Exploring the challenges of rural people affected by leprosy to reintegrate within their community of origin and their coping mechanisms: A Study in ALERT Center, Addis Ababa

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This is to certify that the thesis prepared by Melese Yirga entitled "Exploring the challenges of rural people affected by leprosy to reintegrate within their community of origin and their coping mechanisms: A Study in ALERT Center, Addis Ababa" 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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Acronyms

AHRI - Armahuer Hannsen Research Institute

ALERT - All Africa Leprosy, TB, Rehabilitation, Research and Training Center

ALVRA - Addis Ababa Leprosy Victims Rehabilitation Association

CDC - Center for Disease Control

ECC-MSC - Ethiopian Catholic church Medhin Social Center

ENAPAL - Ethiopian National Association of Peoples Affected by Leprosy

FGD - Focus Group Discussion

FMOH -The Federal Ministry of Health

GLRA-German Leprosy Rehabilitation Association

HIV - Human Immune Deficiency Virus

ILEP - International Leprosy Eradication Program

MDT -Multi Drug Therapy

PAL - People Affected by Leprosy

POD-Prevention of Disability

TB -Tuberculosis

TLMI-The Leprosy Mission International

WHO -World Health Organization

Abstract

People affected by leprosy (PAL) from rural areas in Ethiopia have been suffering from the bio psychosocial and economic challenges but little is known about how they have developed a variety of coping mechanisms. This study explored the challenges of rural PAL to reintegrate within their community of origin and their coping mechanisms after receiving treatment at ALERT Hospital. The study adopted the qualitative method with exploratory purpose. In-depth interview, key informant interview, focus group discussion and observation were employed to collect the data and thematic analysis was used to analyze the data. It applied the non-probability sampling method with purposive sampling. Twenty seven participants were recruited for the study, twenty two of them were PAL the others were key informants. The findings of the study showed the challenges of the rural PAL such as leprosy reaction, loss of sensation, wound, deformity and disability. They also encounter psychological disorders like anxiety and depression. Socially, they have a problem of interaction, stigma, discrimination and marital relationship. Their productivity and property ownership was affected by leprosy. Finally, because of leprosy they were unable to reintegrate within their community of origin after being treated at ALERT hospital. The study also illustrated their coping mechanisms such as hiding their health status, using traditional treatment, migration, going to spiritual places, institutional support and begging. The results of the study would be used for intervention programs by stake holders to enhance the reintegration of rural PAL to their community of origin after their treatment at ALERT Hospital and to increase their coping mechanisms. The study may have implications for different concerned bodies to advocate and to create awareness, for running case management and for further study to improve the health access and quality of care and to have appropriate policy about the rural People Affected by Leprosy.

Chapter One - Introduction

1.1 Background of the Study

Leprosy is a chronic infectious disease that mainly affects skin and peripheral nerves and rarely other organ systems. It is not particularly age or gender specific disease. Poor living standards and inadequate nutrition prone people more susceptible to leprosy. The behavior of individuals also helps the transmission cycle to continue, as many people are unwilling to seek medical care even after being diagnosed because of misconceptions, stigma and superstitions (Sileshi, 2015, pp.31).

In 2005, Mesele Terecha in his research stated that leprosy is the oldest slow killing disease that man has known since time immemorial. The disease infects small and isolated human populations as well as denser populations with the wide-ranging contacts with other populations. For very many centuries, leprosy has huge problems both medical; between the host and the parasite, and social; between the patient and the society (Mesele, 2005, pp.9).

A study by Silleshi (2015) indicated that leprosy had been acknowledged as a major public health problem for more than half a century in Ethiopia. With more than 14% disability rate, more than 700 people are disabled every year and around 5000 new cases of leprosy per year on average are reported (Silleshi, 2015,pp.31&32).

A leprosy control program lead by the Federal Ministry of Health (FMOH, 2008), as scored extraordinary achievements in reducing the prevalence rate of leprosy in Ethiopia. However, the annual new case detection did not show comparable decline. Though, Ethiopia was achieved the elimination target of leprosy that is 1 case per 10,000

according to the WHO standard in the year in 1999, there are areas of high endemic at sub national levels where the leprosy prevalence is still higher.

The major focuses of this research was to assess the challenges of the rural PAL to reintegrate within their community of origin and their coping mechanisms after being treated at ALERT Hospital.

The rationale behind selecting this area of research had the following two main reasons. First, from my daily exposure as a social worker in ALERT Hospital, I assisted a number of rural PALs coming to ALERT Hospital from different parts of the country side in need of specialized treatment and rehabilitation services and they encountered with the multi-faceted challenges to reintegrate within the community of their origin after being treated at ALERT Hospital. Working on this issue would mean working with such vulnerable groups, which is one of the areas of interest for social work.

Secondly, as I have observed the phenomenon the well-known survival strategies of PAL from rural areas is leaving their community of origin and settle in settlements like Zenebeworq area to care for them and to find community of their own. Although different researches have been done on people affected by leprosy in Ethiopia, this research area is not well addressed before and there is shortage of literature on this study area. So, this research could contribute to fill the knowledge gap on the study area.

1.2 Statement of the Problem

In Ethiopia different researches have been done on leprosy and people affected by leprosy like a research by Richard Pankhurst (1984), *the history of leprosy in Ethiopia up to 1935*, Mesele Terecha (2005), *Leprosy, and Society in Ethiopia,* Desalegn Terecha (2014*), the pleasing unspoken voices* and Sileshi Baye (2015), *leprosy in Ethiopia*. The research by Pankhurst and Mesele have many commonalities to mention, both of them give emphasis in the history of leprosy in the world and in Ethiopia, the effects of derogatory words, religious values and laws to mold the misconceptions towards PAL. The study by Desalegn Terecha (2014) emphasized on the endeavors and historical analysis of Ethiopian National Association of Peoples Affected by Leprosy (ENAPAL). Sileshi Baye's(2015) work on the other hand focused on the epidemiological trend of leprosy in Ethiopia.

Pankhurst (1984) and Mesele (2005) acknowledged that leprosy has a long history in Ethiopia. The researches show the effects of pejorative terms in major languages of the country to mold the attitude of people towards PAL.

The study by Pankhurst in 1984 and Mesele in 2005 also mentioned in their respective researches that the Ethiopian outlook to the disease can be seen in the country's traditional code the Fetha Nagast literally (Law of the Kings).The law declared that a person affected by leprosy could not serve as a priest and a patriarch. A person affected by leprosy likewise excluded from being a judge(Pankhurst, 1984,pp.61).

Ethiopian society had little knowledge about the cause and transmission of leprosy. The Ethiopians believed leprosy as not transmittable disease, the belief on the non-infectious nature of the disease was reinforced by the people's attitude that it was a hereditary disease. In relation with the medical treatment a number of traditional medical treatments were applied widely (Pankhurst, 1984, pp.72).

Mesele's research finding (2005) also discussed the emergence, development and expansion of people affected by leprosy settlements and the transformation of those deprived members in Ethiopia. The research added a social history of leprosy sufferers in the 20th century Ethiopia, explains that problems related to marriage were long lasting and profound factors to aggravate social exclusion of leprosy sufferers. The property ownership of people affected by leprosy has been influenced by the society taking over the property of the leprosy sufferers by pushing them in to leprosaria according to the finding.

Desalegn (2014) stated that these days many PALs live in leprosy settlements, labeled with bad names, social injustice and ravaging poverty. Thousands are adding up every year with 7 to 14% of disability rate and newly diagnosed cases alone reach up to 5000 annually. The number of new cases in the past twenty years seems to show no significant decline. As a consequence, thousands have become disabled and forced to live in stigma and socio economic complications.

Leprosy has deep rooted stigma and caused migration of thousands of Ethiopian people leaving behind their family and community of origin. Because of the lack of awareness about leprosy, the affected people loose social dignity, self-confidence and self-disregard in the society. Societal misconceptions about leprosy have huge impact on

marital relationships between the affected people and other members of the community, on income generation, and educational achievement due to peer stigma and because people are forced to use traditional means of treatment (Desalegn, 2014, pp.16 &17).

Desalegn's finding (2014) also acknowledged how leprosy spread from the neighboring countries to Ethiopia due to its strong trade relations and as it is an age old disease in Ethiopia. He discussed the historical development of Ethiopian National Association of Peoples Affected by Leprosy (ENAPAL) since 1984E.C from the local association to national association of peoples affected by leprosy in 1989E.C. Accomplishments and successes of ENAPAL in the areas of awareness raising and advocacy, socio economic rehabilitation and capacity building for its members all over the country was also stated in the research.

A study by Sileshi (2015), indicated that on the average 5,034 cases are recorded nationally every year out of these, the average number of new cases of leprosy is 4,475(88.9%).The findings of the research also showed that the rate of childhood cases among newly detected cases did not show any progressive decreasing trend. The highest proportion of childhood leprosy revealed that leprosy was a real problem of people aged less than 15 years and the existence of high level of transmission in the country. The nation yet again failed to achieve a 100% treatment completion rate according to the findings of the research.

The relapse rate in the country showed significant increase. It also presented the existence of considerable proportion of patients who are diagnosed and treated at an advanced stage of the disease and significant number of patients had received in appropriate health care services. The research as well mentioned that the country would

not be able to achieve disability reduction target in the near future, unless, special disability prevention intervention is in place (Sileshi, 2015, pp.37).

Even though, a variety of researches have been done on leprosy and people affected by leprosy in Ethiopia, I could not find a literature well addressed the bio psychosocial and economic challenges of people affected by leprosy who come from rural areas for the treatment of leprosy at ALERT Hospital. The studies also have not covered their survival strategies in the effort to reintegrate within the community of origin after being treated. There is a shortage of literature in this area of research. Hence, this study attempted to contribute to fill this knowledge gap by assessing the bio psychosocial and economic challenges that affected the rural PAL not to reintegrate within their community of origin and their survival strategy to cope up the challenges after being treated at ALERT Hospital.

1.3 Objectives

General Objective

The major objective of the research was to assess the challenges of rural PAL to reintegrate within their community of origin and the coping mechanisms they use after being treated at ALERT Hospital.

Specific objectives

- To identify the biological challenges that affected rural PAL not to reintegrate within their community of origin after being treated at ALERT Hospital
- To understand the psycho-social challenges that affected rural PAL not to return to their community after being treated at ALERT Hospital

- To assess the economic challenges that prohibits the rural PAL not to return to their community after being treated at alert hospital.
- To assess the coping mechanisms of the rural PAL who did not succeed to reintegrate into their community of origin for the bio psychosocial and economic challenges

1.4 Research Questions

- What were the biological, psychological, social and economic challenges of the rural PAL when they reintegrate within their community of origin after being treated at ALERT Hospital?
- What were the coping strategies of the rural PAL who could not reintegrate in to their community of origin for the bio psychosocial and economic challenges?
- What are the attitudes of people toward PAL?

1.5 Operational definitions of terms

- Biological challenges - the physical, mental, medical and other health related difficulties of the rural PAL's. This might be leprosy reaction, physical deformity, disability and lack of proper treatment.
- Bio psychosocial challenges- problems related to the physical, mental and medical health status, disorders that affect the wellbeing and self stem, socio-cultural and environmental factors and factors that affect the productivity, income generation and property ownership of the of a rural PAL.
- Challenge -a difficult situation encountered by rural PAL. This could be a chronic illness, stigma and discrimination, psychological disorders and a problem of income generation.
- Coping mechanism - the survival strategy utilized by rural PAL who did not succeed to reintegrate within their community of origin. This could be migration and begging.

- Economic challenges - problems of productivity and income generation as a result of leprosy. This might be challenges to fulfill the family basic needs and financial problems.
- Leprosy reaction- an immunological response to the disease causing bacteria.
- POD - All activities at the individual, community and program level aimed at preventing impairments, activity limitations and participation. This might be wound care daily to prevent disability.
- Psychological challenges - psychological disorders that affect the rural PAL well-being and self-stem. This could be anxiety and depression.
- Rural people affected by leprosy - leprosy patients coming from the different parts of the country side for specialized treatment and rehabilitation services at ALERT Hospital.
- Social challenges - the socio-cultural and environmental problems that affect the rural PAL. This could be a problem of marital relationship, educational achievement and topography of the community in which the PAL are living in.

1.6 Significance of the study

The study on the challenges of rural PAL during their reintegration in the community and their coping mechanisms after having treatment at ALERT Hospital may be important in the following ways. First, ALERT Center is the center for leprosy treatment and rehabilitation, research and training services, which provides a variety of services to the rural PAL coming from the different parts of the country side since 1934. Hence, this study could give insight about the problems of the rural PAL who are unable to reintegrate within their community of origin after treated at ALERT Hospital.

Second, because there is a knowledge gap on the bio psychosocial and economic challenges of such PAL to reintegrate within the community, the study can provide

baseline information to stakeholders, policy makers and researchers. Third, if the assessment is found to be successful it would help to suggest ideas to design intervention programs to minimize the sufferings of the rural PAL.

1.7 Limitation of the study

This study was conducted using qualitative approach particularly case study. Lack of generalization is the well known limitation of a qualitative research. Therefore, this research also shares this limitation, which means the result of it cannot be generalized. In addition, I was unable to include the manager of the Addis Ababa Leprosy Victims Rehabilitation Association (ALVRA) as I proposed a key informant in this study because he was not available in the country during the study period. I was also unable to use the tape recorder in the data collection process because of the late response from the ALERT/AHRI Research Ethical Committee to have ethical clearance and to facilitate the permitted budget for the study. I was also unable to review patient cards and case stories of the rural PAL. Finally, I was not able to include other health professionals working with the rural PAL at ALERT hospital in the study such as dermatologist, ophthalmologist, surgeon, prosthesis orthotic technicians, physiotherapists and occupational therapists.

1.8 Challenges in the study process

Some of the challenges during the study process were the late response from ALERT /AHRI Research Ethical Committee to get the ethical clearance and the budget needed for the research. That created a time constraint to start the data collection based on the proposal. Another challenge of the study was the majority of participants were emotionally disturbed during the discussion and the interview period.

Chapter Two - Literature Review

In this chapter literature related to leprosy was reviewed and the literature review has eleven sections. The first section of the literature review defines leprosy as a chronic infectious disease caused by mycobacterium leprae. The second section describes historical background of leprosy. The third section explains the historical background of leprosy. The fourth section deals the microbiology of leprosy. Under this, the global feature of leprosy, the causes, mode of transmission, prevention and treatment of leprosy is stated .The fifth section explains the challenges of people affected by leprosy in relation to health, psychological, social and economic aspects.

The six section of the literature review deals with factors that mold the attitude of people towards PAL such as religion and use of different terminologies. The seventh section describes leprosy in Ethiopia. Within this section the history of leprosy in Ethiopia, challenges of PAL in Ethiopia in the dimensions of health, psychological, social and economic are acknowledged. The eighth section states about factors that mold the Ethiopians' attitude towards PAL, like knowledge about the disease, religions, terminologies and laws of the country. The ninth section explains about the coping mechanisms of PAL in Ethiopia like migration and use of traditional means of treatment. The tenth section explains theories and approach that guided this study. The final section deals with one of the practice perspective in social work that is case management.

2.1Definition of leprosy

Leprosy is a chronic infectious disease caused by Mycobacterium leprae. Its morbidity is low because a large portion of the population is naturally resistant to the disease. Leprosy affects mainly the skin and peripheral nerves. Its diagnosis is based on skin and neurologic examination of the patient (Lastoria, 2014, pp.205). It is not particularly age or gender specific disease since

the infection can take place at any time depending upon the opportunities and levels of exposure, poor living standards and inadequate nutrition prone people more susceptible to leprosy (Sileshi, 2015, pp.31).

2.2 Historical background of leprosy

Leprosy has been known since the biblical times, reports of cases dating over 3000 years ago. There are doubts whether leprosy originated in Asia or Africa (Lastoria, 2014, pp. 205). According to McDougal and Yawalkar (1989) most probably leprosy is originated in India and the first authentic description of different types of leprosy comes from that country in 600 BC. They also added that first indisputable evidence of bone involvement due to leprosy was found in an Egyptian Mummy of the 2nd century BC. The disease was probably brought to the Mediterranean region by the soldiers of Alexander the Great returning from their Indian campaign in 327 -326 BC.

2.3 The Global feature of leprosy

WHO (2012) stated that leprosy is widespread in all countries of the African and South-East Asia and in most countries of the Eastern Mediterranean Region. In the Region of the Americas, leprosy is found in all countries with the exceptions of Canada, Chile and island countries of the Caribbean. In the European Region leprosy is known to persist at low levels in southern and eastern European countries but seems to have disappeared from much of the northern and western part of the continent. In the Western Pacific Region, the disease persists in most large countries apart from New Zealand and with the exception of some small Island nations. Heterogeneity in leprosy frequency and clinical manifestations between populations is a prominent feature of the disease (WHO, 2012, pp.3).

