information, lie to protect their privacy or to avoid revealing unpleasant truths, may offer answers that they believe we want to hear or have faulty recall or interpret events in a way that conflicts with what the researcher "knows" from another source (Padgett, 2008). To avoid respondent biases I tried to develop a good rapport by repeated visit to participants and explain the purpose of the study genuinely.

In addition, a pre exercise was done to orient the researcher to the research project and provide the researcher with insight in to the phenomenon. In most cases it is recommended that a pilot study be carried out prior to the main research using 10% of the actual sample size, however as this study is a qualitative study with the aim of using eight participants only two participants who met the selection criteria were used in the pilot study.

The interview was tape recorded to ensure the correct use of the tape recorder and to listen to the researcher's questions with probing and verbal reactions. These early interviews were transcribed and reviewed. During the exercise attention was given to body language and nonverbal responses as well as the manner of asking questions. This enhanced the researcher's level of confidence. In addition, it helped the researcher to identify any flawed in the procedures designed by the researcher. After the pretest some modifications was made to the interview guiding items.

3.10 Ethical Considerations

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

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

Conducting interview, application of tape recorder and other necessary instruments has to be done only after the researcher got oral consent of the participants. I was made the interview with participants who are voluntary to be recorded. Moreover, issues of confidentiality, anonymity and privacy were communicated well. Confidentiality and anonymity has to be guaranteed by ensuring that data obtained are used in such a way that no one other than the researcher knows the source of the information. No names attached to the information obtained, but codes will be used instead.

Privacy refers to the freedom an individual has to determine time, extent and general circumstances under which private information will be shared with or withheld from others

(Burns & Grove, 2003, P.171). In this study privacy was maintained by conducting the interview in appropriate place and time chosen by the participants.

The researcher informed the participants that results will be disseminated in the form of a research report. Anonymity was assured because the results will not mention the participants' names. The tapes and written documents were safely store and destroyed after the study.

Moreover the participants were told to take a rest or stop the interview any time and to skip any question they do not want to answer.

CHAPTER FOUR: FINDINGS OF THE STUDY

4.1 Background of the Respondents

The main goal of this study is to assess the psychosocial and economic situation of leprosy patients or people affected by disease caused by M. Leprae. To achieve the goal the study incorporated seven leprosy patient respondents. Besides, eight key informants were used in the study.

Respondents of the in-depth interview were fifteen in number among whom seven were leprosy patients, two nurses, two social workers, a physician, chairperson of Addis Ababa Leprosy Victims Rehabilitation Association (leprosy affected), General Manager of Addis Ababa Leprosy Victims Rehabilitation Association and General Manager of Medeihen Social Center, an NGO working for long with leprosy affected people. With regard to their educational level one of the leprosy patient is a grade ten complete. Four of them are from grade three to seven. There were also two leprosy patient respondents who are illiterate. The key informants had either diploma or BA degree. Five of the key informants had a BA degree while two of them had college diploma. There was only one key informant with a high school complete. Regarding their physical damages, four of the leprosy affected respondents lost either their legs or their hands. Two of them lost both their hands and legs. Only one respondent has lost one of her legs. Considering their sex, four of leprosy affected respondents are males while the rest of them are females. Totally, ten of the respondents were males while five of them are females. Their age ranges from 18 to 65. Eight of the respondents reported to have been married while six of them are single. Only one of the respondents is widowed.

Regarding health professionals and other key informants' work experience it varies from one to the other. The minimum being three and the maximum is forty two years. Five of the key informants worked for three to seven years while the remaining three of them served for thirty seven to forty two years in various organizations. All the non key informant respondents were leprosy affected; with the exception of one key informant the rest of key informants were not leprosy affected.

When we come to the background of the FGD, there were two FGD groups. One of the groups had six participants. All the discussants were males. One of the participants had a B.A degree in sociology and social administration and the other had college diploma. Two of the participants

had certificate from TVET, while, the other two have completed grade twelve. All the FGD participants had leprosy. Concerning, their physical situation three of them lost one of their legs, one of them lost both his legs and hands, the other one had only legs but not hand. The remaining discussant had only one hand each.

As opposed to the first FGD, the second FGD consists of female respondents. Similar to the first group, the second FGD incorporated six discussants. With regard to their educational status three of them completed grade four to grade eight. There were also two illiterate discussants. The remaining one respondent was grade ten complete. All of them had leprosy. Although the damage inflicted on them varies from one to the other. Three of the discussants have both legs and hands with varying degree of deformity. While two of them do not have one of their legs but they are capable of walking using artificial leg. The remaining participants had a certain kind of deformity in both her hands and legs.

Table -1 Key informant's background

Role of the informant	Age	Sex	Place of origin	Educational level	Marital status	religion	Service year
respondent-1	29	M	Gojam	Grade 10	Single	Orthodox	
respondent -2	60	M	Dilla	Grade 4	Married	Orthodox	
respondent -3	59	F	Gojam	Grade 3	Widowed	Orthodox	
respondent -4	20	F	Gojam	Grade 7	Single	Orthodox	
Responden-5	18	M	Borena	illiterate	Single	Muslim	
Responden-6	26	M	Gonder	illiterate	Married	Orthodox	
Responden-7	27	F	Sheno	Grade 3	Single	Orthodox	
physician	37	F	NA	BA. degree	Married		5 years
Social worker 1	28	M	NA	BA. degree	Single		6 years
Social worker 2	47	M	NA	BA. degree	Married		More than 7 years
Nurse 1	64	M	NA	College diploma	Married		More than 37 years
Nurse 2	63	M	NA	College diploma	Married		More than 37 years
Keyinformant 1	55	M	NA	BA. degree	Single		3 years
Keyinformant 2	35	M	NA	BA. degree	Married		4 years
Keyinformant 3	65	F	NA	BA. degree	Married		42 years

According to the data, the respondents have been under medical care from 6 months to 20 years. On the other hand the care providers have been serving from five to forty two years .The data obtained from leprosy patient respondents, care givers (health professionals) and other concerned key informants was categorized under five thematic areas. These includes leprosy as a disease, leprosy and its psychological effect, leprosy and its social effect, leprosy and its economic effect and social work intervention areas.

4.2 Leprosy as a disease

Leprosy affects the body's nervous system, skin, eyes, and muscles that alarmed people to respond to the situation. In this regard respondents were asked how they became aware of their status. They were also asked about their and their family's perception about the disease and its causation.

As per the idea obtained from one of my respondents, leprosy is a disease caused by bacteria. He said few people living in his community have wrong conception about the disease. It considers the disease to wrong doing. He also added that since it is uncommon in their community, most people do not have an understanding about the disease. As it was stated by him, leprosy is not a familiar type of disease in their community: "People in my locality know that I have a certain kind of wound in my leg .They do not know that I have leprosy"

All the other respondents support that, leprosy has been considered as a hereditary disease. But, their conception of the disease is now totally changed, since the time they were admitted in to the center .Currently almost all of the respondents are known with the fact that leprosy is a disease caused by a certain bacteria. But, they said that most rural communities insisted in the idea that leprosy is a hereditary disease and some say that it is punishment from God for bad deeds.

Six of the respondents think it is not hereditary. One of the respondents says, "I have wife and children (two) they are ok and in good condition. Also, my family's relatives and grandmother and fathers are not affected now I thought that it is not hereditary" Other respondent reported "I used to ask myself that from where I got these diseases, while my families and relatives are still ok now I got the answer after I came here."

Contrary to the above respondents, the other respondent, told the researcher that, 'still I am sometimes suspicious, because among eight members of a family I am the third person to be infected, my mother, my younger sister and me were medicated here at Alert center'

Majority (six) of the respondent (leprosy affected) indicated that they are the only persons in their respective families that were infected by the bacillus and also do not have children who have shown sign and symptom of leprosy. Only one respondent indicated that three out of the eight family members acquired leprosy. The finding indicates although leprosy is one of the communicable diseases, there is personal variation and conditions in vulnerability to the disease.