Lastoria (2014) documented that the prevalence of leprosy has decreased noticeably since the introduction of MDT in the beginning of the 1980s. However, 105 endemic countries, specifically located in Southeast Asia, in the Americas, Africa, Eastern Pacific and Western Mediterranean, still have a large number of cases. In 2011, 219,075 new cases were detected in the world. In the first quarter of 2012, 181,941 new cases were recorded and there was a prevalence of 0.34 cases per 10,000 inhabitants.

2.4 Microbiology of leprosy

2.4.1 The causes of leprosy

The findings (McDougal and Yawalkar, 1989) showed that leprosy is caused by a specific germ, Mycobacterium leprae; it is discovered in1873 by Armauer Hansen in Norway. In those days leprosy was thought to be a hereditary disease or God's punishment. Leprosy is not an easily communicable disease and more than 90% of the persons have a natural resistance (immunity) to the disease. Therefore only a few of those in contact with leprosy suffered and show recognizable signs and symptoms of leprosy.

2.4.2 The transmission of leprosy

Scott in 2006 indicated that although the mode of transmission of leprosy remains uncertain, the major modes of transmission seems to be contact with humans who have untreated or drug resistant leprosy. Investigators generally agree that the nose is the primary site of inoculation and that the disease causing bacteria in the untreated and drug resistant patients are spread from person to person primarily through infected droplet from the nose. Transmission of leprosy from an untreated, infected mother to an infant is not uncommon.

Leprosy transmission occurs by close and prolonged contact between a susceptible individual and a bacillus infected patient through inhalation of the bacilli contained in nasal secretion or droplets. Less commonly, transmission can occur by skin erosions. Other transmission routes, such as blood, vertical transmission, breast milk, and insect bites, are also possible. It is assumed that infected individuals, even those who did not develop the disease, may have a transitional period of nasal release of bacilli (Lastoria, 2014, pp.207). Sileshi (2015), added that behavior of individuals also helps the transmission cycle to continue, as many people are reluctant to seek medical care even after being diagnosed because of misconceptions, stigma and superstitions.

2.4.3 The Prevention of leprosy

Leprosy has no primary prevention, which means there is no specific vaccine against m. leprae (Goulart, 2008, pp.1). It is a curable disease, but lacks better diagnostic tools and therapeutic strategies which together with the socio cultural prejudice becomes an important barrier for early diagnosis and protection of those at risk population, especially for the house hold contacts of leprosy patients, who should be given priority in disease control programs in order to interrupt transmission and reduce physical and social disabilities (Isabella & Luiz, 2008, pp.12 &13).

2.4.4 The treatment of leprosy

In 2014 Lastoria explained that early diagnosis is very important in the management of leprosy. The timely and proper implementation of treatment will prevent physical disabilities that have an impact on the individual's social life and functioning, which are also responsible for the stigma and discrimination regarding the disease. Scott (2006) shows that despite the wide variety of drug combinations for the treatment of leprosy, the MDT method generally appears to be the

most useful in the treatment of leprosy patients. Furthermore, patients have been encouraged to undergo treatment on a regular basis and completely.

MDT is taking two or three special antibiotics (rifampicin, dapsone and sometimes clofazamine) for between 6 months and 2 years, depending on the nature of leprosy. After only a few doses of MDT people with leprosy are no longer transmittable to others but to cure their disease they need to take all the antibiotics as prescribed by their doctor (CDC, 2013, pp.1).

2.5 The challenges of people affected by leprosy

Although significant advancement has been made in controlling the disease and reducing the disease burden, much remains to be done in order to sustain the gains and further reduce the impact of the disease, especially the burden due to the physical, mental and socioeconomic consequences of leprosy on persons affected by the disease and their families (WHO, 2009, pp.3).

2.5.1 Biological challenges

2.5.1.1 Leprosy reaction

Leprosy reaction is an immunological response to the bacillus. Most of the problems related to leprosy are primarily caused by the harm that results from leprosy reactions. Leprosy reaction is the appearance of symptoms and signs of acute swelling in the lesions of a leprosy patient. Clinically, there is redness, swelling and sometimes tenderness of skin lesions. There may be swelling, pain and tenderness of nerves, often accompanied by loss of function. Early detection and full management of reactions are therefore important activities (FMOH, 2008, pp.119).

2.5.1.2 The physical deformity and disability

Leprosy can often harm nerves and cause deformities, especially if the diagnosis of the disease is late. Unfortunately, the damage that results often to the hands or feet cannot be cured with the antibiotics; these are the scars of leprosy (CDC, 2013, pp.2). The WHO /ILEP (2007) *technical guide on community based rehabilitation and leprosy* confirmed that, Leprosy affects people's lives in a number of ways. Most obviously, it can lead to physical disabilities that make it difficult to perform regular activities. This may diminish the status of the affected person and lead to psychosocial problems.

All leprosy patients are at risk of developing disability at any time. Disability and deformity primarily result directly or indirectly from function loss of peripheral nerves, supplying eyes, hands and/or feet. It is, therefore, the task of all health staff working with leprosy patients to preserve nerve functions and to prevent further deformity and disability in those cases with some irreversible disability present at the time of diagnosis (FMOH, 2008, pp.125&126).

2.5.2 Psychological challenges

Scott (2006) argued that leprosy strongly influences the behaviors of people affected by leprosy. The disease can affect a patient's manners for the rest of their life. The high rate of suicidal attempts highlights the patients' concept of the psychological disorder as a result of leprosy. A variety of emotions are intensely experienced by leprosy sufferers. Grief appears to be the first and most general reaction that leprosy sufferers show after a diagnosis of leprosy. In some cases the morbidity becomes chronic and the incidence of psychiatric disorders is therefore indicated. Segregation and deprivation of the usual privileges of home environments lead to anxiety. They seem to have weak egos and lack independence in feeling, thinking and action. As

a result of defeat and unsuccessful coping with new situations, they often withdraw. On the whole, these patients lack ego integration and poor adjustment abilities (Scott, 2006, pp41).

2.5.3 Social challenges

Regardless of religious and cultural variations among different societies, leprosy has commonly been associated with sin, impurity and rejection incurred from God as a punishment. It has also been commonly seen as hereditary disease. It deserves a reputation as "the death before death" and "the disease of the soul". These societal misconceptions have mainly been traced in their origin from "the age old" prevalence, mysterious pathology, hideous physical deformities of the disease and its chronic nature, in which the infection is not followed by immediate death but rather sever physical deformities and mutilations. Traditions in China, India and Japan have similar traditional conceptions in associating leprosy with sin, impurity and isolation (Mesele, 2005, pp.1-10).

2.5.3.1 Quality of life

Leprosy does not only affect day-to-day functioning in the family, but considerable restrictions are imposed on patients due to the fear of social stigma. The disease may exert great pressure on the relationships of leprosy sufferers who are married. It is substantiated by the fact that the divorce rate among the leprosy sufferers is relatively high. Segregation and institutionalization are in some cases a direct outflow of the rejection that people affected by leprosy experience from the broad community (Scott, 2006, pp.48-52).

Leprosy patients used to be enforced to leave home. Those remain within their families, although are often looked down and may get little or no support from their communities. In a country where poverty, illiteracy and unhygienic environmental conditions occur, the additional

burden of disease is likely to affect the quality of life of people affected by the disease (WHO, 1999, pp.515).

2.5.3.2 Stigma and Discrimination

The reviewed study on leprosy stigma shows that, it is still a worldwide phenomenon and the outcome of stigma varying from the psychosocial dysfunction to segregation and rejection to participation restriction. Leprosy and its stigma have a pervading effect on patients' life affecting marriage, interpersonal relationship, employment, leisure activities as well as participation in religious and social activities. The study shows that in Nepal and South Asian countries to lose affection with their families due to stigma for people affected by leprosy much bears grave than losing their toes and fingers (Adhicari et al, 2013, pp.3). The WHO /ILEP (2007), technical guide explained that Stigma resulting in discrimination and social exclusion can have a major impact on quality of life. Self- stigma causes people to hide their condition or to withdraw from normal social participation.

According to Sermrittirong and Brakel (2014), stigma on people affected by leprosy is a complex phenomenon that has multiple causes as external manifestations like deformities and impairments, religious values that hold the disease as a sanction for sin and traditional believes as a curse and being hereditary, the fear of transmission and leprosy was associated with people considered inferior than others in every aspects.

Lots of similarities were found in leprosy related stigma across countries and cultures. It was assumed that leprosy is caused by sin. This belief has been widespread until the present day as shown in the studies of Alubo in Nigeria, Burathoki in Nepal and Idawani in Indonesia. They showed that communities perceived leprosy as a punishment by God. In Thailand, people

affected by leprosy are still stigmatized by health workers and by their neighbors. Some leprosy patients have been shunned and refused treatment of their ulcers by nurse aids, resulting in delay in diagnosis and poor compliance to treatment (Sermrittirong & Brakel, 2014, pp.36 & 37)

2.5.3.3 The impact of leprosy on Marriage

Family pressure is known to act as an influential force shaping behaviors of leprosy patients. The disease does not only affect regular activity in the family, but considerable restrictions are enforced on patients due to the fear of social stigma. Leprosy impacts negatively on the marital prospects of patients. Furthermore, the disease may exert great pressure on the interaction of leprosy sufferers who are married. It is substantiated by the fact that the divorce rate among the leprosy affected is relatively high (Scott, 2006, pp.52).

2.5.4 Economic challenges

The wellbeing and the self-esteem of a person affected by leprosy are associated with their income generation and the capability to secure employment. In a culture where a person is valued by the ability to support dependents, unemployment because of leprosy can have a long-term effect economically (Adhicari, 2013, pp.3).

Scott (2006) stated that when the income generation of the leprosy sufferer affected, their family encountered economic problems often depriving them of their daily necessities. Generally, change in employment leads to accepting less demanding resulting in a fall in income that leads to economic problems. As people affected by leprosy are discriminated from participating in the economic activities, they become isolated and lose self-confidence. Frustrations with employment, finally force patients into alcoholism, begging and adoption of a

hostile attitude towards society. Eventually, a leprosy patient may be forced to leave his or her home.

2.6Factors that mold the attitude of people towards PAL

2.6.1 The role of religions

In Judeo Christian culture, the social attitudes towards leprosy have mainly been influenced by biblical attitudes which is believed to be "God's punishment for some sins". The Old Testament describes leprosy as an abomination resulting from ritual uncleanness and as a punishment incurred from God for some misdeeds. During the medieval period, traditions of the Old Testament were followed by the Roman Catholic Church in Europe, dispersed the rest of the world through Catholic Missionaries and colonialism from the 16th century AD. Nonetheless, leprosy in the Old Testament is a term that covers a number of scaly skin complaints such as syphilis, scabies etc. Unlike the Old Testament however, the New Testament shows ideas of tenderness, sympathy and condolence towards the patients (Mesele, 2005, pp.3-6).

Similar to the Old Testament, the sayings of the prophet indicate divine causation of the disease and social ostracism towards the patients. In one of the traditions the prophet was quoted to have said..." escape from the leper as you escape from the lion". To all intents and purposes, the association of leprosy with sin, impurity, and rejection was common to other civilizations as well as the Judeo Christian and Islamic worlds (Mesele, 2005, pp.10).

2.7 Leprosy in Ethiopia

The Ethiopian leprosy mapping report (2015), states that among the communicable diseases, leprosy is the leading cause of prolonged physical disability and causes serious social stigma. Ethiopia was considered among high leprosy endemic countries reporting more than 1,000 cases annually. Disability grade II (visual impairment and deformity such as wound, ulcer, foot drop or claw hand) and childhood leprosy rate among the new leprosy cases are still high. All of those indicate the ongoing transmission of leprosy in the community.

A study by Desalegn (2014), states that leprosy has multi-dimensional aspects. It has deep rooted stigma, fear and caused migration of thousands leaving behind their family and birth place. Society's hold misconception, as it is hereditary, calamity of God and curse. It causes affected people to loss their social dignity, absence of social confidence and self-disregard. Sileshi (2014) emphasized that sometimes, the occurrence of the disease in low frequencies and the uneven distribution within the country may influence someone to think that leprosy is about to be eliminated despite the otherwise factual truth.

2.7.1- History of leprosy in Ethiopia

Ethiopia has suffered since time immemorial from a high prevalence of leprosy and one of the countries' most seriously affected by the disease. The Portuguese priest, Francisco Alvares, the first foreign observer to write a comprehensive account of the realm, testified in the sixteenth century that it was settled by "many lepers" (Pankhurst, 1984, pp.57 & 58).

Researches reveal that leprosy is believed to have originally spread from neighboring countries like Nubian, Egypt and countries around the Red Sea, because of Ethiopia's well-built trade relations with these areas. Thousands are adding every year with 7 to 14 percent of disability rate among newly diagnosed cases only which reach up to 5000 annually. The number

of new cases in the past twenty years seems to show no significant change. As a result thousands have become disabled and are forced to live in stigma and the resultant socio economic complications (Desalegn, 2014, pp.15).

Pankhurst (1984) described that there was a better attitude towards people affected by leprosy in the sixteenth century; leprosy sufferers were not segregated by the people, but settled with them. Moreover, several people who out of their devotion, wash them and tend their sores with their hands. However, later in the nineteenth century evidence suggests that lepers by then were often largely cut off from the rest of the society. The reason was that the disease was considered as dishonorable not only for the victim, but also for his or her relatives to the seventh degree of consanguinity. The result was that lepers were supposed to stay away from the healthy persons, even members of their own family, and had to remain in their own separate quarter, far removed from either towns or villages.

2.7.2 The challenges of PAL in Ethiopia

Arulanantham (2014) explained that PAL in Ethiopia still faced issues of stigma due to lack of community awareness about leprosy and also experienced self-stigma and lack of confidence which limited their opportunities. Although access to general health services has improved, it is often of poor quality and there is little thought given to aftercare or rehabilitation.

2.7.2.1 Biological challenges

According to the FMOH (2015) although, Ethiopia achieved the WHO leprosy elimination target of less than 1 case per 10,000 populations in 1999, the new case finding has remained the same for the more than the last ten years. Leprosy in children and disability grade II among new cases has remained high demonstrating ongoing transmission of the disease within the

community. There are places and communities in Ethiopia where the prevalence of leprosy is above the elimination target. Among the infectious diseases, leprosy is the primary cause of permanent physical disability. High disability grade in a newly diagnosed leprosy patients represent a delay in diagnosis which may be due to the patient presenting himself late or due to misdiagnosis at the health center (FMOH, 2015, pp.11&15). Over 30,000 people are living with permanent leprosy related disability in Ethiopia (Deribe, 2012, pp. 5). Mahider (2013) leprosy often affects the poorest of the poor, and if not diagnosed early, leads to disability, which affects people's ability to support themselves financially.

2.7.2.2 Social challenges

Mahider (2013) stated that in Ethiopia, PAL live in a condition with inadequate water and sanitation, because of poverty, segregation or the failure to affirm their rights. Leprosy is not fully understood by communities due to myths, superstitions, ignorance, misunderstanding and stigma. People at highest risk of leprosy are those living in endemic areas with poor living conditions, such as inadequate clean water, sanitation, hygiene, insufficient diet and poor housing conditions. This all contributes to weakening the body and compromising the immune system, increasing vulnerability to disease. Treatment and prevention depend on personal and environmental hygiene conditions and the stability of the immune system.

2.7.2.2.1 Stigma and discrimination

The study by Tesema and Beriso (2015) stated that attitude of the community towards leprosy patients is adverse. They have negative attitude towards leprosy patients, they did not sit with leprosy patients in public transportation, they keep away from leprosy patients in different activities, did not share food from the same plate with leprosy patients, they will not marry one

with family history of leprosy. The community did not agree to do work in the same place with leprosy patients and they did not allow their children to play with child of leprosy patients, feel ashamed if they have leprosy patient in their family. The reason for avoiding leprosy patients was they afraid of their deformities and fear that the patients will transmit a disease to them.

2.7.2.2.2 The impact of leprosy on marriage

Marriage between a family member of persons affected by leprosy and the other community is not possible in Ethiopia (Desalegn, 2014, pp.17). The 2005 Mesele's research finding on the historical study of selected leprosarium in the 20th century like Harar (Bisidimo), Addis Ababa (ALERT) and Shashmene (Kuyyara) also added that problems related to marriage were long lasting and profound factors to provoke social exclusion of leprosy sufferers. The community's recognition of a leprosy victim in a family meant marital isolation for the whole of the members of that family to which the victim belonged. To secure the family members from such matrimonial isolation both the victim and his relatives' preferred for the movement of the sufferer in to a leprosarium before the symptoms of the disease were noticed by the community.