One of the finding of this study is about how the participants became aware of their status and whether there is any symptom to the disease or not. With the exception of one respondent all became aware about their condition very lately. One of the respondents, told the researcher saying

> "I saw something new condition on my skin. I had also a rheumatoid pain, burning sensation in my soul of my feet, and fungal infection. . But, it was not improved with primary care rather my mouth was twisted to the right side and then the local health center referred me to Bahir-Dar Hospital, where I was told that I had Leprosy".

Another female respondent added

> "Before my health situation began to deteriorate, there was pain on my hand. First I preferred to sprinkle my body with the holy water. I stayed for three years without modern medical treatment. But there was no improvement in my health condition, even it became worse, my legs began to bleed. Other part of my body was relatively good. My situation was becoming serious,"

Still the other respondent stated that:

> "At the beginning I was not aware of the diseases (leprosy) I developed sore, burning sensation and numbness of the extremities…. it affects my flesh, nerves and bone. I tried

different types of traditional medicine, like holly water, "*wogesha"*, [1]and so on, but the numbness and burning sensation worsened".

Another respondent states, "I was having small wound at my elbow; I went to a place to get holy water and other different places but no improvement was seen. I came to Alert with my uncle where I was told that I had leprosy."

The remaining two respondents contended that they had used various traditional medications before they were coming to the health care facilities. Only one respondent came to the health facility immediately after he saw the symptoms on his body.

The above data shows that entire respondents reported that the first sign they observed, prior medical diagnose, the biological manifestation of the disease. Majority of them were aware of the symptom after the disease advanced and caused some sore/wound on their extremity.

Four of the respondents reported that the wound was localized around elbow and lower part of their hands that was not responding to none of traditional healing practices. The data also indicated the wound usually followed by burning pain and numbness of peripheral extremities. Only one respondent referred himself to the health facilities at its early stage of the disease. He reported that skin discoloration was the first symptom it worried him. Unlike the rest of respondents who didn't know the sign and symptom of the disease/leprosy, this respondent suspicious of leprosy due to the fact that his family member was also affected by leprosy.

As it was stated by the other key respondents, chairperson of AALVRA, general manager of AALVRA and general manager of Medihen social center (an NGO closely working with leprosy patients for long) have given a similar idea about leprosy as a disease and its causation. All argued that leprosy is a disease caused by a micro bacterium lepray. Besides, they all considered the disease as leading to amputation and disfigurement.

However, all the three key informants, two nurses, the social workers and the physician come up with a similar understanding about a disease .According to the idea obtained from them, leprosy is a disease caused by micro bacterium lepray. Besides, the disease is not hereditary, but, it might

[1] local physiotherapist

be contagious. Long contact with an infected person might be the cause for being affected by the disease.

According to the physician, working with leprosy patients in Alert center, "the disease mostly affected the skin and nerves "it might lead the patient for being mutilated or disfigured". The key informants (health care givers) stated that late detection of the disease is one of the major problems for them to encounter.

One of the two nurses described the late arrival of the client as "Most of the time they arrived here after serious damage of eye, leg and hands. They are also damaged economically and psychologically, especially, if they develop sever ulcer at their leg and hand."

The physician described the situation concerning the clients, "most of the time they arrived at health facility after so many trials by themselves. They went to traditional healers, holly water, and any magic houses. This causes irreversible damage of the body.

From the above data it can be inferred that medical care is one of the last resort for leprosy-affected people. They showed themselves to the health facilities after trial of all other sources of traditional treatment. By the time they arrive to health setting, sever and irreversible damage has happened to their body (eyes, hands and legs). Few respondents also associated further delaines due to misdiagnosis/ lack of professional competence, in accessibility of service as well as cost.

All those male respondents participated in the FGD have a similar understanding about the disease and its causation. Based on the data obtained from the first FGD, Leprosy had been considered as a hereditary disease. Most people have still a similar understanding about the causation of a disease .But, people especially living in the urban centers, began to understand the cause of the disease. They began to know that leprosy is a disease caused by a certain bacteria like some other diseases. Besides, discussants stressed on the fact that still today most leprosy affected people come to the health center very lately. One of those discussants said that: "*abzagochachin beshitaw kecheresen behuala new yeminimetaw*" to mean that "most of us are coming here after the disease damaged our body".

The data obtained from the second group FGD participants indicated that, there is no clear understanding about the disease and its causation among the participants. Unlike other

discussants one of the FGD participant states that "for me leprosy is a disease caused by *yebetamlak*"[2]. The other two discussants stated a similar idea that leprosy is a disease caused by poor hygiene. One of the discussant indicated that leprosy is one of the communicable diseases caused by bacteria. The remaining two do not have any idea about the disease and its causation. With regard to the damage that the disease inflicts on affected individuals, almost all the FGD participants argue that late coming to health care facilities is the major aggravating factor to be seriously considered.

As per the information attained from the two FGD's discussants have a blurred image about the disease leprosy and its causation. Besides, the issue of late coming to the health care facilities is raised as a damage aggravating factor in both FGD's.

4.3 Leprosy and its psychological effect

As far as the impact of leprosy on the psychological wellbeing of affected individuals is concerned the result of the study reveals a feeling of sadness and pain. One of the respondents says:

> "When I compare my earlier life with my current situation, it is really hurting. The fact that I am alienated from friends and unable to work like others is quite difficult for me to accept. I am also feeling sad, observing changes in my body parts because of the relapsing nature of the disease. Besides, I lost my confidence and prefer to be alone for fear of ostracization".

Another respondent says,

> "I feel really sad, because of the fact that I was alienated from relatives. Especially, when I go to my birth place only my mother gives me a warm hospitality my siblings do not want me to visit them". She also added that, it was really hard for her to involve in *'idder'*[3]. She states that, "members of the women *' idder'* do not allow me to touch the food and the materials they are working with, by saying that I am weak, but I do not consider it as they are sympathetic to me it would rather inflict pain in my mind".

[2] local deities

[3] A traditional voluntary self-help association organized for burial ceremony and comfort families of deceased

During the in-depth interview, one respondent told the researcher that, he is currently sad and depressed. He says, "I came here with both my legs and hands, but, currently I lost both. When I think of it I really feel sad and depressed. I began to feel that I am useless, hopeless and lonely, especially after the death of Dr. Solomon, who is a renowned physician at Alert center, particularly for his philanthropic activities for leprosy affected people like me".

Moreover, one interviewee shares all the above feelings and added: "I really feel sorry for my fate, I am not worried for myself, I am rather worried for my single son, whom he suffered a lot due to my situation. I am also highly stressed when I think of his futurity".

The other respondent whom she was not willing to give us her name told the researcher that she strongly hate herself and prefer to die since she was told that her legs are going to be mutilated . She also states that she will never want to go to her family for not disgracing her respected family in their locality. As per the idea of the respondent, it was really hard for her to live in such a situation.

As it can be elicited from the above case study all of the respondents have been found that they developed some kinds of emotional problems .Almost all of them feel depressed, sorrow, lonely and sadness. Three of them are reported that they lost hope of their futurity. One of the respondents also stated that she was found difficult to accept or live with the disease as a result she became stressed. This implies how seriously that leprosy affected their psychological stability. The researcher can also understood that the huge impact of leprosy on the psychological aspects of those affected people. In other words, leprosy made them feel depressed, stressed, feel sorrow and lose their hope about their futurity. This in turn may have its own impact on the healing process of the diseases. This is due to the fact that one's emotion and cognition can play a significant role in physical health.

On the other hand, the clinical social worker, both nurses and the physician have got similar idea regarding the effect of leprosy on the psychological well-being of the patients. One of the two interviewed nurses described leprosy patients as follows:

"Most of the time they are depressed and they become aggressive on small matters. One of the major reasons for being depressed and aggressive is that they don't know where to go after they

are discharged from the hospital and they are mostly too worried about their futurity. "The physician explains,

> "After treatment and long stay at hospital they don't have a place to go, so they become beggars (settle at the church for seeking alms), street boys, and even they might engaged in some other socially undesirable activities, which might in turn be harmful for the society….Besides, since they are neglected by others they tend to develop a feeling of loneliness, poor confidence, and helplessness. Sometimes, they also lose their identity. Even, some might develop a feeling of jealousy towards others".
>
> The other respondent who is the clinical social worker explains, "Sometimes the patients are becoming emotional and aggressive, and sometimes they complain against God. At some other times they feel depressed and stressed when they compare themselves with their friends and other families."

The two key respondents from the association AALVRA contended that leprosy has a huge psychological impact on the part of the victims. One of these respondents says:

> "Most leprosy patients come to us for various services here in our organization and when we critically observe them they seem that they are shunned, and they don't dare to shake hands with us unless we give hands to them, they don't dare to take chairs to sit, they mostly seem feeling being inferior".

Besides, the other key informant from the NGO had explained the psychological impact of the victims as, "it would be difficult for me to isolate the psychological aspect of the disease from its social aspect" She explained to the researcher that these two aspects are two sides of a single coin. One can be the aggravating factor for the other. She also added that there is a wrong perception (psychology or mentality) about the disease. Most people especially in rural areas believe that leprosy as a hereditary disease and could be transmitted up to seven generation. Due to such mentality people are discriminated for being a leprosy affected person or simply for being a relative of the victim. It in turn affects the mentality of the people in question, by lowering their self-esteem, confidence, and their dignity.

The above finding indicates that due to the stigmatized nature of the disease, leprosy patients have developed a feeling of dependency, hopelessness, helplessness, depression and sometimes aggressiveness. This implies that they suffered from different emotional problems which might distort their cognitive thinking about the disease. In general, the finding of the study revealed that, most of the psychological effects of leprosy is highly associated with biological and social nature of the disease.

Based on the data obtained from the FGD, almost all of the participants have agreed on the fact that the disease has a huge psychological implication on those affected people. When they are explaining the psychological effect of the disease, three of the discussants come up with a similar idea. They said that since the disease is leading to disfigurement or deformity, most leprosy patients (affected people) are tending to isolate themselves. They feel inferior to others and sometimes they feel depressed. The other two participants have stated that leprosy makes people to feel that they are loneliness, helpless, and shameful; it also lowers their confidence. The case of one respondent will be presented below:

Case

> *Alemu (pseudonym) is a 59 years old leprosy affected person. He is currently living at kore where a large number of leprosy affected people are still living. He told the researcher that how he was psychologically hurted due to his situation. What he said is presented as follows "Let me tell you how I was psychologically damaged due to being a leprosy patient" "At one occasion I was invited to a wedding which is somehow far from the place where I live ...just like other guests I was weighting a line to take food, and finally I have picked up a plate to take food, then everyone began to steering at me. Even some lost their appetite to eat. To be honest, I don't have words to express how I feel bad at that particular day. I put the plate at its place and I went out to my home. You can imagine how I feel bad. Really, I was ashamed of myself, I totally lost my confidence. Since then I never attend such kind of occasions".*

As opposed to all the above participants one discussant states that he is against what the other discussant said. The participant says:

> "I am capable of doing everything, there are 'normal' people who need my support, why should I be ashamed of myself, why should I get depressed, why should I consider myself inferior to others, whether you believe me or not, I have the confidence to do whatever I would like to do".

One of the finding from the second FGD was that, four of the participants consider self-exclusion as a major psychological impact associated with leprosy. The other participant stated that "I am always sad, and sometimes I condemn the day that I came to this world". The last participant of the second FGD, who remained silent for long while others gave their opinions said that "hulun *biyawerut hode bado yikeral"* an Amharic proverb which is equivalent to "I think it is better to remain silent". As per my own observation she looks that she did not want to talk at all about the issue due to some bad experience she might have faced in the past.

The major finding from the above two discussions was that, in addition to its physical damage to the victims, leprosy had a huge psychological impact on their thinking. As it was stated by most participants, the psychological impact of leprosy led the victims to feel isolated, lonely, shameful, to have poor confidence, to lack self-identity and sometimes to self-criticism or self-blaming. Besides, most of the leprosy sufferers are tend to consider themselves as inferior to others, due to their own predetermined thought that others would consider them as inferior. But, it might be wrong to consider it as it happens all the time, since some might feel inferior due to the trauma of their bad experiences.

4.4 Leprosy and its social effect

One of the huge impacts of leprosy is social stigma and discrimination attached to the disease. As per the information obtained from all the respondents leprosy is a disease highly attached with stigma.

As it was stated by two of the respondents, the social impact of leprosy is huge, especially in relation to marriage. With regard to marriage, one of these two respondents said that "there is a great problem in getting a spouse." It was really tough for those leprosy affected people to get a non-leaper marriage partner. Two of the female leprosy patient respondents added that those leprosy affected people are highly suffers from social stigma and discrimination. They stressed

that leprosy affected people particularly women are discriminated and neglected from various social engagements like *idder, senbete*[4]*, tsiwam ehaber*[5]and the like.

Case

Beletu, is a 38 years old woman. She was born in Dangla, Gojjam. She was the only person among the family members to be affected by leprosy. She has got marriage for three consecutive times there in Gojam, but unfortunately all the marriages are ended in divorce. She remembers her third marriage as follows: "my third, husband was a rich farmer, he does not know about my situation since it was an arranged marriage, besides my physical condition was not as such deformed. I remember it was only three days after my wedding date that I was thrown away by his famlies he was also agreed by what his families did to me. From that time on wards no one dares to ask members of our family for marriage. It was hurting for me. Not to see it I decided to leave my village and came here to Addis before five years"

Another respondent suggests that "it is obvious that the disease resulted in isolation, discrimination, and banishment." He also added that "I heard that people used to have buried leprosy affected people while they are alive for fearing that the disease would transmit to others." As it was stated by him the social implication of the disease is immense. Besides, he also mentioned that, due to lack of awareness about the disease and attitudinal problems, the stigma begins at home, from one's own family. He also told the researcher that, "currently, no one is visiting him; he is left alone in there, Alert center. Currently, he is supported by some philanthropic associations and charitable organizations". The other respondent partly shared the feeling and stated that "the stigma started with even from one's own family. He also told the researcher that some medical practitioners are among the one who discriminated leprosy affected people. "If not all, few medical practitioners do not want to have any kind of physical contact with us".

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

[4] A kind of religious feast
[5] A voluntarily monthly get together association organized by the orthodox Christians

> "Since I was living in leprosy colony there is no as such strong stigma towards me. But, I cannot deny that leprosy affected people face stigma and discrimination by outsiders. When I went out of my locality the stigma begins, currently I lost my family, I totally am detached from my relatives. Communities in my birth place do not want to keep in touch with me, because they still believe that it is a hereditary disease and or a curse from God for our bad doings. There are few people who think otherwise".

The information collected from the social workers support the idea mentioned above, which states that the social stigma starts from one's own family. Since most rural families do not want to be identified with leprosy, they mostly lock leprosy affected people in a certain isolated room. The social workers also stated that leprosy affected people suffer from insult, ridicule and they sometimes are nick named. Both of the social workers stressed on the fact that the disease has a huge implication on marriage. One of the social worker stated that "it is unthinkable for leprosy affected people to have a marital relationship with a non-leprosy affected people."

Almost all of the explanations forwarded by the social worker are supported by the key informants particularly by the physician and the nurses. What was said new by the physician was that sometimes leprosy affected people might end up with committing suicide. It is mainly due to the psychological problems they face, which is rooted from the social impact of the disease. As it was directly stated by the physician it is really hard to separate the social and psychological impacts of the disease on the victims. They are totally inseparable.

The other key informant, who is working as a chair person of Addis Ababa leprosy patients association told the researcher that, a significant number of leprosy patients are rejecting themselves with a predetermined conception of being rejected by others. This self-isolation might hinder them not to achieve what they aspired. The other points forwarded by the key informant includes most rural parents who had a leprosy affected child/children do not expose their child/children to the community fearing that the community would stigmatize them and it would possibly bring a problem for other non-leprosy affected children of the family. It is to say that it might reduce the possibility of getting marriage partner of non-leprosy affected children of the family. The other reason for hiding their children could be, some of these families do not want to be considered as destitute. They do not want to see others sympathizing for them. The informant also stated that, most parents who had a leprosy affected child tend to discourage and

disregard him/her. Even some times non- leprosy affected parents considered their leprosy affected child as inferior to other non-leprosy affected child/children. It is common to see that children are ashamed of their parents and some children having leprosy affected parent or family do not want to be seen with them.