2.7.2.2.3 Challenges at school

Children of leprosy family in Ethiopia hate to go far from their settlement to follow their education by fearing stigma and discrimination by their peers at school. Even if they travel to far institutions, they prefer to keep secrete their address by fearing the stigma and discrimination and to follow their education properly (Desalegn, 2014, pp. 17).

2.7.2.3 Economic challenges

2.7.2.3.1 The problem of Property ownership

The social history of leprosy sufferers in the 20th century Ethiopia showed that society taking over the assets of leprosy sufferers using the occurrence of the disease to a member of the society as a pretext to dislocate the victim from their community to leprosaria (Mesele, 2005, pp.161&162).

2.8 Factors that mold the Ethiopian attitude towards PAL

2.8.1 Knowledge about leprosy disease

Popular belief towards leprosy in the 20th century Ethiopia was also strongly influenced by customary attitudes. The most widely held views to the cause of leprosy attributed it to a blow from the devil, adultery by moonlight, intercourse during menstruation, sorcery and above all hereditary (Mesele, 2005, pp.29&30). "The Ethiopians believed leprosy as not contagious, the belief on the non-contagious character of the disease was reinforced by the popular view that it was an inherited compliant. In relation with the medical treatment a great variety of traditional medical cures for leprosy were in wide spread use" in the country (Pankhurst, 1984, pp.67 -72).

2.8.2 The role of Religions

Pankhurst (1984, pp.59 & 60) explained the influence of biblical ideas and values to shape the attitude of people towards PAL in the country, "Ethiopian Christians paid considerable attention to statements on leprosy (lamtse) in holy writ. They were thus well aware of the Old Testament belief that lepers were "unclean" as stated in God's injunction to Moses and Aaron in Leviticus13, 44-46: "Their literature also contains many legends of miraculous cures. He is leprous man, he is unclean....such texts made a big impact in Ethiopia, where they found their way in to numerous legends".

The pre 20th century Ethiopian popular conceptions of leprosy were shaped by religious values. In Muslim dominated areas in Ethiopia social milieu was similar to the rest of the Islamic world, in which the patients were strictly ostracized from society following the pious traditions of the prophet. Unlike the Judeo Christian and the Islamic worlds, the Ethiopian Orthodox Church rarely followed the Old Testament traditions on leprosy. Given that everyone living in this world has been impure, corporeal suffering was incurred by chosen people whose devotion and patience God wanted to test. However, sometimes the church has also related the cause of leprosy with immoral sexual practices and the breach of taboos. Moreover, the church banned, leprous priests from officiating from alter of God and from being a judge. Above all, the Church emphasized miraculous cures of the disease (Mesele, 2005, pp.23-29).

2.8.3 The role of derogatory words

Pankhurst (1984) and Mesele (2005) stated that leprosy as described as quesalasega or segadawe (ulcerated body) in Amharic and Tigrigna or talaqdawe (major disease) in Amharic. Leprosy was most frequently referred to explicitly as qumtena (amputate) in Amharic. In Oromo society it is called Kurchi or Juzam (cut or break) etc. This demonstrates the effects of terminologies in major languages of Ethiopia to mold the misconceptions of the people towards leprosy is very huge which signify either the divine causation, incurability, fear of the disease or pathological implications of leprosy.

2.8.4 The role of Laws

Pankhurst (1984) illustrated that the Ethiopian attitude to leprosy can be seen in the country's traditional code, the Fetha Nagast literally (the Law of the Kings), which took an essentially empirical and humanitarian view of the disabling disease. The Law declared that "a people affected by leprosy could not serve as a priest and a patriarch but stated that this was not on

account of his being unclean for such was not the case once he was baptized, but he would cause priests to be despised". Similarly, "to be a judge he had to be free of leprosy", only because "the infection would keep away many people who have to come to see him". Mesele (2005) substantiated that the Fetha Nagast allows the separation of a healthy husband from a leprous wife giving her an outfit and dowry.

The Ethiopian Civil Code incorporated leprosy as a permissible ground for marriage dissociation. The civil code edict number 165 of 1960 article 591 (2c) states that "error on the state of health or the bodily confirmation of the spouse who is affected by leprosy or which does not have the requisite organs for the consummation of the marriage". Up until 2000, this article in book II of family law was enforced for the last 40 years and was repealed (from article 550 - 825) by a special family code proclamation No.1/2000 (Desalegn, 2014, pp.16). The revised family code of Ethiopia states that "Any laws, regulations, directives, decisions or practices inconsistent with this Code shall not be applicable on matters provided in this Code (Federal Negarit Gazetta, 2000).

2.9 The coping mechanisms of PAL in Ethiopia

2.9. 1 Migration

The PAL survival strategy for the alienation of their property ownership by the society is, either by forming a new segregated leprous community or moving to relatively peaceful and old leprous village. Hence, a search for PAL communities was a means for self-protection. Throughout the 20th century urban areas were economically favorite places for leprosy sufferers where they earned means of income by exhibiting the leprosy dreaded parts of their body and engaging in begging (Mesele, 2005, pp.168).

A study by Desalegn (2014), states that due to the stigma and discrimination on people affected by leprosy in Ethiopia, they are concentrated in leprosaria and there are over about 40 settlement sites such as Gindeberet, Kuyera, Bisidimo and Zenebeworq in Ethiopia. Leprosy has caused migration of thousands, leaving behind their family and birth place in Ethiopia. Nowadays, thousands of people affected by leprosy, including their families and relatives, live in leprosy settlements labeled with bad names, with fear, social injustice and ravaging poverty.

2.9.2 Use of traditional treatment

In Ethiopia People affected by leprosy are far away from modern medical services, rather they use traditional means of treatment because of the problem of access and lack of awareness like going to Healers, Sorceress, holy water, and use soil given by religious fathers (Desalegn, 2014, pp. 17).

2.9.3 Begging

Begging has been acknowledged by the people affected by leprosy and the society as appropriate survival strategy other than provision of decent employment or self-employment and has been the main source of income for many families in Ethiopia (Desalegn, 2014, pp.17).

2.10 Theoretical frame work

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

2.10.1The ecological system theory

The ecological systems theory is one of the sociologically based, social work theories applied in social work practice, human behavior analysis and intervention (Zastrow & Ashman, n.d, p.24). The ecological systems perspective emphasizing that people and their problems are understood holistically they have bodies (biology), minds (psychology) and a social context (Coady & Lebmann, 2008, pp.89-90).

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

This is one of the theories which guide this study; it helps to consider the socio-cultural and physical environmental factors on the rural PAL not to return to their respective community after treated at ALERT Hospital.

2.10.2 The social constructionist theory

To understand human behavior, the social constructionist perspective focuses on actors, the way in which they construct social reality, and the action that results from such construction. To the social constructionist, there is no singular objective reality, only the shared subjective realities that are created as people interact. Constructionists emphasize the existence of multiple

social and cultural realities, developed in changing configurations of persons and environments (Hutchison, 1999, pp.49).

Constructivists consider humans to be active participants in the creation of their own reality. They view that "reality" is a co-creation between the individual and the external stimuli to which he or she is responding. Prior experiences, conceptualizations and associations mutually interact and collectively operate to affect each individual's unique brand of meaning making. They added "Reality" is dynamic, rather than a static condition. Consequently, while some meanings are rather unalterable over time, other meanings are highly subject to reconstruction. Furthermore, negative constructions often prevail over more positive meanings (Coady, 2007, pp.401-405).

The social constructionist theory helps to understand the impact of socially constructed realities on the rural PAL in this study. The socially constructed misconceptions about the disease cause, mode of transmission and treatment result for stigma and discrimination that affects the rural PAL not to reintegrate within the community of their origin after treatment.

2.10.3 The bio psychosocial approach

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

self-esteem, and emotional resources; and "social" refers to the social environment that surrounds and influences the patient (Beder, 2006, pp.4).

The bio psychosocial perspective used in this study to assess the participants from the multidimensional point of view and to understand their challenges to return to the community of origin after treatment at ALERT Hospital holistically.

2.11 Social work practice perspective

2.11.1Case management

While there is not a single, generally accepted definition of the term, case management can be defined as an approach to social service delivery that attempts to ensure that clients with multiple, complex problems and disabilities receive the services they need in a timely, appropriate fashion. Service objectives in case management include continuity of care, accessibility, accountability, and efficiency. The concept of case management emerged in mental health literature during the 1970s, but the practice can be understood as the modern application social casework techniques. The case manager is responsible for service coordination and helping the client hold elements of the service system accountable for adequate service delivery (Walash & Holton, 2008, pp.139).

Case management can be applied in social work practice implication to link the rural PAL with service delivery organizations to address their problem holistically and enhance their reintegration after treatment at ALERT Hospital.

Summary of the literature review

Leprosy is a chronic infectious disease caused by Mycobacterium leprae that affects mainly the skin and peripheral nerves. Leprosy has been known since the biblical times, with reports of cases dating over 3000 years ago. Prevalence of leprosy has decreased markedly since the introduction of MDT in the beginning of the 1980s. However, 105 endemic countries, specifically located in Southeast Asia, in the Americas, Africa, Eastern Pacific and Western Mediterranean, still concentrate a large number of cases. In the first quarter of 2012, 181,941 new cases were recorded and there was a prevalence of 0.34 cases per 10,000 inhabitants in 105 endemic countries of leprosy. Although the mode of transmission of leprosy remains uncertain, the major modes of transmission seem to be contact with humans who have untreated or drug resistant leprosy.

Leprosy transmission occurs by close and prolonged contact between a susceptible individual and a bacillus infected patient through inhalation of the bacilli contained in nasal secretion. Leprosy has no primary prevention, which means there is no specific vaccine against leprosy. The timely and proper implementation of treatment will prevent physical disabilities that have an impact on the individual's social and working life, which are also responsible for the stigma and prejudice. Religions and terminologies had roles to mold the attitude of people towards PAL.

Ethiopia has suffered since time immemorial from a high incidence of leprosy and one of the countries' most seriously affected by the disease. Research by Desalegn (2014) revealed that leprosy is believed to have originally spread from neighboring countries. Ethiopia was considered among high leprosy endemic countries reporting more than 1,000 cases annually. PAL in Ethiopia encountered with health, psychological, social and economic challenges. There are factors that mold the Ethiopian attitude towards PAL such as knowledge about the disease,

religions and terminologies in major languages of the country and lows of the country. To cope up the bio psychosocial and economic challenges PAL use their own survival strategy like migration and using traditional means of treatment.

In the effort to review literatures for this research I could not find literature about the bio psychosocial and economic challenges of the rural PAL to reintegrate within their community of origin and the coping mechanisms they utilized after treated at ALERT Hospital.

Chapter Three - Research Methods

The aim of this chapter is to clearly outline the procedures that guided the research design, the study area, selection of participants, quality assurance, ethical consideration, data collection and analysis issues. The characteristics of the study participants are also included in this chapter

3.1 Research design

This study was based on the qualitative inquiry particularly case study with exploratory purpose. Abiy, Alemayehu, Daniel, Melese &Yilma (2009) stated that qualitative research seeks to describe various aspects about behavior and other factors in detail. Often the goal of qualitative research is to clarify the situations. It is characterized by adherence to diverse array of orientations and strategies for maximizing the validity of trust worthiness of study procedures and results.

The reason to choose the qualitative research in this study was to have a detailed understanding of the bio psychosocial and economic challenges and the coping mechanisms of the rural PAL in their effort to reintegrate within the community of their origin after treated at ALERT Hospital. As a method it allowed the participants to tell their stories and experiences.

It was exploratory research because it helps to better understand and clarify a problem. It was conducted in the area where few or no earlier studies to which references can be made for information. The results of exploratory research can provide significant insight into a given situation (Abiy, Alemayehu, Daniel, Melese &Yilma, 2009, pp.30-35). The justification to choose exploratory research in this study was to increase our understanding of a situation, the bio psychosocial and economic challenges and the coping mechanisms of the rural PAL, which are not much studied in relation to the challenges after treated at ALERT Hospital. In terms of time

dimension, I used cross sectional research in order to examine situations of rural PAL at one point in time.

3.2 The Study area

The selected area for the study was ALERT Center which is the core for leprosy treatment and rehabilitation, research and training in Ethiopia. ALERT stands for All Africa Leprosy, Tuberculosis, Rehabilitation, Research and Training Center. According to Mesele (2005), it is the second in the country established in 1934 next to Harar's St. Anthony Leprosaria established 1904. ALERT Center is administered under the FMOH and lead by board of directors and has 1304 staff including physicians, specialists, researchers and admin staff.

In the umbrella of ALERT center there are three large Directorates; Armauher Hansen Research Institute (AHRI), Training division and Hospital service directorate. The hospital services being expanded and improved in its quality and access and becomes a general hospital from a center for leprosy treatment. The following specialized services are rendered in the hospital in addition to leprosy Anti Retroviral Treatment, Tuberculosis, Multi Drug Resistance Tuberculosis, Rehabilitation services, Orthopedics, Physiotherapy, Reconstructive and Plastic Surgery, Ophthalmology, Dermatology, Maternal and Neonatal Care, Pediatrics, Dental and Gum, Psychiatry and Counseling and general medical care for leprosy and non-leprosy patients. The Hospital Services Directorate of ALERT Hospital is divided into three broad service directorates; outpatient, inpatient and emergency service directorates. The hospital serves for 360,736 patients in the outpatient, 7,066 in the inpatient and 8,084 in the emergency services yearly. Among them 20% are leprosy patients.

ALERT Hospital has been providing medical and rehabilitation services for the rural PAL from all over the country side without any referral paper from their respective community. It is preferred by many and considered as their second home due to the historical back drop of the hospital with PAL, friendly services rendered in the hospital, free medical and rehabilitation services for the PAL and their families, the specialized treatment and rehabilitation services and the attitude of professionals and supporting staffs are sympathetic for the PAL.

From my experience as a social worker at ALERT Hospital even those rural PAL having similar health service access in their community of origin preferred ALERT Hospital like patients from Shashemene (Kuyyera), Harar (Bisidimo) and Wollo (Borumeda). It is located in the south west periphery of Addis on the way to Jimma road. It was preferred for the study area as patients from all over the country are available; it has historical attachment with the PAL and the availability of key informants, service delivery organizations for the rural PAL and different documents substantiated the reason to select it as a study area.

3.3 Selection of study participants

I applied the non-probability sampling method with purposive sampling. The participants comprised of 27 individuals: 22 rural PAL and 5 key informants. Among the rural PAL study participants 8 were inpatients and 14 out patients of ALERT Hospital, who passed through the challenge to survive in their community of origin and decided not return back. Out of the 22 rural PAL participants 4 of the rural PAL selected from the terminated clients of ALERT Psychosocial Case Team of ALERT Hospital.

Out of the 5 key informants, 1 social worker, 1 Rehabilitation Service Directorate Director (Medical Doctor), a Psychiatrist, were recruited from ALERT Hospital, 1community

development worker from within the umbrella of Ethiopian Catholic Church-Medhin Social Center (ECC-MSC) and 1 managing director from the Ethiopian National Association of Peoples Affected by Leprosy (ENAPAL). The reason for this sample size was that, these numbers of people expected to achieve the purpose of the research together with other means of data collection method (observation). The key informants selected due to their exposure with rural PAL as they are working with the rural PAL who decided not to return to their community of origin after treated. In addition, they have referral and linkage with ALERT Hospital to rehabilitate them.

The rural PAL participants of this research selected purposively in two ways, the first was in collaboration with the social worker of ALERT Hospital and in collaboration with ALERT Hospital Inpatient and Outpatient directorates, since the participants were clients of these directorates. Before conducting the interview I passed through the following study procedures, first I confirmed that whether they were really experiencing the challenges before to return to their community at least once. To assure, I asked them the reason for not to reintegrate within their community origin after treated. When they were appropriate for the study, I explained them the objectives of the study and asked them to be part of the research voluntarily. For those who were willing to participate in the study, I gave or read them the consent form and the information sheet. We arranged the appropriate interview time and place together.

The inclusion criteria of the participants were those rural PALs, who decided not to return back to the community of their origin in the past ten years due to the challenges they experienced in the effort to reintegrate within their community of origin. And again those rural PAL who started or planned to start a new life in a new social and physical environment after treated at ALERT Hospital due to the challenges they were facing in the community of origin. The rural

PAL with new cases of leprosy, not passed through the real challenge in their community of origin at least once, who cannot communicate in Amharic very well and those rural PAL not terminated from ALERT Psychosocial Case Team before the study period was excluded from the study to minimize the research bias.

3.4 Method of data collection

3.4.1 In-depth interviews with the rural PAL

To obtain detailed information in depth interview with 8 rural PALs has conducted. I used semi structured and unstructured interview to have detailed information. Field notes used for all of the interviews conducted. I was the one to conduct the interview and to take notes to increase the quality of data. The in depth interviews carried out with the rural PAL inpatients and out patients from ALERT Hospital. The participants were purposively selected in collaboration with the Social Worker of ALERT Hospital and Service Delivery Directorates of ALERT Hospital like Inpatient, Outpatient and Rehabilitation Directorates. The interview took place at different settings to assure the privacy and confidentiality of rural PAL. Inpatient and out patients of the hospital have interviewed on private rooms. 3 of the interviews were held at the teaching room, 3 Psycho Social Case Team and 2 Psychiatry and Counseling Case Team Offices of the hospital.

The in-depth interview participants of the rural PAL were asked about the biological, psychological, social and economic challenges which affect them not to reintegrate within their community of origin after treated at ALERT Hospital and their coping mechanisms (refer to Annex V: In-depth Interview Guide).

3.4.2 Key informant interviews

I used semi structured and unstructured interview to have detailed information. I was the one to conduct the interview and to take notes to increase the quality of the data. Key informants selected based on their experience in relation with the rural PAL and based on their positions. The Social Worker, the Rehabilitation Directorate Director and the Psychiatrist recruited from ALERT Hospital. And the community development worker was from ECC-MSC which is the main partner of ALERT Hospital and currently working on the socio-economic rehabilitation of the rural PAL in the community of Zenebeworq by providing holistic support. And the Managing Director was from ENAPAL which is mainly engaged in the awareness creation, capacity building, POD on PAL and coordinating the whole anti leprosy campaigns in Ethiopia. Regarding the issue the interview was set separately at their respective offices.

The key informants were asked about the biological, psychological, social and economic challenges which affect the rural PAL not to reintegrate within their community of origin after treated at ALERT Hospital and their survival strategy to cope up the challenges (refer to Annex VII: Key Informant Interview Guide).

3.4.3 Focus Group Discussions

The FGD conducted with two groups of the rural PAL comprising of 14 members (7 females and 7 males). The number of participants in each FGD was odd to reach in consensus. Inpatients and out patients of ALERT Hospital who came from the country side and passed through the challenge to reintegrate with their community of origin and finally not able to return included in the FGD. The discussants complete strangers and homogeneous (sex and background) to have a better discussion and counter argue. The researcher had a moderator role to facilitate the discussion. As a moderator the researcher tried to involve all the participants in the discussion

and to keep the discussion points to be on track. The researcher also tried to balance the discussions and not to be dominated by some individuals and facilitated the group to reach into consensus on the discussion points. The assistant data collector took notes on the outcome of the discussion or how the discussants articulated the phenomena. The researcher focused on the group (majority and minority) views not who said what or individuals and point of departure. It was held at separate rooms at ALERT Hospital. It enriched the data collection and helped to triangulate the data gathered from in depth interview, key informant interview and observation.

The FGD guide-line consists of the following major issues: the biological, psychological, social and economic challenges which affect the rural PAL not to reintegrate within the community of their origin after treated at ALERT Hospital and how they cope up the bio psychosocial and economic challenges (refer to Annex IX: FGD Guide).

3.4.4 Observation

Throughout my observation in the study period for two month, I visited the rural PAL who came for the specialized treatment and rehabilitation services and not able to reintegrate within the community of their origin. They were inpatients and out patients of ALERT Hospital in different service directorates. As a method, I observed the client situation as a complete observer, with observation checklist, to observe the physical and psychological situation, social interaction, all common experiences of rural the PAL and I tried to job dawn what I feel significant on the note book.

3.5 Data processing and analysis

Creswell (2003) stated that basic principle of a qualitative research is that, it is an ongoing process involving continual reflection about the data, asking analytic questions and writing memos throughout the study. It is not sharply divided from the other activities in the process, such as collecting data or formulating research questions. Strauss (2003) also said that data collection never entirely ceases because coding and writing memo continue to raise fresh if at all feasible. It follows also that the next interviews and observations become informed by analytic questions about categories and their relationships. Alston and Bowles (1998) added qualitative study produces vast amounts of new data, often unstructured, which must be coded; categorized and analyzed. The methods of data analysis, therefore, attempt to capture the meanings and relationships involved in these complexities.

The data analysis process in this study was that it goes simultaneously with data collection. The data analysis started in the field during data collection as notes were recorded, initial interpretations made. Thus, Data analysis consisted of preparing and organizing the data for analysis, transcription, translation in to English as all the data collection was made in Amharic, typing, identifying and emphasizing the most important statements, sorting, building relationship of the data, identifying core categories and identifying themes and finally representing the data in terms of figures, tables and discussions to have relationship and meaning.

Steps for the data analysis of this study were;

Pre-coding

Creswell (2003) affirmed Pre-coding implies the organization and preparation of the data for analysis. This involves transcribing interviews, typing up field notes or sorting and arranging the

data into different types depending on the sources of information. It is read through all the data to obtain a general sense of the information and to reflect on its overall meaning.

As all the interviews were conducted in Amharic, each day after data collection, I was going through the interview transcription over and over again until understandings of the main points were achieved. I stressed on important statements that provided an understanding of the participants' situation. Highlighters with different colors were used to differentiate the central ideas. The copy of the original interview transcript used to highlight these statements; in order to avoid uncertainty and keep the original material untouched. These helped to maintain the possibility of making reference whenever needed. I then translated the data or field notes into English while typing highlighted on the soft copy.

Coding

The pre-coding process followed by coding. According to Rossman & Rallis (1998) Coding is the process of organizing the material before bringing meaning. It involves taking text data or paragraphs into categories, and labeling those categories with a term, often a term based in the actual language of the participant (called an in viva term) (as cited in Creswell, 2003). Besides, the researcher needs to code the associated subcategories which reflected within the same or different interview (Strauss, 2003, pp.27). It is a careful examination and thinking about the data, which leads to asking generative questions. It is a sort of analysis that creates categories, as well as exploring the relationships between them (Alston and Bowles, 2003, pp.208).

As the most important sayings and feelings that showed the situation of participants were highlighted in the pre-coding process, in the copy of the original data, following that I selected the actual terms of the participants from the collected text data, then I brought the text data and

sentences from the different means of data collection and labeled with the term that helped me to have categories and relationship among the data gathered.

A core Category

The phases of data analysis may take long periods of data collection, coding and memo taking before the researcher decides on which categories and concepts are the most important. Once core categories have been established, the researcher concentrates on relating other categories to them. Additional categories and properties related to the core categories will continue to be discovered throughout this process (Alston and Bowles, 2003, pp.209). In this phase of the data analysis, I continued creating categories from the codes in the coding process. After that I selected the main categories among them. Some of the categories were reaction, loss of sensation and wound, the physical deformity and disability, lack of early diagnosis and proper treatment, lack of POD and rehabilitation services, problem of property ownership and loss of assets.

Themes

The main theme is the main concern or problem for the people in the setting (Strauss, 2003, pp.34&35). Creswell (2003) these themes are the ones that appear as major findings in qualitative studies and are stated under separate headings in the findings sections of studies. They should display multiple perspectives from individuals and be supported by diverse quotations and specific evidence.

Hence, in this study, themes were derived from the core categories by extracting common and significant linkages. Some of the themes of the study are leprosy reaction, loss of sensation and wound, the physical deformity and disability, lack of proper treatment and timely diagnosis, lack of pod and rehabilitation services, self-stigma, suicide attempt, the role of leprosy on social

interaction, the role of stigma and discrimination, the impact of leprosy on marriage, the impact of derogatory words, the impact of leprosy on education, the weather condition, the topography of the land, the infrastructure development, productivity, loss of assets and a problem of property ownership.

Write up

After all these processes, I examined those themes and I wrote the final composite analysis.

3.6 Quality assurance

To maximize the trustworthiness and the internal validity of the qualitative data in this research, I used method of triangulation of different methods, (in depth interview, key informant interview, focus group discussions and observation). I conducted the research as fresh mind and try to reduce the influence of previous experiences in the area through emphasizing on the research questions and purpose of the study. I also stated word by word what the participants said and the feeling of participants in the finding. Creswell (2003) stressed that in some research situations, power can easily be abused and participants can be coerced into study. The researcher involved individuals voluntarily and collaboratively during the study that helped to achieve the purpose of the study. To build rapport with the participants I frequently visited the inpatients in wards and met the out patients at least twice before the interview. To reduce power differentiation I was conducted the interview as researcher. Except four of the participants recruited from the psychosocial case team they were not aware of my being social worker. In doing so, those participants of this study chosen from the Psycho Social Case Team of ALERT Hospital have terminated clients to minimize the research bias. The relationship between the participants and the researcher was collaborative as well participatory to meet the purpose of the research.

3.7 Ethical consideration

The researcher gave a brief explanation about the study to introduce the participants about the purpose, benefits, risks of the research; the confidentiality of the participants and their rights. Then they asked their willingness to take part in the study. Those who found out eager to join in the study gave their consent (The information sheet and the informed consent form are annexed at the end of this document at Annex I and Annex III).Those that wanted to leave or interrupted the research, had the right to self-determination at any point in time.

In addition, I used paramount care to ensure privacy, confidentiality and anonymity of participants. The place and time of the interview arranged at most to be conducive for each participant. Settings for interviews were as private as possible so that participants could feel freedom to express their thoughts and their information kept confidential. I used codes that only the researcher can understand and used instead of names to identify participants. All of the research process based on the social work ethical principles and again passed through the ethical committee of ALERT/AHRI. The participants have got 100 birr for lunch and water after the interview. Almost all of the participants encountered emotional disturbance during the interview and the discussion and they were referred to the Psychiatrist who was arranged by the researcher to take care of them and to manage unexpected consequences after the interview.

Chapter Four-Findings

This study explored the challenges of rural PAL to reintegrate within their community of origin after treated at ALERT Hospital and their coping mechanisms. All the findings of the study are presented in this chapter. The challenges and the coping mechanisms of the rural PAL are categorized in to the biological, psychological, social and economic challenges to show the finding in detail.

In order to maintain the anonymity of the in-depth interview and FGD participants, pseudonyms are used instead of their actual names.

4.1 Background information of the study Participants

The Rural PAL, Social Worker, Director of Rehabilitation Directorate (Medical Doctor) and Psychiatrist from ALERT Hospital, Managing Director from ENAPAL and Community Development Worker from ECC-MSC were recruited and interviewed in this study. This purposive sample comprised of twenty two rural PALs, one social worker, one Medical Doctor, one psychiatrist, one managing director and one community development worker who met the inclusion criteria and the purpose of the study.

4.1.1 The rural people affected by leprosy

The following tables (tables 1 & 2) show some demographic variables of the rural PALs. As table one and two show the youngest age is18 and the oldest one is 52.The largest number of rural PAL participants are males. Educationally, the majority of the participants have attended primary and elementary school and there is one 10^{th} grade complete, which is the higher level for a high school and there are PALs who cannot read and write. The majority of them are engaged in petty trade. Almost all are Orthodox Christians. The majority of them are single followed by

divorced the others are married and separated. Gojjam is the community of origin for the majority of the participants.

Table one: Background information of the in-depth interview participants

No	Pseudonyms	Age	Sex	Education	Occupation	Religion	Marital status	Origin	How long in Addis (in years)
1	Sisay	37	M	Read and write	Farming and trade	Orthodox	Divorced	Wollo	Four
2	Alem	26	F	Not read and write	Unemployed	Orthodox	Single	Gojjam	Three
3	Teshome	19	M	6th	Trade	Orthodox	Single	Chefa Donsa	Three
4	Kidanu	52	M	Read and write	Farming	Orthodox	Separated	Tigray	One
5	Tefera	45	M	Read and write	farming	Orthodox	Separated	Gojjam	One
6	Samson	34	M	5th	Trade	Protestant	Single	Hadyia	Four
7	Ayinadis	23	F	7th	Student	Protestant	Single	Butajira	Three
8	Ahmed	23	M	Read and write	Farmer	Muslim	Single	Arsi	Six

Table two: Background information of focus group discussants

No	Pseudonyms	Age	Sex	Education	Occupation	religion	Marital status	Origin	How long in Addis (in years)
1	Addisu	20	M	7th	Student	Orthodox	Single	Guragha	four
2	Nigatu	20	M	5th	student	Orthodox	single	Guragha	Nine
3	Abebaw	22	M	5th	unemployed	Protestant	divorced	Bonga	One
4	Yemata	18	M	4th	student	Orthodox	single	Gojjam	Ten
5	Daniel	38	M	6th	unemployed	Orthodox	divorced	Gojjam	Nine
6	Abera	24	M	6th	Student	Orthodox	Single	Arsi	Six
7	Mitku	28	M	Not read and write	unemployed	Orthodox	divorced	Gojjam	Four
8	Bekelu	24	F	5th	unemployed	Orthodox	single	Shoa	One
9	Yeshi	50	F	6th	trade	Orthodox	divorced	Shoa	Four
10	Tigst	38	F	Not read and write	trade	Orthodox	married	Gojjam	Two
11	Mintwab	40	F	Not read and write	House hold	Orthodox	divorced	Gojjam	Ten
12	Manaye	38	F	Not read and write	trade	Orthodox	married	Ficha	Two
13	Sosna	28	F	10th	trade	Orthodox	single	Gojjam	Three
14	Chewa	40	F	Not read and write	trade	Orthodox	Divorced	Gojjam	Three

Table three: Back ground Information of key informants

No	Pseudonyms	Position	Year of experience	Profession
1	Terefe	social worker	28 years	Clinical nursing diploma, BA sociology and social work
2	Fikadu	Community development worker	24 years	12+2
3	Alemu	Psychiatrist	Above 15 years	Clinical nursing diploma, MSC in Integrated clinical and community mental health
4	Ngussie	Rehabilitation department directorate director	25 years	Medical doctor
5	Tesfaye	Managing director	11 years	Sociology and social administration

4.2 The bio psychosocial and economic challenges of the rural PAL

4.2.1 The biological challenges

The in-depth interview participants of the rural PAL were asked about the biological challenges, which enforced them not to reintegrate within their community of origin, after treated at ALERT Hospital. Their responses are presented as follows in thematic areas:

Reaction, loss of sensation and wound

According to the in-depth interview participants' reaction of leprosy was manifested on the majority of them and it is one of the biological challenges that cause burn, arthritis, joint pain, lack of sensation and rash in their body. As participants reported, reaction forced them to visit the health centers frequently, to occupy hospital beds for long period of time and separated them from their children, family, farm and cattle for long period of time. The participants of this study added that they are suffering from partial and/or full loss of sensation on their hands, eyes and legs, due to the sensory nerve damage because of leprosy.

They also mentioned that their body repeatedly was likely to have blisters and wounds as a result of loss of sensation. The infected wound again affects their day to day activities, social interaction, marital relationship, mobility and productivity. As stated by the participants the bad odor because of the infected wound, causes for huge shame and segregation from their marriage partner, family, community and health professionals in their community of origin.

For instance Alem,a rural PAL from Gojjam said that:"As a result of the loss of sensation on my legs because of leprosy, my leg was eaten by a rat, when I was sleeping. I did not recognize it at that time, until I confirmed through my eyes on the next day".

One of the key informants, Fikadu, Community Development Worker at EEC-MSC described that, most of the rural PAL are unable to reintegrate within their community of origin after treated at ALERT Hospital. Because, when they reintegrate to the community of their origin, leprosy reacts repeatedly. According to him the rural PAL believe that when the soil and the water in their community of origin touch their body, their body reacts immediately and the disease aggravates. Thus, the reaction of the disease forced them to come back again even after reintegrated within their community of origin.

Another key informant, Terefe, ALERT's Hospital Social Worker, confirmed that:

> *When leprosy is not treated properly, it may react again and again. So, the rural PAL fears to reintegrate within their community of origin by fearing the health complications following the reaction of leprosy. The Loss of sensation also causes for the loss of detection, when the rural PAL may be harmed by their shoes, artificial leg, sharp materials, stones, fire, hot things and drinks and so on, unless, they checked the senseless parts of their body through their eyes daily. Thus, they are at high risk of getting infection, further amputation and disability, as a result of the infected wound formed because of the loss of sensation. Due to that the rural PAL fear to reintegrate within their community of origin after treated at ALERT Hospital.*

The physical deformity and disability

The interviewed rural PAL added that the physical deformity and disability as a result of leprosy is one of their challenges, which cause them not to reintegrate within their community of origin once treated. As they stated, they usually got deformity on their nose, lip, eyes, bone, fingers of their legs and hands. As a result of the change in the structure of their body due to leprosy, they face enormous dishonor and isolation from their family, relatives, peers, and community and health professionals in their community of origin.