The information obtained from the other key informant indicated that leprosy affected people are highly excluded from various social engagements like wedding, and idder other social occasions In fact, the informant said, this social exclusion is being mitigated in degree from time to time, but, it is not as such satisfactory.

During the in-depth interview one of the key informants indicated that, some people excluded not only leprosy patients and their parents but also other people who are working and close to those affected people. She told the researcher that, "some people sympathized for me thinking that I am leprosy affected, although I am not". Continuing her explanation, the key informant contended that, "indeed, we see changes, before some years no one comes to the village where leprosy patients are resided. But, currently it is common to see a line of automobiles whenever there are social occasions like wedding and sorrow. Really, it is something which makes me pleasant".

The data obtained from the FGD, revealed that almost all of the FGD discussants considered leprosy as a disease highly attached with social stigma. Two of the respondents emphasized on societal rejection or to be shunned as a major social problem most leprosy affected people are identified with. With regard to the social effect of leprosy on the patients (affected person) there are a lot of issues to be raised there. The first FGD revealed that, leprosy is not only a biological entity but it is also a social issue. Almost all of the respondents have agreed that it is one of the most stigmatized diseases known to human society. During the FGD, one of the participants said that," I would rather prefer to be an HIV patient instead of being a leprosy patient". It is to show how the disease is highly attached with stigma which leads to discrimination. While the FGD was proceeding a large amount of time was taken talking about social exclusion. Most of the respondents talked about their experience related with social exclusion. What one of the participants said as follows:

> "I frequently use bus numbers two, which goes from 'Kore'[6]to 'Merkato'[7], and I usually take it early in the morning to go to my work place... I often noticed that no one wants to sit beside me... at one time someone comes to me and ask me to move a little bit and I did and share my seat to him. When he saw my hand, suddenly stood up and went to the front without saying anything"

During the second FGD, the idea discussed in the first FGD was raised again and they added that giving nick name to the leprosy sufferers is another effect of the disease which the victims encountered. As it was stated in the FGD, leprosy patients had used to be nick named using various derogatory terms such as, *"komata", "dikuman", "kuntish", "korata", "dush"* and others. All these derogatory names were mentioned by five of those FGD participants on a turn by turn basis. The other point raised by one of the FGD participants was that

> "Let alone us, our families are also nick named and are victims of social exclusion simply because they are our family members. People nick named our family members as " *yekomatalij", " yekoratalij", yekuntishlij", " yedikumanlij", " yedushlij"* and the like which is too hurting for us".

Besides, both the FGD participants considered the social effect of leprosy is too huge as compared to other aspects of the disease.

One of the major reasons for social exclusion is the societal wrong perception about the disease and its causation. To that end, the respondent's perception about how they are socially excluded was presented as follows using the respondents' case examples:

One respondent stated that "My neighbors and friends were not comfortable to be with me. Even they backbite me when I touch their hands to say hello, since my hand was so rough to touch. They told me to take holly water."

In a similar fashion the respondent who do not want to tell the researcher his name, stated that "At the beginning of the diseases my family hidden me at home not to be seen by others, they

[6] A place found in Addis Ababa where, a large number of leprosy affected people are living
[7] A popular market place in Addis Ababa

have no idea what it is, it was called "Tiliku Besheta[8]" .They separated the material which I use for drinking and eating".

The other respondent of the study has said that. "There were times that I spent some nights at the street with street children after I was discharged from hospital." It was after his first admission to that center. He also added that:

"The kind of understanding which my family has towards Leprosy is as if it is caused by a sin or a curse, as something associated with traditional beliefs of being hereditary. I prefer to get a modern medical treatment, but my parents did not encourage me to get access to a modern health care facility, which they were not concerned much. After, I came to Addis, my family never visited me. No one is encouraging me, especially after I was found to be a Leprosy patient, except my grandparents. The community attitude towards Leprosy is that, as it is associated with evil spirit, traditional beliefs, sin, or a curse and as is hereditary".

Another female respondent of the study indicated that

"I don't exactly know what my family could say about the cause of Leprosy since I lost them when I was a kid. But some people say that it is 'kumtena' being seriously injured or mutilated with sore. Neighbors know about my condition, but they all were not interested to have contact with me. They never visit me. They do not encourage me. Every one develops hatred towards me and I was isolated (stigmatized). I went to a place of the holy water alone; no one was interested to accompany me".

As we can see from the above case study all of the respondents accept the idea that leprosy has a strong social effect on the lepers. Patients could suffer from stigma and discrimination. They were discriminated and stigmatized by the community, which they live in and at some case they were even stigmatized by their family. Furthermore, the above case can also indicate how the community associated the cause of the diseases toward evil and sin. They associated the diseases to myths and superstitions, which was a wrong perception and might contribute a lot for the destructive social problems which the patients was being suffered.

[8] The great disease

On the other hand, the clinical social worker, nurses and the physicians have got similar idea regarding the effect of leprosy on the social well-being of an individual. The clinical social worker stated that:

> "The community has wrong perception about the cause of Leprosy. They take it as if it is a curse from God. Because of this understanding the community stigmatizes not only the Leprosy patients but also their families. Their isolation from the community led them to be beggars and exacerbated dependency. Most of the Leprosy patients were not interested to return to their homes. That is why they mostly resort to begging".

Most people do not accept that bacteria cause the disease. They consider it to be hereditary; even some others consider being a result of evil spirit or a curse. So the Leprosy patients highly suffer from stigma and discrimination."

The physician in the health care facility also indicated that "after medication, when they return to their home some suffer from stigma by their own family. For instance patients are locked in a certain house, not to have contact with other people assuming that the disease is contagious due to eating together and touching. Moreover, as the physician stated, these people are denied their human rights. For instance, there are some countries who do not give visa to leprosy affected people. These countries require leprosy status as a medical requirement.

As it can be elicited from the finding of the above professional case respondents, leprosy greatly affects patients' social relationships. It made patients to be stigmatized and to be discriminated even by their closest family members. Leprosy may also lead the patients not to get back to their community due to fear of stigma and discrimination .As a result they are easily exposed for being baggers, settle to church and there by being economically dependent on the community and lead them to develop a feeling of helplessness and hopelessness.

4.5 Leprosy and its economic effect

As it was depicted by one of the respondents, leprosy is mostly associated with poverty .A respondent told the researcher that the major reason for leprosy affected person to be poor is that the nature of the disease. The disease is mostly resulted in physical mutilation and disfigurement. The respondent reported that "I can say that, economically most leprosy people in this area (the surrounding of Alert) are poor, and there are also a significant number of beggars. Since most of

them are crippled, they are dependent on others, expecting alms from other people and or voluntary organization". But there are few people who organized themselves to engage in some small industries like engaging in a certain kind of handicrafts.

As it was explained by the respondent, in fact some leprosy patient had large tracts of land and other prosperities in their birth place. Most of them are left what they have there and migrated far from their home of origin. It is mainly due to, fear of stigma. Most of them prefer to be dependent on others, instead of facing rejection and exclusion in their own community.

Respondent stated that, leprosy affected people are known to be highly disadvantaged in the job market .It is uncommon to see equal job opportunity given to those people affected by leprosy and those who are not affected . In this reared, leprosy affected people often suffer from unjust treatment while they are applying for a job. When such an encounter frequently happens, leprosy patients began to consider themselves us incompetent and in capable.

One respondent tried to explain the economic impact of leprosy by considering his own case as an example.