The study participants further explained that due to the softening of their bone, muscle weakness and the sensory nerve damage by the disease causing bacteria, their hands become clawed, weak and not fully functional as it was before. As a result of the physical deformity and disability their mobility and productivity was reduced. The damage on their hands because of the loss of sensation, they have got a difficulty to handle, to open and close, to use a crunch, wheel chair and to lift things properly. Because of the bone deformity on their leg, they face a challenge of mobility. Due to walking carelessly with the injured legs they are exposed to repeated surgery and amputation.

They added that after they get amputated, they were forced to use prosthesis orthotic materials like artificial leg and hand, crunch and wheel chair that assist their day to day activity. They also informed that the artificial leg and crunch given to assist their mobility, productivity and daily activity but usually it damaged their skin, bone and becomes cause for amputation and further disability. In time when one of their legs gets amputated and move using an artificial leg, it creates a burden on the other leg, which causes to blisters, swelling, ruptured, create infected wound and finally they become bilateral amputee. As a consequence of the leprosy, they also got

a problem of partial and /or full vision impairment. As the study participants reported during the interview, finally they become a disabled person because of leprosy.

Sisay, a rural PAL from Wollo put the situation as follows:

> *Because of leprosy, I have been amputated my legs frequently at ALERT Hospital; my deformed bone has been removed from my legs surgically. Currently, I am using an artificial on my right leg which prohibited me to move freely and to produce as well. My right artificial leg created a burden on my left leg and because of that my left leg repeatedly swollen, ruptured and wounded. My two hands have got clawed, thus it is not working properly, due to the nerve damage. As a result of that I encountered with a challenge to use a crunch, wheel chair, to engage on farming, rearing cattle and to engage on petty trade also.*

Like the above participant Samson, a rural PAL from Hadiya stated that:

> *I have been amputated ten times at ALERT Hospital because of leprosy. My right hand is not functional because of the frequent amputation. My two legs do not have any fingers and both of my legs lost sensation below my knees. I have only clawed left hand. I try to accomplish my daily activities with the help of it and sometimes, I am forced to use my teeth .As a result of the disability, I have got a difficulty to eat, drink, to keep my personal hygiene and to use a toilet properly.*

Lack of proper treatment and timely diagnosis

Almost all the participants of the interview stated that there is a lack of proper treatment and early diagnosis in their community of origin. This plays its part in the decision not to reintegrate within their community of origin once treated. According to them there is a lack of early and proper diagnosis. As they mentioned as a result of the misdiagnosis and lack of early case detection the rural PAL are labeled as HIV/AIDS patients by their family and the community. The segregation following the labeling was huge as they mentioned during the interview.

As they stated during the interview, due to the problem of untimely detection by the health professionals, they encountered with further health complications that caused for the physical deformity and disability. The misdiagnosis also caused for the prescription of unrelated medicine and mistreatment. Because, of the lack of awareness on the treatment of leprosy the rural PAL discontinued their treatment and become vulnerable for further health complications. They further explained that the health professionals' in their community of origin are not familiar with the signs and symptoms of leprosy very well.

However, one of the participants, Kidanu, from Tigray has a different experience. He stated that he got timely and proper diagnosis and treatment at the early stage but he has got the physical deformity and disability due to his negligence, created as a result of misconception and he prioritized to care of his children first.

For instance, Alem and Tefera's experience of the problem of leprosy treatment shows that, due to the lack of proper and early diagnosis and treatment of leprosy in their community of origin, they were suspected as HIV/AIDS patients, by observing the change on their physical

appearance and body weakness only. Alem added that due to the pressure from her family and the community, she was forced to have HIV test repeatedly.

Teshome, a rural PAL from Chefa Donsa/Oromia region added that:

> *I had visited and get examined at different health centers in my community of origin but they did not diagnose me properly and identified my disease timely. Finally, when I went to Debrezeit Hospital, after the disease affected my body. They suspected it as leprosy by observing the signs and symptoms of the leprosy on me and they referred me to ALERT Hospital.*

Tefera, a rural PAL from Gojjam also stated that:

> *I was going for the treatment of leprosy at the early stage of the disease. But they did not examine me very well and detected my disease properly at that time. They gave me another medicine before. "If I were diagnosed properly that time, I would never be affected like this". The physicians tried a variety of treatment on me, but they did not confirm as it is leprosy. I came to ALERT Hospital with the help of leprosy affected man, whom I met in the health center in my community of origin. He identified me by observing the signs and symptoms of leprosy in my body. He advised me to ask a referral paper and to go to ALERT Hospital early. Based on his advice I came to ALERT Hospital and have got treatment.*

A key informant Terefe, again supplemented the above mentioned health related challenges that, he suspected the knowledge and the willingness of health professionals to assist the rural PAL in their community of origin. He added that there is no availability of proper and early case detection for the rural PAL. As a consequence; many of the rural PALs have got health complications like leprosy reaction, infected wound, deformity and disability. Some of them again treated wrongly as a nerve and bone disease and come to ALERT Hospital after highly affected by leprosy. He further explained that health professionals in the rural areas are not willing to care their wound. They stigmatized, discriminated and pushed them to go to ALERT Hospital.

The key informant Fikadu, also mentioned that, the rural PAL fear the treatment in their community of origin as it may not be strong enough and may cause the loss of their hands and legs if they return back to the community of origin. He added due to the lack of modern treatment access and awareness, they were forced to go to traditional healers, witchcraft and herbalists before they come to modern treatment centers. Because of the arriving late to the modern treatment, they encountered with a variety of health complications.

Lack of POD and rehabilitation services

The participants were also asked about whether POD and rehabilitation services are rendered in their community of origin for the rural PAL or not and its impact in the reintegration to the community of their origin. Almost all of the interviewed participants replied that there is a lack of both POD and rehabilitation services in their community of origin. According to them there is no proper health education about POD and self care, rehabilitation services are not available, no

facility of prosthesis orthotic materials for the rural PAL like wheel chair, crunch, foot wear and artificial leg and hand.

They acknowledged that the lack of the two services in their community of origin plays its role in the decision not to reintegrate within their community of origin. Contrary to the above mentioned points, one of the respondents, Kidanu has a different view; he mentioned that there is availability of health education about POD and self care, availability of rehabilitation services and prosthesis orthotic materials in his community of origin.

As the report from the FGD participants showed that the rural PAL encountered with a variety of biological challenges which influences their reintegration in their community of origin after treated at ALERT Hospital. According to them the health professionals are not willing to treat the infected wound. They added that the bad odor from the infected wound highly affected the day to day functioning of them while using transportation and move from place to place. A problem to wear a cloth due to the skin dryness is another challenge mentioned by the rural PALs. In relation to the treatment of leprosy they stated that there is scarcity of leprosy treatment and there are many rural PALs who are not diagnosed and treated properly. The physicians prescribed unrelated medicine for leprosy as the discussants said.

They also mentioned that they were not treated at the early stage of the disease. In some communities there is lack of MDT and other essential drugs. They also stated that due to the problem of timely diagnosis and proper treatment they forced to go in to traditional treatments. The FGD discussants' concluded that the biological challenges are one of their challenges which prohibit them not to succeed to reintegrate within their community of origin.

4.2.2 The psychological challenges

In relation with the psychological challenges that affected the rural PAL not to reintegrate within their community of origin after treated at ALERT Hospital, all of the interviewed participants informed that the psychological challenges prohibited them not to reintegrate within their community of origin. As mentioned by the in-depth interview participants they have got psychological disorders like anxiety and depression due to the impacts of leprosy and its resultant problems.

According to them they have got anxiety, when they know their leprosy status for the first time, when they see the signs and symptoms of leprosy in their body, when people labeled them as HIV/AIDS patient due to the change in their physical appearance and when separated from their marital partner, children, family, relatives and friends. The study participants added that they have got anxiety by fearing the frequent amputation, further health complications, disability due to leprosy and the fate of their health conditions in the future and then depression follows. Some of the signs and symptoms of anxiety and depression shown on the rural PAL are described below:

Self-stigma

All of the interviewed participants stated that the self-stigma was practiced by them, due to several factors. According to them, the stigma and discrimination from their family, relatives, friends, community and the health professionals following their infected wound, the physical deformity and disability, is the reason for the self-stigma. They added that the bad odor coming from their infected wound is also another factor. As they mentioned it is shameful to interact

with people with the infected wound, the physical deformity and disability, because the community underestimate the PAL.

They also affirmed that the family, community and the health professionals perceive the signs and symptoms of leprosy as the symptoms of HIV/AIDS, by watching the change in their physical appearance and body weakness of the affected people. They stated that, due to the stigma and discrimination as a result of the above mentioned factors, the rural PAL feel as they are inferior and unique from the other members of the community. As a result they were not willing to participate in different social events rather prefer self-stigma.

Teshome explained the situation that "When I was in Chefa Donsa, I preferred to be lonely because, every one discriminated me. My family hated me, mainly, my father. My colleagues were not willing to play with me".

Kidanu on his part said that "To prevent the transmission of leprosy to my children, I usually tried to isolate myself from my family mainly from my children. I was also not willing to participate in any social events, due to the bad odor coming from my infected wound".

Tefera added that:

> *Due to the stigma and discrimination and the nature of the disease, I become frustrated and my moral was fallen. When I go to the church people started segregating me, and then I started isolating myself. Even when I go to social events rarely, I prefer to go and sit lonely due to the stigma and discrimination following the physical deformity and disability on me.*

Suicide attempt

The in-depth interview participants were asked whether they have an experience of suicide attempt or not, due to the multifaceted challenges of leprosy. Almost all of the study participants confirmed that, they have an experience of suicide attempt, when they were in their community of origin. They tried to commit suicide using various methods like poisoned drink, holding electric wire and strangle using rope. According to them one of the causes for their attempt was when their body becomes weak to function properly. They added that they attempted suicide due to the frequent amputation and disability.

They further explained that they tried to murder themselves when they divorced from their spouse and separated from their children, family, relatives, friends and community. The fear of long term misery due to the chronic nature of the disease and considering themselves as hopeless, lonely, unique and useless person, whom waiting for his/her death, is another motivating factor to attempt suicide by the rural PAL. Alem said that "I have tried to commit suicide, when my hands and legs become senseless and becomes out of work. I was rescued at Fnote Selam hospital after I drank poisoned drink to kill myself".

Sisay put the situation like this:

> *Specially, after the second amputation my behavior changed completely. I became hopeless and I was frequently in conflict with health professionals at ALERT Hospital and I was thinking to commit suicide, specially, when I discharged from the hospital, I do not have any alternative to go because my marriage was dissolved.*

However, two of the in-depth interview participants, Teshome and Tefera, have a different view on that. According to them they did not attempt suicide before due to leprosy and its resultant problems. Tefera added that, "I had no plan to commit suicide before, but my coping mechanisms, when I encountered with challenging situations, was to migrate to the city. I never give up still now and I believe as I can lead a normal life as people not affected by leprosy".

A key informant Alemu, psychiatrist at ALERT Hospital confirmed that, the rural PAL usually encountered with fear of stigma and discrimination in their community of origin, financial problem to follow their treatment properly, unable to reintegrate within their community of origin and to be productive, loss of social acceptance and negative attitude towards being leprosy affected person. Because of these impacts they usually got psychological disorders mainly, anxiety and depression.

Anxiety and depression are very common among the PAL specifically the rural PAL who is not succeeding to reintegrate within their community of origin after treated at ALERT Hospital. Some of the manifestations of anxiety are worry about the disease (whether it is curable or not, Sever or not), fear about their future life and indicators of depression are self-stigma, hopelessness, suicide attempt and so on as the psychiatrist of ALERT Hospital illustrated.

As stated by the FGD participants they were encountered with different psychological challenges due to leprosy and its resultant problems. They stated that the psychological disorders start when they know their leprosy status for the first time. They said that as they are not interested to interact with the people and they were hiding the affected parts of their body from the family, relatives, peers and community. The majority of FGD participants illustrated that they attempted suicide due to the pain; stigma and discrimination. They also mentioned that they became hopeless due to disability and stigma.

4.2.3Social challenges

The social challenges of the rural PAL to reintegrate within in their community of origin after treated at ALERT Hospital are presented in detail in thematic areas:

Leprosy and social interaction

All of the interviewed participants reported that, they have got a challenge of social interaction in different settings such as in churches, schools, market places, working environments and in social events like wedding and funeral ceremony, due to the misconception about leprosy. They added that the infected wound and the bad odor following this, the physical deformity on their hands, legs, mouth, eye, nose and bone and the physical disability in their legs, hands and eye is also another factor that limited their social participation. They further explained that many people gave them a special attention when they tried to involve in the social events.

Stigma and discrimination due to Leprosy

The in-depth interview participants were also asked about the role of stigma and discrimination not to reintegrate within the community of their origin. The entire interviewed rural PAL in this study declared that they have been stigmatized and discriminated by the family, relatives, peers, and community and health professionals in their community of origin. According to them it was difficult to accomplish day to day activities for the rural PAL. They added that it was challenging not only to eat and drink together but also to interact with the inhabitants of the community.

They added that by fearing the stigma, discrimination, assault and labeling as a ''zere qomata" (leper family) by the community, the family and relatives stigmatize and discriminate the affected member. The participants added that they are forced not to return back to their community of origin after treated by their marital partners, family members and relatives. Fikadu, a key informant confirmed that in some community it is not allowed to reintegrate again for the rural PAL, after they recognized as leprosy affected person in the community.

Teshome, from Oromiya region of Chefa Donsa, put it the situation as follows;

> *Being a leprosy patient is considered as being against the family honor in my family, because, leprosy is considered as a shameful disease which underestimates the affected people, their family and the relatives. I was highly stigmatized and discriminated in the family. I was eating and sleeping lonely from my brothers and sisters. I was not allowed to accomplish any role in the family. My father was not giving me appropriate love and care as my brothers and sisters. As a result of the wound in my hands and the signs and symptoms of leprosy in my body, I was segregated by my peers in the school. As a result I was usually absent from the school, my academic performance was weak and finally, I was forced to drop out of school.*

Samson also said:

> *I was isolated from my parents, neighbors, relatives, friends and the community. I was forced to stay at home. No one was interested to care of me, because of that I have got a challenge to get drinking water and diet. No one assisted me to use a toilet. One day when I was very thirsty and trying to drank water from the tanker, the tanker failed on me and I was forced to drunk from the soil as an animal that day. When I was amputated ten*

times and admitted long period of time at ALERT Hospital; no one from my family and relatives visited me. Even I have not heard and attended the funeral ceremony of both of my parents. .

In relation with the stigma and discrimination the FGD participants stated that because of the segregation at school by their peers, they were forced to drop out of school. In view of social participation the rural PAL were forced to hide in the home by their family members by fearing stigma and discrimination from the community. According to them the community underestimate and hate the rural PAL. The community is not interested to use the diet prepared by the rural PAL. Settlement of PAL in their community of origin was a cause for the loss of family's honor. They also mentioned that they have an experience of an assassination attempt by their family members, relatives and the community. They added that the house hold utensils used by them was separated from the tools that the other members of the family used.

However one of the FGD participants from the Oromia region had a different experience. He described that ''the disease did not affected me physically, as a result of that I have never encountered stigma and discrimination from the community. My family knows as I am leprosy affected person but there was no segregation, I have eaten and slept with them''.

The impact of leprosy on marriage

Participants of the interview were also interviewed about the impact of leprosy in their marital relationship and not to reintegrate within their community of origin. Almost the entire interviewed rural PAL stated that leprosy affected them, their family and relative's marital relationship as well as their reintegration to the community of their origin, because, the members

of the affected family and the relatives are labeled by the community, as a "zere Qomata" (leper family).

Sisay described his experience as follows:

> *As a result of the loss of sensation my body frequently gets swollen, ruptured, wounded and amputated. I frequently was admitted and occupy hospital beds for long period of time. Because of that I was unable to support my family's basic needs and care of my children properly. I become a burden on my wife in addition to the stigma and discrimination from the community. My wife having three children from me was exhausted to care of me, my children, farming land and cattle's. Finally, she decided to divorce and divide the property with me .Finally, we got divorced, I let three of my children in Gojjam and I came to ALERT Hospital, settled in the community of Zenebeworq since 2012 and married my second wife. She is pregnant now.*

Kidane expressed the situation like this:

> *I was hiding my health status and the infected wound from my wife and my children by fearing stigma. My wife separated the bed, due to the bad odor coming from my infected wound. As a result, I migrated to Addis, we are now separated. She is now living in Tigray with my children and I am settled in Addis lonely.*

Tefera, like the above two said that:

> *The family and the community labeled me based on my physical appearance as HIV/AIDS patient and tried to influence my wife also, she was suspecting me as an HIV/AIDS patient. She considered me, as I am hiding my HIV status from her. She said to*

me repeatedly, as it is sexually transmitted disease and as she is at risk of getting HIV. She frequently asked me to separate from her and to search my own way of living in the city.

Ayinaddis on her part said, "Leprosy is the cause for my being single today. Many people were interested to marry me, when I was in my community of origin. Though, they dropped me repeatedly because of the information they have got as I am leprosy affected woman".

The FGD discussants illustrated that they cannot marry non leprosy affected inhabitants of the community. There is a misconception that sexual intercourse aggravates leprosy in the rural community. They discussed that we cannot reintegrate within our community of origin for the sake of our families and relatives respect and marital prospects. Some of the discussants also mentioned that they were divorced and separated from their spouse because of leprosy.

The impact of derogatory words by the community of origin

Nearly all of the interviewed participants of the rural PAL informed that, derogatory words have its own role in their effort to reintegrate within the community of origin. As to them leprosy is known as "tilqu beshita or Talaqu Dawe" (the major disease), due to its multi dimensional impact on the physical, psychological, social and economic aspects of the affected people, their family and relatives. They added that the community called it "the major disease" as it is believed that a punishment from God due to sin or misbehavior. They further explained that it is also called "korachu beshita" (a cutter disease) as a result of the repeated amputation on the legs and hands of people affected by leprosy. That undermines the status of the affected people, their family and relatives.

Two of the interviewed participants, Alem and Tefera, have a different view on that as they stated it is known as "yeqoda beshita" (skin disease) in their community of origin together with other skin diseases. The community has a little awareness about leprosy disease and there are no known people affected by leprosy in their community of origin before them. Samson said that "Leprosy is known as "shishira" in Hadiya which means the cutter disease. Its name implies a very bad disease which is hated by the community".

The social worker of ALERT Hospital, Terefe confirmed that, a rural PAL are victims of different pejorative terms given to them like "qomata" (leper), "qoorata"(amputee), "yeteregeme"(God punished) and "yeseyitan qurach" (part and parcel of devil) by the community of their origin, due to the misconception about leprosy. So, it is challenging to reintegrate within this type of community again.

Fikadu another key informant also added that, the pejorative terms given by the community to the rural PAL prohibits them not to reintegrate within the community of their origin once treated. It is called "gabcha kelkil" (marriage prohibitory) and "zer atfi" (heredity killer) by the community. The affected person is called "qomata" (a leper). As he is identified as leprosy affected person every member of his family and relatives recognized as "yeqomata zere" (leper family). In some family they forced not to reintegrate again as he/she believed to be prohibits the whole family marital ties.

The impact of leprosy on educational life

The in-depth interview participants were interviewed about the impact of leprosy on their educational life. Nearly all of the participants reported that leprosy affected their educational life. According to them they were segregated by their peers for their being leprosy affected person and by observing the leprosy affected parts of their body. They added that they were assaulted by their class mates in pejorative terms and sometimes they encountered an opposition to attend class together. As a result they used to be absent from the school and their educational achievement was low as a result of that. Finally, they were forced to drop out from school completely. Teshome said that "When my peers see my wound in my hands and harassed me, I become ashamed of my body and I was frequently absent from school and went to the holy water sites. Finally, I dropped out school and migrated from my community of origin".

Samson also added that:

> *Leprosy extremely affected my educational life. I was a regular student. I dropped out school four times due to leprosy. My class mates complained to my teachers due to my presence in the class. My peers gave me a special attention in the class, because of my incompetency in writing speed, as I am writing using my clawed left hand and unique handling of the pen. They also harassed me through pejorative terms as "qomataa" (leper). When the pressure becomes beyond my control, I started attending school in the extension program. The same as the regular students, the students in the extension program also started laughing at me, when the pen dropped from my clawed left hand. One day I let my exercise books in the class and went to home before the class ended due to the insult and the opposition from my class mates for my presence in the class.*

The physical environment

In relation to the role of the physical environment on the rural PAL not to reintegrate within their community of origin after treated at ALERT Hospital, most of the rural PAL replied that the weather condition, the topography of the land, the level of development of infrastructure in their community of origin has played a role in their decision not to reintegrate within their community of origin. Similar with the interviewee on the impact of the physical environment in the reintegration of the rural PAL after treated, the majority of FGD participants stated that when they reintegrated with in their community of origin their disease aggravated because, of that they fear to reintegrate within the community of origin. Except one of the participants of the discussion the participants agreed that the topography in their community of origin is not favorable and as it is rocky and have ups and downs.

The weather condition

According to the rural PAL participated in the interview both the cold and hot weather conditions are not favorable for them. They added that the hot weather aggravated their wound, infection, the physical deformity and disability. The cold weather on the other hand caused for muscle weakness, joint pain, pain on their bone and their extremities, caused for lack of feeling, arthritis and a problem of mobility. As a result it influenced their reintegration to their respective community after treated. The weather is not favorable for the rural PAL to return back to the community of origin as the FGD discussants confirmed during the discussion.

The topography of the land

The rural PAL added during the interview, that the topography of the land in their community of origin was not conducive for the rural PAL. It affects their mobility and productivity because, of the forests, rocks and ups and downs. They further explained that it is not accessible for all means of transportation and difficult to use prosthesis orthotic materials like artificial leg, foot wear, crunch, and wheel chair and so on. Sisay put the impact of topography as, "The topography of the land is not favorable for me. It has ups and downs. To use a crunch my two hands are clawed due to the nerve damage. It did not function properly. To use a wheelchair there is no access and the land was not conducive for all means of transportation".

Infrastructure development

In relation to the impact of infrastructure development in their community of origin, the interviewed rural PAL stated that they have to travel from two to eight hours on foot to get the main road to have transportation access. They added that it has no entry point in summer for all means of transportation. They further explained that the roads are not well constructed and difficult for the mobility of the rural PAL. It is also full of dust in winter and muddy in summer seasons that complicated the health and mobility of the rural PAL.

4.2.4The economic challenges

The in-depth interview participants were asked about the economic challenges that prohibited them not to reintegrate within their community of origin. All of the participants acknowledged that economic challenges are one of the factors that affect their reintegration, after treated at ALERT Hospital. According to them, the cost of transportation from their community of origin to ALERT Hospital and vice versa, the expenses of nutrition, the expenditure of housing before

admission and after discharge while following rehabilitation services and the lack of finance due to the frequent travel to ALERT Hospital has created the economic challenges on the rural PAL.

Productivity

They added that the repeated reaction of the disease, loss of sensation, muscle weakness, wound, the physical deformity and disability affects their mobility and productivity. The problem of mobility hindered them not to engage in farming, rearing cattle and petty trade as before. They further explained that they have been adding additional farming land on share before affected by leprosy. Currently, they were forced to give their farming land on equal bases. As participants illustrated leprosy also prohibits them not to engage in labor intensive works. Because, of the muscle weakness, by fearing further health complication and disability.

Sisay explained that:

> *I left the military service due to leprosy. It prohibited me not to engage on farming and rearing cattle. Because of that I gave my farming land on equal bases. I contributed my farming land and the other person his skill and labor then we share the product equally; before that I was adding extra farm land from the community on share. Due to the difficulty to feed and handle my cattle properly, I sold my cattle. I was engaged on petty trade but my body frequently wounded and affected me. My right leg, which is an artificial prohibited my mobility and created load on my left leg when I tried to mobilize. As a result I passed through frequent amputation and surgery at ALERT Hospital.*

A key informant from ENAPAL, Tesfaye confirmed that leprosy by its nature develop disability, that develops from time to time. He added that most of the rural PALs are farmers because of the difficulty to engage on farming and labor intensive works, they have encountered economic challenges. As a result they decided not to reintegrate within the community of their origin. They also fear further disability and health complication due to heavy works. Because of the less social participation and the misconception of the society their productivity reduced.

The key informant, Terefe added that deformity means damage on the hands, legs, eyes and nose; as a result they are vulnerable for stigma and discrimination in the job recruitment. He also stated that it is difficult to reintegrate within their community of origin, unless they are productive and self-sustained parts of the community.

Property ownership and Loss of assets

The in-depth interview participants stated leprosy causes them to loss their assets. The majority of participants informed that they lost their assets due to leprosy. As the participants said they lost assets mainly to cover the cost of transportation, housing and diet while they came to the city for a variety of treatments. Because of that they forced to engage on begging finally. Moreover, they stated that due to the problem of proper handling of their cattle, the frequent travel in need of treatment and lack of capacity to feed regularly, some of their cattle's have died. They also said that they were forced to sell them in cheap price before dying.

Tefera put the problem as follows "When I trace back to the community of my origin, after a long period of admission at ALERT Hospital, all of my cattle's were dead except one due to hunger and lack of proper care".

Alem also said:

> *I was forced to sell three cattle which have been reared in my aunt's house for long period of time for the sake of nutrition, transportation and house rent, as I was repeatedly traveling to the city to seek a variety of treatment and to follow the holy water. I am very angry due to the loss of my assets which did not bring me any significant change in my health status.*

The information from a key informant, Terefe, stated that the rural PAL usually forced to sell their land, cattle and home to cover the cost of their transportation, house rent, nutrition and other costs while they are trying a variety of treatment like going to holy water, herbalists and witch-crafts, traditional healers and modern treatment centers. He added that they may also be forced to sell and consume their assets as they are not able to earn additional income.

In relation to the economic challenges the rural PAL FGD participants testified that their productivity was affected by leprosy and its resultant problems. Because of the long term admission in the hospital, a problem of mobility and difficulty to accomplish heavy works and the health complications following the effort to be productive part of the community, are some of their reasons for them to leave their community of origin.

4.3 The Coping mechanisms of the rural PAL

The in-depth interview participants were asked about the survival strategies, utilized by them to cope up the bio psychosocial and economic challenges, they encountered with in the effort to reintegrate within their community of origin after treated at ALERT Hospital. They stated that they have a variety of coping mechanisms to cope up the multidimensional challenges due to leprosy. Some of the survival strategies utilized by the rural PAL are stated below;

Coping with the biological challenges

The interviewed participants stated that to cope up the biological challenges related to their physical, medical and health related conditions, they used a variety of survival strategies. According to them they tried to cope up with the biological problems by following their treatment properly. They also added that they tried to cope up with daily self care such as oiling their skin, dressing proper shoes, reducing mobility, washing in cold water daily, using hot drinks by cooling and so on. They further explained that the care and support given at ALERT Hospital by people affected by leprosy, the health professionals and the supporting staff helped them to cope up the multifaceted challenges. The experiences of Alem, Kidanu,Tefera and Aynaddis showed that they tried to cope up the biological problems because of leprosy by following their treatment properly and through daily self care activities such as oiling their skin, washing their leg in cold water daily, using appropriate foot wear and so on to prevent further disability.

The FGD discussants expressed that as they tried to cope up the biological challenges by hiding their health status and the affected parts of their body, the support from the family members, health professionals and religious fathers and through self care. The majority of FGD participants also testified that they have tried traditional means of treatment to cope up the biological challenges in their community of origin.

The key informants from ALERT Hospital and ECC-MSC confirmed that the rural PAL tried to cope up the health related challenges by following variety of treatments, both traditional like going to the holy water, herbalists, traditional healers, witchcraft and modern treatment. From my observation during the study period I have seen many rural PALs following their treatment properly to cope up the health related challenges indifferent service delivery units of the hospital, such as in the Ulcer Clinic they have followed wound care, in the Prosthetic Orthotic Work Shop they have got appropriate foot wear based on their damage and artificial leg and hand, in the Red Medical Clinic followed MDT and leprosy reaction control and in physiotherapy and occupational therapy to have a variety of therapies which enable them functional parts of the community after surgery and amputation

Coping the psychological challenges

In relation to the coping mechanisms of the psychological challenges, the interviewed rural PAL stated that they used a variety of survival strategies to cope up the psychological challenges due to leprosy. Self-stigma from their family, friends, relatives and different social activities is one of their coping strategies as stated by the interviewed rural PAL. They went to the spiritual places and the holy water sites to cope up the psychological problems.

They added that marrying the rural PAL having similar experience and bringing their children to the community of Zenebeworq was another coping strategy. They further explained that

sharing the experiences of PAL and observing the most vulnerable PAL at ALERT Hospital and in the community of Zenebeworq helped them to cope up the challenges. Finally, they stated that the support from health professionals, the supporting staffs of ALERT Hospital, the community of Zenebeworq and their peers helped them to cope up the psychological challenges.

Sisay explained the situation that:

> *I have been in stressful situation and I had a plan to commit suicide because of the multifaceted challenges of leprosy mainly, psychological challenges. However, my second wife t that I married after I settled in the community of Zenebeworq, helped me to cope up the situation at that time. My second spouse gave me the strength by saying that "though your legs are amputated, you have a mind and you can live also by the name of Saint Mary". She helped me also to observe the most vulnerable PAL who have bilateral amputee, who lost their hands, legs and eyes and leading their life properly. Finally, she helped me to bring one of my daughters from Gojjam. Before that the day and night was too long for me. In the moment I am following my treatment properly, engaged in petty trade (cloth and shoes) and educating my daughter.*

The rural PAL FGD participants confirmed the above information that, they try to cope up the psychological challenges in the effort to reintegrate within their community of origin through the following survival strategies. According to them they try to cope up the psychological challenges by going to spiritual places and holy water, health education, psychiatry and counseling services at ALERT Hospital. From my exposure during the study period I have also observed the support of the social worker and psychiatry to help the rural PAL to cope up the psychological disorders due to leprosy.

The life experience of one of the FGD discussants showed that, "when I was treated leprosy in my community of origin. The doctor said to me that "look at that tree" by pointing to the dried tree without leaf; "your body will be like that in the near future. Leprosy made people's body to dry while they are alive". When I heard this explanation from the physician while I was treated, I became totally mentally ill person for a long time. I was recovered by the support of psychiatric drugs".

Coping the social challenges

The in-depth interview participants were also asked about their coping mechanisms of the social challenges they encountered with in the effort to reintegrate within their community of origin. According to them their survival strategy to cope up the social problems was social isolation, hiding their health status and the affected parts of their body from their children, family, peers, relatives and community. Another coping mechanism by the rural PAL was migration to the city in search of better treatment, awareness and community having similar experience like Zenebeworq. They also stated that the support from some members of their family, relatives, peers, health professionals, teachers and the affected people helped them to cope up the social challenges. At last they mentioned that participation in different social associations like "Idir" was their survival strategy. Tefera expressed his coping mechanism that "Staying at home for a long period of time was my coping strategy, for the physical and the social environmental challenges in my community of origin. Usually, I walk on the night".

Teshome's survival strategy for the social problem was:

> *By fearing the influence of stigma and discrimination from the community, I was hiding my health status and the affected parts of my body. When people asked me about the wounds in my hand I told them as it is a skin disease caused by unclean water, I got when I was swimming. I tried to cope up the challenges from my family and friends also by the help of my mother's sister (aunt). She was the reason for my survival next to God. She helped me to stay with her family long time after I leave my home due to the oppression from my father. Because of the resistance from her husband and children for my being there, she brought me to ALERT Hospital then we went to the Psycho Social Case team of the hospital. We met the social worker there and we discussed the problem I was encountered with. They appointed me to facilitate institutional support from ECC-MSC. They gave me a referral paper and the institution providing me house rent payment, cloth, food, business development skill training and initial capital to engage on petty trade (candle and church pictures) as my colleagues in the Zenebeworq. That helped me to have many friends having similar experience with me and to share experience. That also assisted me to follow my treatment properly and to be self sustained individual.*

The FGD participants confirmed that they strived to cope up the social problems due to leprosy by social isolation and institutional support from ECC-MSC, ALSA and Addis Ababa Leprosy Victims Rehabilitation Association (ALVRA). The researcher observed that the rural PAL who has got accommodation services at ALSA shelter near to ALERT Hospital.

The experiences of some of the FGD participants showed that they were able to cope up the social problems after joining ALSA shelter. They have got friends who share similar experience

in the shelter and able to continue their education after long period of time that gave hope for them.