Case

Melaku is a twenty five years old youngster. He was living at kore since his birth. Both of his parents were leprosy affected, and none of them are alive. With the help of some charitable organizations and some people he was able to complete high school and then join university. Melaku told the researcher that although he has got a B.A degree in Sociology and Social Anthropology, he could not able to find job. As he said, the major reason for his inability to get a job is his situation. "Because of the fact that I am affected with leprosy, no one dares to hire me. Even if I, I was competent enough in doing exams and good at interviews, employers are mostly reject me using various reasons which do not convince me. Now, I am totally tired of it and I do not apply for vacancies. As you saw me, that I am ended up being a shoe shiner".

The other respondent told the researcher that, "the disease by nature makes people bed ridden and incapable of doing some jobs. Even if we are doing our best, what we did is most likely being rejected".

Explaining the economic impact of the disease, a respondent who lost both his legs and hands argued that "let alone being productive, we leprosy affected people who had lost both our legs and hands, could not able to urinate. You can take me as an example, I can't urinate by myself, I am always in need of others support. My survival is totally dependent on others".

During the key informant interview session, the chairman of A.A .L.V.R.A told the researcher that

> "Economically, leprosy affected member of the community always suffer from getting equal opportunity on the job market. It is obvious that most employers are not confident on leprosy affected persons, fearing that there would be a great risk of losing one's customer and they also thought that leprosy affected individuals are less capable and competent as compared to non-leapers in performing their task . Besides, employers are also not ready and willing to support them in enabling them competent and confident. Since they are expected to pass through all these obstacles, leprosy affected persons are less likely to achieve what they aspired. That is why, I think, most of them are living in absolute poverty, most of them are living in a very difficult condition, expecting alms from others. You can find large number of leprosy affected people begging around churches."

Extending his explanation, the chairman stated that

> "One of the basic reason to be a beggar is that the social stigma. Most of them are coming from the northern part of the country and their economy is known to be agriculture. When they are being detected by the disease, most leprosy affected people tend to desert their village, leaving their relatives, land, and other resources behind. They never want to return to their homes of origin. They would rather want to live in leprosy colony with similar people, mostly for fearing of the social stigma." He finally said the Amharic proverb that is "*zemed kezemedu ahiya keamedu*" which has an equivalent meaning to "birds of the same feather flock together".

According to this informant, the other reason for them to be economically weak and dependent is that, the nature of the disease itself. The disease makes people to lose their body parts especially their legs and hands, it make them less capable in performing tasks as compared to others if not

incapable completely. This is also one of the points raised by all health care practitioners as the major reason for the economic dependency of leprosy affected people in general and leprosy patients in particular

The other key informant, from the NGO stated that, leprosy and economy are highly inter related especially in the case of our country. Since most people are living in congested situation the possibility of the bacteria to be transmitted from the positive agent to others would be high. She also added that if leprosy patients are rehabilitated they might be capable of withstanding the disease. Besides, although some of the leprosy affected people are engaged themselves in various small scale businesses like preparing and selling [9] *'enjera'* and other food items most people do not want to buy what the leprosy affected people have produced.

All the points raised during both the FGDs, strengthen begging as a survival strategy for leprosy patients takes the lion's share of time. Almost all the participants from both groups argued that leprosy patients resort to begging as a survival mechanism.

In general, the finding of the study revealed that the major reason for most of leprosy patients to be economically weak is the nature of the disease. It makes the victims to be incapacitated. Moreover, the social stigma attached to the disease has also contributed a lot for leprosy patients to be economically dependent. Accordingly we can say that the social impact of leprosy cannot be seen in isolation from the economic impact, the latter is mostly exacerbated by the former.

4.6 Social work intervention

One of the questions raised during the study was that whether the social work intervention is significant or not, in alleviating or at least minimizing the psycho-social and economic challenges of leprosy affected people.

During the in-depth interview, the physician stated that, social work has a role to play in treating any patients in general and leprosy patients in particular. As it was indicated by her since many leprosy patients are coming from rural areas, they mostly do not have a place to stay and could not afford their food, transportation and other costs. In such a time the social work department plays a huge role in fulfilling what the patient needs. Besides, the informant indicated that those leprosy patients are mostly amputated and unable to work and becoming economically

[9] Ethiopian staple food usually made of teff

dependent. In such a case the social workers are among the one who is responsible to rehabilitate and make them a productive being.

The other key informant, who has been working with leprosy affected people for long stressed that social work has a huge role to play. According to this informant, one of the major contributions of social work is advocacy. It is to say that social advocacy helps the victims be heard by the community and empower them to support themselves.

Creating awareness among the community and affected people is also something expected from the social workers working there in the hospital. The key informant also added that as a social worker we should invest on education because what matters most with regard to the problem in question is that the issue of societal perception and attitude. The informant said "we should tell them leprosy is less contagious as compared to poverty".

According to the clinical social worker, social work as a profession has a significant positive role to play around health care facilities. Social workers are also important beings in smoothening treatment of patients in health care arenas. He also suggested that, it would have been better if the entire health care giver have to be familiar with the concepts of social work. Besides it would also be better if each and every department in the Hospital have specialized social workers, since there are multi-dimensional social problems with in the Hospital.

The key informant said that, the prior mission of the social workers there at Alert Center is case management. It incorporates all the following services like; Identifying strengths and weaknesses, link the clients (in our case the leprosy patients) with institutions, assist them with the necessary materials like crunch, shoes, and wheelchair, link the bed ridden patients with various humanitarian or charity organizations, provide out and in patients with the necessary psycho social support, invite those rehabilitated patients to share their experience; to be served as a role model, advocate for admitted patients; whenever there is problem with food and other services in the hospital, help leprosy patients to get free medical service for those who are not capable of paying a service fee; especially for those who are coming from rural areas, whether they have a referral or not, working with governmental and non-governmental organizations in an integrated manner such as leprosy associations,, donor, charity and humanitarian organizations such as Catholic Missionary of Charity, Contemplative Missionary Organization

for Aids, Medehin Social Center and G.L.R.A (German Leprosy Rehabilitation Association).Treating biological problem may not be suffice for those leprosy affected people since they have a much more psycho-social and economic challenges to encounter. Social work intervention can minimize the psycho-social and emotional challenges which leprosy affected people have frequently encountered. These challenges would be hardly be considered by most health care givers especially in developing countries like Ethiopia.

CHAPTER FIVE: DISCUSSION

This section is presents the discussion of the findings under different sub themes in light of research objectives, research questions and the related literatures. The major themes which the researcher discusses in relation to various literatures encompasses: leprosy as a disease and its causation, the social effect of leprosy, the psychological effect of leprosy, and the economic effect of leprosy. Besides, this section, discusses how social work intervention could be used to tackle all the challenges faced by leprosy patients.

5.1 Leprosy as a disease and its cause

Based on the finding of the study, all non-key informant respondents talked about the cause of the disease when they were asked about leprosy. The researcher found out that there is some kind of confusion among those leprosy patients about the disease. But, all the care givers and key informants were all familiar with what leprosy meant as a disease and social problem.

As to the cause of leprosy a lot of myth and believe has been involved. Majority of the respondents used to believe that leprosy is linked with sin and punishment. Some of them used to believe that they are predestined to be leprosy affected. But, the findings of this study were not consistent with most literature. For example the Hindus in India consider deforming due to leprosy is a result of divine punishment. A similar view is shared in China where leprosy is considered as a punishment of 'moral lapse'. They believe that the disease has been transmitted during sexual intercourse with prostitutes (Ramakrishana and Weiss, 2001). Moreover in Ethiopia, the survey study in Gunichire Gurae Zone, southern region shows that among the leprosy affected, non-leprosy and non-leprosy family respondents 52.7% believed that leprosy is the result of curse and calamity, while only 13% of the respondents understand the causes of the disease to be a kind of bacteria (ENAELP, 2003). With regards to the construction of beliefs and myth in relation to the cause of leprosy, Kazeem & Adegun (2011, pp. 104) argued that social constructions of leprosy are commonly steered by cultural, traditional and religious beliefs or myths about disease and illness not only in low resource settings like Ethiopia and many African countries but also in Western developed countries. Nicholas Aboon, (2006) also indicated that spiritual pain is endured as they are forbidden to enter places of worship due to the prevailing belief that the disease's etiology is their 'sinful' state.