Coping the economic challenges

The rural PAL was interviewed about the coping mechanisms of the economic challenges. According to them they make an effort to cope up the economic challenges they faced in the attempt to reintegrate within their community of origin by giving their farming land on share, they sold their cattle, land and home. They added that to minimize the risk of health complications because of farming, they engaged in petty trade (cloth, shoes, candle, spiritual books and pictures) and shoe polish in front of Abune Aregawi Church by the institutional support from ECC-MSC nearer to the hospital after referred from the Psychosocial Social Case Team of ALERT Hospital. Begging using their leprosy affected parts of their body was also another coping mechanism by the rural PAL. They further explained that the support from governmental and non governmental institutions like ALSA which provide accommodation service, vocational training and initial capital for the rural PAL, ECC-MSC provides holistic support for the rural PAL socio-economic rehabilitation such as basic needs, business development skill training, initial capital, credit, saving and treatment cost support and ALVRA provides temporary accommodation for the rural PAL before admission and after discharged from the hospital while following rehabilitation services.

Sisay said:

> *After divorced from my ex-spouse, I stopped farming, cattle rearing and came to Addis and settled in the community of Zenebeworq. After I followed my treatment as an outpatient, I admitted for amputation at ALERT Hospital. When I discharged from the hospital after the amputation, I went to the Psychosocial Case Team of ALERT Hospital then the social worker of ALERT Hospital assed my situation and referred me to Medhin Social Center. The social worker of the center also assessed me again. The center provided me cloth, oil and food, allowed me financial support to rent house. It also gave me business development skill training and facilitated initial capital to engage in petty trade in front of Abune Aregawi church nearer to the hospital. Currently, I am earning an income to support my family and to educate my child.* Kidanu aded that: *To cope up the economic challenges, as a result of disability due to leprosy, when I was in Tigray, I gave my farming land on lease. When the challenges became out of my control, I migrated to Addis. Then, I engaged on begging to survive, after I come to ALERT Hospital around Abune Aregawi Church. Currently*, I am engaged on petty trade (selling candle) by using the money earned from begging.

From my observation on the research participants during the study period I saw a number of rural PALs engaged in income generating activity such as petty trade (cloth, shoe, candle, spiritual books, church pictures…) and shoe shining in front of Abune Aregawi church with the support of ECC-MSC. The FGD participants further explained that they cope up the economic problems through Credit, engaged in non labor intensive works, institutional support from ECC-MSC and ALSA, by engaging on income generating activities like petty trade and begging.

The key informant, Tesfaye illustrated that begging is seen as the syndrome for the rural PAL. However, they do not have any alternative beyond this to survive. Some of the rural PAL attempted to be productive and self sufficient but the damage on their body affected their effort. Many of the rural PAL are not well educated, because of that they engaged on labor intensive works and become vulnerable of health complications. He added that support from different leprosy based associations like ENAPAL and ALVRA and institutions working on leprosy around Zenebeworq are another coping mechanism for the rural PALs. They also engaged on a variety of income generating activities. Changing their place of origin is another survival strategy for the rural PAL which gives them relief, as there is no more labeling and there are people having similar experience with them. As the informant explained they marry people of their own fate, after migrated to the community of Zenebeworq to support each other. Finally, he said that they cooperate in leprosy based cooperatives to cope up the bio psychosocial and economic challenges.

Chapter Five – Discussion, Conclusion and Implication to Social Work

5.1 Discussion

In this section, the main points from the findings of the study are discussed in different thematic areas in relation to the research objective and questions.

Research question one: what were the bio psychosocial and economic challenges of the rural PAL?

Contrary to their attempt to reintegrate within their community of origin after being treated at ALERT Hospital, the rural PAL encountered with multifaceted challenges to reintegrate within the community of their origin. That forced them to return back frequently and finally, settled in a new social and physical environment, because of the cyclic impacts of the bio psychosocial and economic challenges.

The biological challenges

The biological challenges are the physical, medical and other health related challenges in this study which enforced the rural PAL not to reintegrate within their community of origin after treated at ALERT Hospital. As stated in the finding section of this study PAL from rural areas usually faced health related challenges like reaction of leprosy, loss of sensation, skin dryness, wound, the physical deformity, disability and muscle weakness as a consequence of leprosy, the disease mainly affects sensory nerves, sweat glands and bones.

Similar to the finding of the study FMOH (2015) stated that most of the problems related to leprosy are primarily caused by the injury and impairment that result from leprosy reactions. There may be swelling, severe pain and tenderness of nerves, often accompanied by loss of function (FMOH, 2008, pp.119). The other study conducted by the FMOH confirmed that among

the infectious diseases, leprosy is the primary cause of permanent physical disability (FMOH, 2015, pp.11&15).

The findings of the study also revealed that the health related challenges of the rural PAL are aggravated due to the lack of timely and proper case detection and treatment of leprosy in their community of origin. In line with this the FMOH (2015), stated that high disability grade in a newly diagnosed leprosy patients represent a delay in diagnosis which may be due to the patient presenting himself late or due to misdiagnosis at the health center. In addition leprosy can often harm nerves and cause deformities, especially if the diagnosis of the disease is late (CDC, 2013, pp.2).

The WHO /ILEP (2007) *technical guide* revealed that, leprosy affects people's lives in a number of ways, most obviously, it can lead to physical disabilities that make it difficult to perform regular activities. Lastoria (2014) explained that early diagnosis is very important in the management of leprosy. The timely and proper implementation of treatment will prevent physical disabilities that have an impact on the individual's social life and functioning, which are also responsible for the stigma and discrimination regarding the disease.

Those rural PAL participated in this study explained that the disease also causes for chronic illness. As a result, they are obliged to visit health centers frequently and occupy hospital beds for a long period of time. As to them reaction control, wound care, surgery, amputation and following rehabilitation services are some of their reasons to stay long period of time in the health center. They also mentioned that there is a lack of both POD and rehabilitation services in their respective community of origin. From the above mentioned findings of the study we can infer that the health related challenges such as leprosy reaction, loss of sensation, skin dryness,

muscle weakness, wound, the chronic illness and lack of appropriate health care and rehabilitation services played a part for a rural PAL not to succeeded to reintegrate within the community of their origin after treated at ALERT Hospital.

The psychological challenges

According to the participants of the current study the impacts of the bio psychosocial and economic factors, mainly following the stigma and discrimination, the infected wound, the physical deformity, disability, the change on their physical appearance and body weakness, the rural PAL encountered with a variety of psychological disorders. They usually faced disorders like anxiety and depression. Some of the manifestations of anxiety and depression on the rural PAL participated in this study are stress, worry, fear, loneliness, hopelessness, self-stigma and suicide attempt.

The findings of Scott (2006) stated that leprosy strongly influences the behaviors of people affected by leprosy. According to him the high rate of suicidal attempts highlights the patients' concept of the psychological disorder as a result of leprosy. He added a variety of emotions are intensely experienced by leprosy sufferers. Scott also stated that grief appears to be the first and the most general reaction that leprosy sufferers show after a diagnosis of leprosy. Segregation and deprivation of the usual privileges of home environments lead to anxiety. As a result of defeat and unsuccessful coping with new situations, they often withdraw.

Unlikely to the findings of the above mentioned study by Scott (2006) the experience of some participants showed that they have not given up for the challenges of leprosy and attempted suicide however, they left the community for a better treatment, to care of their health in a better way. From the reports of the study participants I can conclude that the psychological challenges

which are mainly due to the stigma, discrimination, physical deformity and disability and the chronic nature of the disease are some of the factors that caused the psychological disorders that affected the reintegration of the rural PAL after treated at ALERT Hospital.

The social challenges

The most devastating drawbacks for the rural PAL to confront was the social challenges as the participants of the current study, which was created due to the social misconception about the cause, means of transmission and treatment of leprosy. The social problems mentioned in this study include both the social and the physical environmental challenges which affect the lives of the rural PAL who were not able to reintegrate within the community of their origin after treated.

Findings of the study showed that the rural PAL is socially disregarded, hated, stigmatized, labeled, discriminated and isolated from social involvement by their family, relatives, peers, health professionals and the community. Because of that their participation in different social activities are very limited. Similar to the findings of the study another study states that leprosy does not only affect the day-to-day functioning in the family, but considerable restrictions are imposed on patients due to the fear of social stigma. Segregation in some cases a direct outflow of the rejection that people affected by leprosy experience from the broad community (Scott, 2006, pp.48-52).

Like wise to the finding of the study, the reviewed study on leprosy stigma supplemented that, stigma and discrimination are still a worldwide phenomenon and the outcome of it varying from the psychosocial dysfunction to segregation and rejection to participation restriction. The previous finding also declared that leprosy and its stigma have a pervading effect on patients' life, affecting interpersonal relationship, leisure activities as well as participation in religious and

social activities (Adhicari et al, 2013, pp.3).In addition to the above findings, the stigma and discrimination enforced the PAL to leave their home, family and property without any condition. Those who remained within their families are often looked down and may get little or no support from their communities (WHO, 1999, pp.515).

Similar to the participants of the study Sermrittirong and Brakel (2014), stated that stigma on PAL is a complex phenomenon that has multiple causes as external manifestations like deformities and impairments. Like the participants of this study the findings illustrates that lots of similarities were found in leprosy related stigma across countries and cultures. In Thailand, people affected by leprosy are still stigmatized by health workers and by their neighbors. Some leprosy patients have been refused treatment of their ulcers by nurse aids, resulting in delay in diagnosis and poor treatment.

In addition to the above mentioned challenges leprosy patients used to be victims of derogatory words which affect their self-esteem, day today functioning, productivity, marriage ties and reintegration as the participants confirmed during the study period. The findings of Pankhurst (1984) and Mesele (2005) as well stated that pejorative terms on leprosy demonstrate that the effects of derogatory words in major languages of Ethiopia to mold the misconceptions of the people towards leprosy which signify either the divine causation, incurability, fear of the disease or pathological implications of leprosy.

Similar to the previous studies the finding of the study signifies that leprosy has huge impact on the affected people, their family and relatives marital prospects. According to the participants the disease highly affects them not to marry with known leprosy status. Those marriages started before were also divorced, separated and the family was disintegrated even those who bear

children. As a result of its impact on marriage ties the rural PAL were pushed by the families and relatives to leave their community of origin, as not to be marriage prohibitory for the family and the relatives.

The previous study confirmed that the disease may exert great pressure on the relationships of leprosy sufferers who are married. It is substantiated by the fact that the divorce rate among the leprosy sufferers is relatively high (Scott, 2006, pp.48-52). In addition marriage between a family member of persons affected by leprosy and the other community is not possible in Ethiopia (Desalegn, 2014, pp.17).

Similar to the current study the 2005 Mesele's research finding added Problems related to marriage were long lasting and intense factors to provoke social exclusion of leprosy sufferers. The community's recognition of a leprosy victim in a family meant marital isolation for the whole of the members of that family to which the victim belonged. To secure the family members from such matrimonial isolation both the victim and his relatives' preferred migration of the sufferer in to a leprosarium before the symptoms of the disease were noticed by the community.

More over the rural PAL study participants described that their educational endeavor was highly affected by the disease and forced to drop out from school due to stigma and discrimination from their peers at school. In line with the findings of the study Desalegn (2014) confirmed that children of leprosy family in Ethiopia hate to go far from their settlement for education by fearing stigma by their peers at school.

The physical environment is also another challenge which inhibited the reintegration of the rural PAL after treated, which includes the topography, the infrastructure and the weather

condition, which highly influences people affected by leprosy's health, mobility, productivity and aggravated their vulnerability as a cause for wound formation which leads to amputation and disability, if not properly and timely managed as the study participants explained. From the findings of the study we can conclude that the misconception about leprosy by the rural PAL themselves and the community has played a vital role in aggravating stigma and discrimination, which influenced the marital ties of the affected people, their family and relatives and the major challenge for the reintegration of the rural PAL to the respective community after treated.

The economic challenges

In addition to the bio psychosocial challenges the study finding showed that economically, the rural PAL become partial or non functional parts of the community, due to the muscle weakness, loss of sensation, wound, deformity and physical disability. Their productivity was declined from time to time and they become dependent on the family members.

More over due to the frequent travel to ALERT Hospital and other health centers the rural PAL are obliged to sell their assets such as farming land, house and cattle to cover the cost of transportation and basic needs. They also forced to consume their assets when they are unable to earn any additional income. In some areas their property is alienated by their family, relatives and community due to leprosy. In line with the prior study approved that the social history of leprosy sufferers in the 20th century Ethiopia showed that society taking over the assets of leprosy sufferers using the occurrence of the disease to a member of the society as a pretext to displace the victim from their community to leprosaria (Mesele, 2005, pp.161&162).

According to the findings of the current study the treatment of leprosy by its nature seeks long period of time, due to the chronic nature of the disease and the frequent travel in need of

treatment of leprosy and rehabilitation services, they have got a problem to manage their family and to meet the basic necessities of their families, to manage their cattle and farming land. After they expend all the money while trying to follow their treatment, they usually became dependent on their families and/or engaged on begging. Similar to the finding of the study, Scott (2006) as well stated that when the income generation of the leprosy sufferer is affected, their family encountered economic problems often depriving them of their daily necessities. Frustrations with employment, finally force patients into begging. Eventually, a leprosy patient may be forced to leave his or her home.

Research question two: What were the coping mechanisms of the rural PAL?

Regarding the coping mechanisms of the rural PAL, they make an effort to cope up the bio psychosocial and economic challenges they encountered with, in the endeavor to reintegrate within their community of origin through a variety of ways. According to the participants of the study, they cope up the health related challenges by hiding their health status and the affected parts of their body from their family, peers and community, by following the treatment properly, by the support from the family members, health professionals, teachers and religious fathers and through self care. They have also tried traditional means of treatment such as go to holy water sites, witch-craft, herbalists and traditional healers. As the findings of another research revealed in Ethiopia People affected by leprosy are far away from medical services, rather they use traditional means like healers, sorceress, holy water, and use holy soil given by religious fathers (Desalegn, 2014, pp. 17).

According to the findings of the research the rural PAL tried to cope up the psychological challenges by self-stigma, going to spiritual places and holy water sites, through experience

sharing from PAL who admitted in the hospital and out patients. The other coping strategy is by observing the most vulnerable parts of the rural PAL at ALERT Hospital and in the community of Zenebeworq. They also stated that the counseling, awareness creation and health education services at ALERT Hospital helped them to cope up the situation.

As the finding of the study showed, the rural PAL tried to cope up the social challenges by changing their geographical location. Alike the study finding Mesele (2005) stated that a migration to PAL communities was a means for self protection. Likewise a study done by Desalegn (2014) again stated that due to the stigma and discrimination on people affected by leprosy in Ethiopia, they are concentrated in leprosaria. Leprosy has caused migration of thousands, leaving behind their family and birth place in Ethiopia. The finding also showed that some of their survival strategy was participation in different social associations like "Idir".

Finally, the rural PAL participants of this study struggle to cope up the economic challenges by engaging on the income generating activity like petty trade (spiritual books and pictures, cloth, shoes...), shoe polish, by engaging on begging using the leprosy affected parts of their body, engaged in non labor intensive works, by associational support like ALVRA and institutional support from ECC-MSC and ALSA. They also tried to cope up the economic problems by building marital relationship with the community of their own to support each other.

The previous research on the PAL revealed that throughout the 20th century urban areas were economically favorite places for leprosy sufferers, where they earned means of income by exhibiting the leprosy dreaded parts of their body and engaging in begging (Mesele, 2005, pp.168). However, despite my expectation before the study that most of the rural PAL participated in this research may be engaged on begging as a survival strategy, the study

confirmed that the majority of them are engaged on income generating activity like petty trade, shoe polish, and following their education after joining ALSA shelter. This shows attitudinal change on the rural PAL as they can be productive parts of community instead of begging.

5.2 Conclusion

This study will provide some insight about the bio psychosocial and economic challenges and the coping mechanisms of the rural PAL in the endeavor to reintegrate within the community of their origin after treated at ALERT Hospital. The study assessed the biological, psychological, social and economic challenges and coping mechanisms of the inpatients and out patients PAL at ALERT Hospital to reintegrate within the community of their origin.

The current study indicated that the major biological challenges of the rural PAL to reintegrate within the community of their origin after treated was leprosy reaction, loss of sensation, skin dryness, wound, muscle weakness, physical deformity and disability. As reported by the participants' lack of timely and proper leprosy detection, treatment, POD and rehabilitation services are also some of the biological challenges encountered by them. This finding indicated that the need for the improvement of health care and rehabilitation services access and quality and the need to raise the capacity and awareness of health professionals in rural areas about leprosy.