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

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

From the above discussion the researcher understood that there is some kind of awareness on the part of the leprosy patients in understanding about the disease, how it is caused and transmitted. But still there is a lot to be done on sensitizing the public in general and the victims in particular since the misconception is still existing especially in rural areas.

5.2 Leprosy and its psychological effect

Based on the findings, six of the respondents have reported that, most leprosy patients have developed some kind of emotional problems. As it was indicated in the finding, some of the major emotional problems which leprosy patients feels includes depression, shame, dependency and even aggressiveness. The study also found out that, leprosy can affect the mentality of its victims by lowering their self-esteem, confidence and their dignity. These findings are consistent with several studies. Kufman, Senknesh, &Neville (1986) demonstrated that depression is a very common reaction to loss of parts of the body or loss of body function such as appearance of deformity. They also depicted in their work that, the presence of physical deformity or disability,

frequently makes the patient to be depend on others, at least for a certain period of time. As it was indicated by Kaur & Brackel (2002) leprosy leads to emotional distress caused by feelings of shame and of being different. Frist (2001) also contribute idea which supports the above finding. In that work it was stated that, saddest of all, even people affected by the disease will believe many of the myths about leprosy as a result suffer from low self-esteem.

The finding of the study also showed loneliness as a major psychological problem which people living with leprosy encounter. As most of the respondents stated, the major reason for such a feeling to develop is the fact that leprosy patients are mostly separated from their families as well as their beloved ones. It might lead them even to commit suicide. Supporting the above finding, Dennis (1987), contended that, loneliness may expose persons to trauma. Consequently, those persons may get in post-traumatic problem unless they get appropriate counseling and support. In addition, due to either their loneliness or stigma attached to the disease, peoples with leprosy have high risk to be exposed to mental health and committing suicide.

The finding of the study also showed that many leprosy affected people are hiding themselves from other people. They mostly tend to develop a sense of being secret. Similarly, Frist (2001) stated that one should not be surprised if people affected by leprosy continued to hide their condition from employers, colleagues and others, since they know that the consequence of its discovery would be worse.

Kaur & Brackel (2002) argued that feelings of fear, shame, low self-esteem, isolation or feeling ‘different’ are all considered signs of self-stigma. As one of the respondent stated, self-stigma can occur when people are affected by a stigmatizing condition became ashamed of their condition because of the attitude of others towards the disease and or the deformities they might have. In a similar manner, the finding obtained from the FGD show the same. Three of the FGD participants said that since the disease leads to disfigurement and deformity and even sometimes disability, most leprosy affected people tend to isolate themselves and some even develop a feeling of fear and inferiority.

Moreover, society in general, considers and accepts persons affected by leprosy as social out casts. These attitudes have become instilled in the minds of those affected by leprosy so they lead gloomy lives, prefer to live solitary lives, live in ghettos, and develop low self-esteem and

absence of self-confidence. This is worsened by the seemingly accepted culture of the society that ex-leprosy disabled persons should live on alms or by begging.

5.3 Leprosy and its Social Effect

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

What was stated above might be supported by the societal misconception appeared in various societies including Ethiopia. People have a wrong perception about leprosy, they consider the disease as the worst of all disabilities as seen in the expression *"Tilku Beshita*" meaning that the great disease. This is aggravated by a number of sayings that despise the person affected by leprosy, for instance, *"Komatan komata kalalut gebeche lefetfit maletu aykerim"*, meaning if you do not call a leper that is leper, he dares to touch and mix the food. Moreover, other sayings, "*Yezriews Bered komata Yasakfal*" meaning today's chill forces you to hag a leper.

The above idea was verified by the finding of the study, as it was stated in the FGD, leprosy patients used to be nick named using various derogatory terms such as, *"komata", "dikuman", "kuntish", "korata", "dush"* and others. As was depicted in the study allmost all of the respondents have stated that they suffered from these societal prejudice, nicknaming and ridicule. Teklehaymanot stated in Subramansam (1999) that the name 'Kumtina' was also given to leprosy in Ethiopia, denoting "state of amputation or mutilation".

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

respective birth places report that their families hares them and threaten death by incinerating in huts. If persons are leprosy disabled everybody hardly wants to, eat, share, seat and merry member of their family. In a similar way, Scott (2005) stated that many leprosy affected people fear ostracism by society and feel for their family members who also may be rejected by an intolerant and ignorant community; they mostly prefer to migrate away from their village. In contrary, Frist (2001), see segregation in a different way.

> *Segregation sometimes can be a way of life that they freely choose. They may feel more comfortable living with people who dress, eat and think like they do and have had similar life experiences*

Both the in-depth interview and FGD result showed that, getting non leprosy affected spouse is a difficult undertaking for those leprosy patients. This finding is supported by, Scott (2006), leprosy in the family makes a marriage arrangement difficult, if not impossible. As opposed to the finding and Scott, Heinjer (2004) sees leprosy patients' difficulty to find ones non leaper spouse as positive due to the fact that its rate of diverse becomes less.

The study also found out that leprosy affected people have been neglected from participating in various social engagements and denied access to some social services. One of the respondent stated that, she was neglected from participating in her *'idder'*. Besides, during the in-depth-interview, one of the other respondents told the researcher that there was also negligence from the side of health care givers. Other respondents and participants of the FGD said the same. Consistent with this idea, (Sen, 2000) talks about lack of participation as one major challenge which leprosy patients' experience. They mostly are neglected from playing different roles in the society they live in. Sen (2000) added that, stigmatized people are not considered as capable to perform the social function as others. Thus, they are isolated from participating in community based organizations, formal and non-formal community meeting and from cultural and religious festivals. As stated by Kazeem&Adegun,(2011, pp. 104), leprosy patients may not be sympathetically treated in medical instances; in India, cases have been reported doctors refusing to treat leprosy patients .But, none of health care giver informants of the study said this.

The large majority of the respondents and the key informants stated that leprosy is a highly stigmatized disease. They also mentioned that social exclusion as being one of the major manifestations of the disease. As it was demonstrated in the finding of the study, most leprosy patients were excluded from their community. As they most argue, the exclusion started from their own families. MOH (2007, pp1) report that leprosy can affect people in many ways, not just physically. In some countries, largely due to myths and superstitions, there is a great deal of fear associated with leprosy. People diagnosed with the disease can be stigmatized, rejected by their families and communities. Similarly, J Scott (2005) indicated that leprosy patients were and are rejected by their families on account of the latter's fear of leprosy. Sometimes they may even request the patient to leave home. Nicholas Aboon, (2006) verified the above ideas, by stating that, for some of its victims, leprosy means being rejected by their communities, or divorced from their spouse. It can be tough for people affected by leprosy to get the help they need. The researcher found out that the largest portion of the research findings is consistent with literatures. It was also found out that there are a lot of things to be done in trying to consider social aspects of the disease.

5.4 Leprosy and its economic effect

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

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

The other finding of the study was that some respondents have reported that persons with disabilities (PWD's) in general and leprosy patients in particular were and are suffering from getting equal opportunity in the job market. As they reported they often face unjust treatment when they are applying for a job. Respondents told the researcher that employers were mostly not confident with PWD's in which leprosy patients are incorporated. Besides, some employers do not want to hire them for fear of losing their customer. These findings are consistent with Terusew(2005: 176-177) who demonstrated that PWDs encountered serious challenges in obtaining jobs even though they were equipped with the necessary skills through training and education. According to his findings, employing agencies disqualified candidates with disabilities regardless of eligibility for the job. Abreham and Woldesenbet (2005:35)stated that "obviously, it is difficult for disabled persons to get employment in the open labor market. Yet it is even more difficult for them to advance in their jobs." In contrary, Abreham and Woldesenbet (2005: 6) stated that placement of Ministry of Education for graduates of higher educational institutions, trained in teaching, have contributed more for teachers with disabilities not to be discriminated in obtaining employment.

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

The health care givers and other key informants have revealed that, there is a strong relation between slum (congested houses), which is one of the manifestations of poverty, and the disease. As it was indicated in the findings, health caregiver informants argued that, one of the reasons for the disease to transmit from one to the other is long contact with a positive agent. So the researcher found out that, the fact that most leprosy affected people are living in slums might aggravate the magnitude of the disease. Frist (2001) stated that leprosy remains closely associated with poverty as ever. The people who contract the disease are often very poor already, and it exacerbates their poverty in several ways: if they have insensitive hands and feet, they can

injure themselves by carrying out the heavy manual labor generally associated with unskilled, low-paid jobs. Having these injuries treated also means time off work and a loss of wages or production. One of the key informant has stated that "leprosy is less contagious than poverty," and stressed on investing on education as a way out from poverty for lepers. What Frist (2001) stated below coincides with the finding. Poverty probably has as much to do with the incidence of leprosy as it do with most other public health problems. Poor people seldom have access to healthy food, adequate sanitation and basic medical care. They also live in more crowded conditions. As a result, the disease is far more common among very poor people. Eliminating poverty would probably help to eliminate leprosy as well. 5.5 Social work intervention

The finding of the study revealed that all of the health care givers were not a such familiar with the contribution of social work intervention in treating people affected by leprosy. They associate social work as if it only plays the role of linkage. Besides, medical personnel mostly tend to focus on the biological aspects of the disease, by overlooking the psycho-social aspects of the disease. Contrary to this finding, Arole (2002) argued that, during the process of diagnosis, the importance of assisting the patient to maintain both his self-identity and social identity cannot be overemphasized. Similarly, Michael (2009) also advocated the need for a medical ecological approach to the problem of disease in general and leprosy in particular. He signified that health problem disrupt personal, family, and social life, intimate behavior, and self-image and place additional dimension on family and friends. Medical treatment can produce further disruptions and reduce patient's motivation and ability to comply, if it could not consider environmental and cultural context of the patient. Appropriate treatment planning, Michael added, requires an understanding of client's socio-cultural environment. As per the finding of the study, the health care givers are less concerned about the socio cultural environment of clients in general and leprosy patients in particular. Besides, the client's families are hardly to be incorporated in the planning of both health care givers and social workers. As opposed to this, referring to the work of Lim &Zeb rack (2004) Barbara suggested that social worker role of assisting patient must include families in the treatment planning, not only as therapeutic allies, but also in regard to the multiple stresses that care giver experience. But, none of the findings show the idea of incorporating families in the treatment plan.

As shown in the study result almost all of the interviewed respondents had a positive role about the importance of social work intervention in playing a role in treating all diseases in general and

leprosy in particular. The result of the study also show that, as opposed to the medical personnel, who have a limited knowledge regarding the importance of social work intervention, the social workers have a better understanding about it. The finding showed that social workers at rehabilitation centers play the role in case management, linkage, facilitator, advocator, enabler and the like. Besides, they also deliver psycho-social counseling and awareness creation to those leprosy affected people. The other issue demonstrated by the study was the fact that the social workers are engaged them in playing the role of rehabilitation.

The researcher uses the biopsychosocial approach as one of the guiding theories to have lead this particular study. To that end lack of utilizing a holistic approach in the health care system could be one of the impediments for the persistence of the psycho-social problems which leprosy affected people usually face. Following a holistic approach, like the biopsychosocial and or medical ecological approach to health care could be a remedy.

CHAPTER SIX: CONCLUSIONS AND RECOMMENDATIONS

6.1 Conclusions

In a nut shell, it has been found in the study that a great number of our respondents were, emotionally unstable, developed low self -confidence and lack self-esteem, stigmatized, discriminated, economically dependent socially out casted and physically disabled.

It has also revealed in the study that leprosy is one of the disabling illnesses by altering anatomy and physiology of musculoskeletal system of the affected person. The situation is worsened by social problems with extreme dimensions such as ignorance, fear, and superstition characterizing the problem of leprosy. The synergetic effect of the biomedical as well as psychosocial and economic problems significantly affected the quality of life of leprosy affected person and their family.

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

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

6.2 Recommendations

This study recommends that to reduce the psychosocial impact of leprosy on the individual appropriate social work intervention mechanisms should be applied. The intervention mechanisms should necessarily focus not only on the bio medical aspect but also on the psycho social effect of the diseases. A holistic approach / treating the whole person is a key in prevention; care as well as rehabilitation of the person should be implemented to address the problem very well.

To meet the psycho social needs of leprosy affected people, the government has to establish leprosy division, which is common in various developed countries. The division would be capable of giving a psycho-social and economic support in addition to the medical service they rendered.

In order to alleviate the psychological impact of the disease, people affected by the disease, service providers and the general public have to combat negative stereotypes about leprosy. Besides, these three groups have to strongly cooperate to alleviate the effects of the disease and bring about genuine social integration.

Since one of the major problem faced by leprosy affected people is the social stigma attached to it, the only way to stop the stigmatization of people affected by leprosy is to do away with the situations that caused the stigma in the first place: Raising public awareness, educating clients (leprosy affected people) about the disease how it is caused, transmitted, prevented and cured. Leprosy affected people are suffering more from psychosocial and economic problems than the biological pains the disease causes. To tackle this problem, designing implementation and evaluation of a training programme for leprosy field workers regarding the effective counseling of leprosy sufferers and the development of strategies to de-institutionalize leprosy sufferers and to integrate them into the community is very crucial. It would be better if integrating leprosy work into non-medical programmes, addressing the general population be implemented.

To overcome the social problem which leprosy patients face, it is also recommended that the help rendered to them should be done in their home communities, participating in the same activities, enjoying the same rights and carrying out the same duties as they would have done had they not contracted the disease.

It is also advisable to bring to an end the segregation that places people affected by leprosy in specialized institutions, or that bars them from schools, churches, public housing, recreation facilities, hospitals, rehabilitation centers, and homes for older and disabled people, etc. So as to eradicate the economic problem which leprosy patients faced, the right of people affected by leprosy to have the same access to jobs and access to services has to be ensured. Since the effects of leprosy have made it impossible for them to work, to ensure that they have the support of their family and receive help such as special vocational opportunities for disabled people and access to homes for destitute people and to any disability pensions available to the general population is recommended. Access to economic assistance should not be based solely on the criterion of being affected by leprosy, but on more specific factors such as age, extent of disability, financial need and availability of alternative sources of support**.**

6.3 Social Work Implications

The traditional medical model to health care primarily focuses on the biological causes of the disease. However, the psycho-social aspects of the disease were overlooked for long. Therefore the existing gap in the service provision needs to be approached from different angles since they bear various implications for various concerned bodies.

Implication for Social Work Education

In general, Social workers should advocate the full participation and equal opportunity of persons affected by leprosy and also creating awareness among the society of the misconception and fear of the society about leprosy by giving health education and through mass media. Moreover, social workers should involve in rehabilitating persons affected by leprosy by breaking their cultural, social, psychological and economic chain to become productive part of the society and encouraging and supporting people affected by leprosy to participate in sports, music, and other recreational activities to develop positive self. To that end there is a need to

produce adequate, well qualified, and competent social workers. In this regard the mandate is to be left for higher institutions, especially for the school of social work.

The social work intervention can be seen at different levels: Ranging from micro to macro level intervention. These can be seen at an individual, community, institutional and policy level. Besides, interventions must be participatory, targeting individual, community and policy levels**.** Before program planning there should be comprehensive needs assessment and the planning must use appropriate planning model. It has to also involve the concern of the community.

At the individual level, educational programmes have to be set which targeted at health care givers or health professionals, leprosy patients and their families so that their prejudicial attitudes towards the disease might be mitigated if not eradicated at all. In addition to educational programs group counseling of people with leprosy has been shown to be time-efficient and productive in tackling leprosy stigma.

Besides, inducing empathy for a leprosy affected people can help to change the attitudes of other people. It is also very important to rehabilitate leprosy affected people physically, socially, and economically.

At community level, health education campaigns must shed light on leprosy through messages that sensitively deal with the local community's beliefs and misconceptions while driving home the right information about leprosy to the people. The messages must be structured to make sense within the logic of the peoples' worldviews whilst they tackle leprosy stigma in broad contexts.

Research implication

As most literatures are revealed there is a gap in research work, conducted on the psycho social aspects of leprosy. Hence the researcher believes that research should be conducted on the psycho social aspect of the disease. Besides it is also essential to conduct a research on how to improve the economic situation of leprosy affected people, since they are highly characterized by poverty.

The existing knowledge, attitudes, beliefs and practices of the target population pertaining to the disease should be explored and researched before appropriate awareness programmes are

designed and implemented. This is best done through a combination of qualitative methods such as focus groups and quantitative methods such as surveys. Studies should also be conducted among health care providers to assess their beliefs and attitudes on leprosy. Cross-cultural studies should be carried out to compare factors that have led to the differing attitudes towards leprosy patients. We can learn from communities with more favorable attitudes and apply and adapt what we have learnt from them to less favorable communities.

In addition, the sample size of the study was small and the site was also only a single center. Therefore a macro level study that incorporates large samples would help to arrive at different result, which might help to introduce a better intervention plan.

Social work implication at a Policy level

Since the major problem for the psycho social and economic problem of leprosy is stigma attached to the disease effort has to be exerted at a policy level so as to reduce the stigma. To that end, governments and non-governmental organizations have to implement stigma reduction programs.

Efforts at policy level should include:

- ✓ The use of non-discriminatory terminology such as Hansen's disease to describe people with leprosy.
- ✓ More support and rehabilitation services have also been provided to patients and their families. Besides, leprosy control programmes should be integrated into the general health care system.
- ✓ As stigma may be perpetuated by the negative attitudes of health care providers themselves, many leprosy programmes have also focused on training health care providers to be more sensitive and empathetic to leprosy patients' concerns.
- ✓ To dispel the fears about the non-curability and infectiousness of the disease, community health education have to be arranged.
- ✓ Used the mass media to disseminate more positive messages about leprosy.
- ✓ Involve traditional healers, community leaders and community in disseminating health messages on leprosy and facilitating early detection and treatment.

Advocacy

At policy level, advocacy efforts must centre on a supportive, enabling environment that favors legislative and policy change. To ensure organization of various information into a logical structure advocacy effort must use a target-specific stigma-change framework. There is also a need to pay greater attention to the human rights violations faced by people affected by leprosy. Here social workers should play the role of advocacy through promoting appropriate policy options and intervention programs.

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APPENDIX A

ADDIS ABABA UNIVERCITY

SCHOOL OF GRADUATES

DEPARTMENT OF SOCIAL WORK

Date_____ Place_____
Time_____

Consent Statements

Introduction

You are being invited to participate voluntarily in the study entitled that "A review on the psycho-social and economic situation of leprosy patients in Ethiopia: the case of admitted patients of Alert center" My name is Yonas G/Mariam. I am a master's student at AAU school of social work.

The purpose of this study is to gather information on how your experience is on the psycho-social and economic situation of leprosy patients. You will be asked to discuss your thoughts, experiences and feelings related to the psycho-social and economic situation of leprosy. You understand that your interview will be recorded. The interview will take approximately 45 minutes to 1 hour of your time. Prior to the interview you will be asked some personal questions including your age, marital status, religion, ,level of education and length of time in a treatment. The interview will take place in a convenient place. You may stop the interview at any time and can end your participation in this study if you wish. You may refuse questions if you want. You are free to ask questions and receive answers at any time throughout this study.

Risks involved with the interview

The risks associated with this study are possible emotional upset while sharing your experiences. If you do become emotionally upset during the interview, you can stop the interview completely or resume the interview at a later time.

Benefits of participation and compensation of time

Information from this study may assist social service providers and other health professionals to better understand the psycho-social and economic situation of leprosy on the affected people. This may affect how the situation of leprosy affected people are treated in the future. There is no cost to you for participation .

Confidentiality

In the course of our discussion I want to assure you that, the information you will share, will be kept confidential and will be used only for educational purpose. The finding of this study will be presented and reported to the school of social work AAU. When the findings are reported you will not be identified. You will be assigned with a pseudonym/code to protect your confidentiality.

Demographic data will be kept in a locked cabinet during the study, but will be destroyed once the study is completed.

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

Participant's signature_____ Date_____

Thank you very much for your participation!

APPENDIX B

ADDIS ABABA UNIVERCITY

SCHOOL OF GRADUATES

DEPARTMENT OF SOCIAL WORK

In-Depth Interview guide for admitted leprosy patients

Part I: Personal Information

- Age_____
- Sex_____
- Marital status_____
- Educational status_____

Part I: **Leprosy as a disease and its cause**.

- How do you know you have leprosy? Was there any symptom which led you to go to clinic/hospital for test?
- What did it affect your physical or any other part of your body?
- How did you get about the diagnosis and treatment?
- Do you and your family know about leprosy? What are the causes for it? Do your families have any role in your test? How does leprosy affect the health and wellbeing of individuals, families, groups, and community?

Part II: Leprosy and its psychological effect

- ✓ What do you think about the psychological effect of leprosy on the affected persons?
- ✓ How does your condition affect your personal relation with people and environment? Probe, does it have similar impact on the family members? Does it bring behavioral change on you? If there is any, can you tell us?

Part III: Leprosy and its social effect

- ✓ What are the social and economic impacts of leprosy?
- ✓ How do you perceive the reaction of Leprosy patients to wards that social stigma and discrimination?
- ✓ How do the family members respond to your condition? How about friends, neighbors, & community?

- ✓ How do the people around you and the community understand the causes, aggravating factors and the social effects of leprosy? Probe what were their responses to your test result?

- ✓ Have you or your family experienced negative effect on involving and benefit from social services? Probe, can you tell us some of those experiences, if there is any?

- ✓ How does your condition affect your personal relation with people? Does it have similar impact on the family members?

- ✓ Did you face any kind of discrimination and stigmatization for being affected by leprosy? Probe, how do you cope up with it? If there is any?

Part IV: Leprosy and its economic effect

- ✓ What do you think the economic effect of leprosy on the affected persons?
- ✓ How do you explain the economic situation of people affected by leprosy? Probe, what coping mechanism did they use?
- ✓ What is/ are their source of livelihood?

Part V: Social work intervention areas

- ✓ What do you suggest for improving the psycho- social & economic situation of leprosy patients? Probe, what coping mechanism did you utilized to overcome these problems?

Thank you for your cooperation!

APPENDIX C

ADDIS ABABA UNIVERCITY

SCHOOL OF GRADUATES

DEPARTMENT OF SOCIAL WORK

Interview guide for health care providers/Social Service Providers

Part one: Personal information

- Sex_____
- Years of service working with Leprosy patients_____
- Educational status_____
- Occupation_____

Part II: **psycho – social and economic situation of leprosy**

- For how long you have been working here?
- What are the major psycho social & economic challenges faced by leprosy patients?
- What are the roles of health care /social service to providers improve the psycho- social & economic situation of leprosy patients?
- What are the major problems of health care /social service providers face improving the patients' situation?
- What is your experience on leprosy related social stigma and discrimination? What social wok interventions could be put in place to improve the living conditions of people with leprosy?

APPENDIX D

ADDIS ABABA UNIVERCITY

SCHOOL OF GRADUATES

DEPARTMENT OF SOCIAL WORK

Focus group guide for leprosy patients

- Introduction-introduce self and explain how long the session expected to run.
- Focus group discussion objectives-introduce the aim of the study.
- Warm up discussion was held like How is work, family and other thing to establish a good rapport.

Discussion Themes

1. What leprosy is to mean
2. Psycho-social impacts of leprosy
3. Economic impacts of leprosy
4. Coping strategies to overcome challenges related the psycho social and economic impact of to leprosy

Thank you for your cooperation

Declaration

I declare that "A review on the psycho-social and economic situation of leprosy patients in Ethiopia: the case of admitted patients of Alert center" is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before for any other degree at any other institution.

Yonas G/Mariam

Signature: _____

Place: Addis Ababa University, Ethiopia

Date: _____

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

Hailom Banteyirgu (PhD.)

Signature _____