Among the psychological challenges anxiety and depression are the major psychological disorders reported by the rural PAL in this study. Some of the manifestations of anxiety and depression reported by the participants were fear; worry, stress, self-stigma, suicide attempt; hopelessness and loneliness. From the reports of the study participants I can conclude that the psychological challenges which are mainly due to the stigma and discrimination, the physical

deformity and disability and the chronic nature of the disease are some of the factors that affected the reintegration of the rural PAL after treated at ALERT Hospital.

In addition, some of the social challenges mentioned by the study participants were a problem of social interaction, stigma, discrimination, marital relationship, educational drop out and the community misconception towards the rural PAL. Moreover, the findings of the study showed that the impact of derogatory words in molding the misconceptions of people towards the rural PAL and leprosy. The impact of the physical environment such as the weather condition, topography and infrastructure was huge in the reintegration of the rural PAL as the participants stated during the study. However, the study showed that the need for strong awareness creation for the rural PAL, community and health professionals by stake-holders to reduce the misconception about the cause means of transmission and treatment of leprosy to reduce the stigma and discrimination.

Another problem encountered by the rural PAL mentioned in this study was economic challenges such as the reduction of productivity, a problem of property ownership and loss of assets. The finding indicated that the impacts of the bio psychosocial and economic challenges on the rural PAL and the need for holistic intervention to enhance the physical, psychological, social and economic rehabilitation of the rural PAL to increase their coping mechanisms and to enhance their reintegration after treated.

The study findings further showed that some of the coping mechanisms of the rural PAL. According to the findings of the study the rural PAL tried to cope up the bio psychosocial and economic challenges through different survival strategies. They attempted to cope up the biological challenge by following their treatment, POD and rehabilitation services properly and through traditional means of treatment.

Self-stigma, going to spiritual places and holy water sites, health education, counselling and psychiatry services, experience sharing from the PAL inpatient and out patients of ALERT Hospital and by observing the most vulnerable parts of the PAL in ALERT Hospital and in the community of Zenebeworq were some of the coping mechanisms of the study participants for the psychological challenges they encountered with.

The study participants also struggled to cope up the social challenges through migration to cities and leprosarium, by hiding their health status and the affected parts of their body and the support from their family members, relatives, peers, religious fathers, teachers, community and medical professionals. In addition the rural PAL tried to cope up the economic challenges by engaging on non labour intensive income generation activities like petty trade, shoe polish and begging, the support from governmental and non governmental institutions and leprosy based associations. They also attempted to cope up by marrying the person having similar experience and health status to support each other.

In general, the current study indicated that the multifaceted challenges of the rural PAL to reintegrate within their community of origin after treated at ALERT Hospital and the need for holistic intervention by stakeholders to enhance the coping mechanisms of the rural PAL to reintegrate within the community of their origin after treated at ALERT Hospital.

5.3 Implications to Social Work

The finding of the study indicated that even though the rural PAL coming for the treatment of leprosy at ALERT Hospital from the different corners of the country have developed their own coping mechanisms for the multifaceted challenges they encountered in the effort to reintegrate within the community of their origin. There is a need to enhance them to reintegrate within their community of origin after treated at ALERT Hospital. That needs to be approached in different

ways and have various implications for different concerned bodies like the FMOH, FMOLSA and ALERT Hospital.

5.3.1 Implication to Policy and Programs

1. To reduce the biological, psychological and the socio- economic challenges of the rural PAL the health policy should give a higher emphasis for leprosy by considering its chronic nature, multifaceted challenges and uneven distribution in the country. To improve the quality of health care services in rural areas in terms of well trained professionals and medical equipment to provide appropriate treatment for the rural PAL including POD and rehabilitation services.

2. The economic empowerment of the rural PAL should be given a special emphasis to enhance the income generation, productivity and property ownership of the rural PAL. As a result, Federal Ministry of Health, and Federal Ministry of Labor and Social affairs can enforce those improvements through rules and regulations.

3. To reduce the burden of leprosy patients from all over the country in Ethiopia, ALERT Hospital should facilitate outreach trainings and experience sharing using its expertise in the area, where leprosy disease is widespread and having higher patient flow to the hospital. Providing training on leprosy, POD and rehabilitation for health professionals in rural areas, in collaboration with the FMOH, ENAPAL and other partners like GLRA (German Leprosy and TB Rehabilitation Association) and The Leprosy Mission International in Ethiopia (TLMI). As the treatment of leprosy is integrated in the general health services, those rural PALs coming for the treatment and rehabilitation services should have formal referral paper as other patients. The FMOH should give higher emphasis for leprosy as Neonatal Care and TB and needs to have a strong monitoring and evaluation program to control the integration of leprosy treatment in the

general health services, the knowledge and attitude of health professionals to treat rural PAL and the availability of treatment facility.

5.3.2 Implication to Social work education;

1. Vulnerable groups like the rural PAL are one of the interests of social work education. The rural PAL is one of the most vulnerable groups in Ethiopia that seeks the support of social work education. General as well as health social workers need to have awareness and knowledge about leprosy and the PAL that enables them to assist the PAL. The education curriculum for the health professionals should give higher prominence for the early detection, treatment and rehabilitation of leprosy, by considering its life time impact and its multidimensional influences. The Federal Ministry of Education can contribute a lot by revising the education curriculum and the Federal Ministry of Health also should have played its role by building the capacity of health professionals on leprosy treatment and rehabilitation.

2. Awareness rising is an effective tool to mold the social misconception about the cause, means of transmission and treatment of leprosy in the world. Awareness raising on the rural PAL, the community and health professionals to reduce the stigma and discrimination on the rural PAL is very essential. In addition to that health education and counseling should be given by hospital social workers and other health professionals to reduce the misconception about the disease, health complication and disability. As a result, the hospital social workers, other health professionals in the hospital, Federal Ministry of Labor and Social Affairs, Federal Ministry of Health, nongovernmental organizations and leprosy based associations can play a great role in this regard.

5.3.3 Implication to Social Work Research;

1. I could not get any study which deals holistically the bio psychosocial and economic challenges and coping mechanisms of the rural PAL after treated at ALERT Hospital in Ethiopia. However, the finding of this study showed the impacts of the bio psychosocial and economic challenges of the rural PAL in the effort to reintegrate within the community of their origin. Thus, I feel that more research is needed in regard to the bio psychosocial and economic challenges and coping mechanisms of the rural PAL. Therefore a wide-ranging study that includes other health professionals of ALERT Hospital such as Dermatologist, Ophthalmologist, Surgeon, physiotherapist, occupational therapist, prosthesis orthotics technicians, associations of PAL and other institutions working on the PAL such as GLRA and TLMI would help to have a better insight of the challenges and coping mechanisms that will enhance for appropriate intervention.

5.3.4 Implication to Social Work Practice;

1. As the finding of this study, the rural PAL is encountered with multifaceted challenges to reintegrate within the community of their origin. In addition, those coping mechanisms are not strong enough to enhance them to return back to their respective community after treatment. As a result, enhancing the coping mechanisms of the rural PAL to reintegrate within the community of their origin should be issued through accessible and quality health care, community based rehabilitation and POD services, creating awareness for the rural PAL, community and the health professionals to avoid stigma and discrimination because of misconceptions about the pathology of leprosy, enhancing the income generating capacity of the rural PAL to be productive parts of their community and to avoid health complications in the effort to earn an income.

2. We can advocate for the rights and the social injustice on the rural PAL such as stigma and discrimination by the family, community and health professionals, the right to get accessible and quality health care, marital right and the right to live and own property in their respective community.

3. Case management can be applied to enhance the reintegration of the rural PAL who is encountered with the bio psychosocial and economic challenges after treated at ALERT Hospital. The rural PAL has many needs that have to be addressed to enhance their reintegration. Many of them are unable to meet their basic needs before admission and after discharged from the health centers, because of that they expend all the money and forced to sell their assets like land and cattle, they have got financial problems for transportation to return back to the community of origin, some needs prosthesis orthotics materials such as artificial leg, wheel chair, crunch and foot wear, some want to get temporary accommodation services while following the rehabilitation services after discharged from the hospital etc.

So, linking the needy rural PAL with service delivery organizations should be one of the main tasks of hospital social workers to enhance their reintegration and to protect them not to engage on begging and labor intensive works as a survival strategy. The rural PAL, the community, Leprosy based associations and nongovernmental and governmental organizations working on leprosy should have their part to enhance the reintegration of the rural PAL to the community of their origin.

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Annexes

Annex I: Participant information sheet for the rural PAL

Background

People Affected by Leprosy from rural areas in Ethiopia have been more suffering from problems of health, social, psychological and economic challenges within their community of origin. That affects their reintegration within the community of their origin after treated at ALERT Hospital. Reducing the sufferings of rural PAL and maximizing their coping capacity seeks well-integrated holistic interventions by different stake holders.

Aim of the study

This study will explore the challenges of rural people affected by leprosy to reintegrate within their community of origin and their coping mechanisms after treated at ALERT Hospital.

Duration of the study

The whole process of the research project is expected to be conducted from March 2016 to June 2016.

Risks and complications

Some risks are expected to happen in this study like it may take more than an hour, some of the assessment questions my create discomfort, some of the participants may be emotional and privacy and confidentiality of FGD participants may not keep and there may be stigma and discrimination following the research.

Benefits

You as a volunteer participant in this study will receive no direct benefit from the study .When you are willing to participate you will be compensated for lunch and water (100 birr).

Role of participants

Participants will have the role of providing information on their bio psychosocial and economic challenges in the effort to reintegrate within their community of origin and their coping mechanisms.

Right to refuse/withdraw from participation

Your participation in this study is entirely voluntary; you can refuse or withdraw to participate in this study at any time. Your refusal or withdrawal from this study will not affect you in any way. We are only going to use your information as long as you choose to continue to participate in this study. If you choose to withdraw your information will not be used against your will.

Confidentiality

All your personal records will be kept confidential. No personal information will appear in any report from this study. All your information will be treated confidentially with use of coded labels on the data. Identity documents will be kept locked in cabinets. If you have any question associated with the study, you can contact the researcher and for questions related to your participation rights you can contact Armauer Hansen Research Institute / All African Leprosy, Tuberculosis and Rehabilitation Training Centre Ethical review committee (AAERC) secretariat.

Armauer Hansen Research Institute

AAERC secretary

Office Tel. 0118-962183

Annex II: Amharic Version of Information Sheet for the rural PAL
ቅጽ 2፡ የጥናቱ መረጃ ለስጋ ደዌ ተጎጂዎች

መግቢያ

ከገጠሪቱ ኢትዮጵያ የሚመጡ የስጋ ደዌ ተጎጂዎች በአለርት ሆስፒታል ህክምናቸውን ከተከታተሉ ቡኃላ ወደ መጡበት አካባቢ ለመመለስ የጤና፣የማህበራዊ፣ስነልቦናዊ እና ኢኮኖሚያዊ ችግሮች ይገጠሙአቸዋል። በዚህም የተነሳ የኖሩበትን አካባቢ ለቀው ለመሰደድ ይገደዳሉ። ይህንን ዘርፈ ብዙ ችግር ለመፍታት የተቀናጀ እና ሁሉን አቀፍ ስራ ከሁሉም ባለድርሻ አካላት ይጠበቃል።

የጥናቱ ዓላማ

ከገጠሪቱ ኢትዮጲያ የሚመጡ የስጋ ደዌ ተጎጂዎች በአለርት ሆስፒታል ህክምናቸውን ከተከታተሉ ቡኃላ ወደ መጡበት አካባቢ ለመመለስ የማያስችሉአቸውን የጤና፣የማህበራዊ፣ስነልቦናዊ እና ኢኮኖሚያዊ ችግሮች አንዲሁም የሚወስዱአቸውን መፍትሄዎች መዳሰስ ነው።

የጥናቱ የቆይታ ጊዜ

የጥናቱ የቆይታ ጊዜ ከመጋቢት 2008 እስከ ሰኔ 2008 ይሆናል።

ጥናቱ የሚያስከትለው ጉዳት

ጥናቱ በተሳታፊው ላይ የተወሰኑ ጉዳቶች ሊኖሩት ይችላል ።ተሳታፊው ከ60 ደቂቃ በላይ ሊቆይ ይችላል፣ለተሳታፊው የማይስማሙ ጥያቄዎች፣ተሳታፊዎች ስሜታዊ ሊሆኑ ይችላሉ እንዲሁም የአትኩሮት ቡድን ተሳታፊዎች ሚስጥር በተሳታፊዎች ላይጠበቅ ይችላል።

የጥናቱ ተሳታፊ የሚያገኙት ጥቅም

ተሳታፊው በዚህ ጥናት የሚሳተፈው በራሱ ፍቃደኛነት እንደመሆኑ ከዚህ ጥናት በቀጥታ የሚያገኘው ምንም አይነት ጥቅም የለም።ተሳታፊው/ዋ ለውሃና ለምሳ የሚሆን 100 ብር ይሰጠዋል/ታል።

የጥናቱ ተሳታፊ ሚና

በዚህ ጥናት ውስጥ የጥናቱ ተሳታፊ ወደ መጣበት ማህበረሰብ ለመመለስ ያጋጠሙትን ችገሮች እና የወሰዳቸውን መፍትሄዎች ማስረጃ የመስጠት ሚና ይኖረዋል።

በጥናቱ የመሳተፍ ወይም አቋርጦ የመውጣት መብት

ተሳታፊው በዚህ ጥናት መሳተፍ ካልፈለጉ አይገደዱም።እንዲሁም መሳተፍ ከጀመሩ ቡኃላ በማንኛም ጊዜ እና ሰዓት አቋርጠው መውጣት ይችላሉ።ይህንን በማድረግዎ ምንም አይነት ተጽህኖ አይደርስብዎትም።ከርሰዎ የተሰበሰበውን መረጃም እርሰዎ ፍቃደኛ ሲሆኑ ብቻ እንጠቀምበታለን።ፍቃደኛ ካልሆኑ ግን ምንም ዓይነት ስራ ላይ አይውልም።

የጥናቱ ምስጢራዊነት

ሁሉም የጥናቱ ተሳታፊ መረጃዎች በሚስጥር ይጠበቃሉ። ከተሳታፊው መረጃዎች ውስጥ ምንም አይነት የግል መረጃዎች ሪፖርት ላይ አይወጡም።ሁሉም መረጃዎች ሚስጥራዊ መለያ ቁጥር ስለሚሰጣቸው የመረጃዎቹ ሚስጥራዊነት የተጠበቀ ነው። የተሳታፊው መረጃዎች በሚቆለፉ ሳጥኖች ስለሚቀመጡ መረጃዎቹን ማግኘት የሚችለው ተመራማሪው ብቻ ነው።

ከጥናቱ ጋር ተያይዞ ማወቅ የሚፈልጉት ጉዳይ ካለ ወይም ጥያቄ ካለዎት የጥናቱን ተመራማሪ በሚከተለው አድራሻ ማግኘት ይችላሉ።እንዲሁም ከተሳታፊነት መብትዎ ጋር ተያያዝነት ላላቸው ጥያቄዎች የአህሪን ምርምር ስነ ምግባር ኮሚቴ ከታች በተገለጸው አድራሻ ማነጋገር ይችላሉ።

የአህሪ ምርምር ስነ-ምግባር ኮሚቴ

ስልክ ቁጥር 0118-96 21 83

Annex III: Informed Consent Form for the rural PAL

I am asked to participate in this study and I have read the information given about the study or the information given is read to me. I hereby agree to participate in this research conducted by Addis Ababa University in collaboration with AHRI on the challenges of rural people affected by leprosy to reintegrate within their community of origin and their coping mechanisms after treated at ALERT Hospital. I am informed that I am participating freely and without being forced in any way to do so. I also understand that, I can stop participating at any point if I am not willing to continue and that my decision will not affect me in any way. I understand that this is a research project whose purpose is not necessarily to benefit me personally in the short term.

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

Participant's name_____ Signature_____

Researcher Name _____ Signature _____

Witnesses' Name_____ Signature _____

Date _____

Annex IV: Amharic Version of Consent form for the rural PAL

ቅጽ 4፡የስምምነት ቅጽ ለስጋ ደዌ ተጎጂዎች

እኔ በዚህ ጥናት ውስጥ ለመሳተፍ ፍቃደኛ መሆኔን ተጠይቄአለው፡፡ስለጥናቱ የሚገልጸውን መረጃ አንብቤ ወይም ተነቦልኝ ተረድቻለው፡፡እኔም በአዲስ አበባ ዩኒቨረሲቲ እና በአህሪ ትብብር የስጋ ደዌ ተጎጂዎች ህክምናቸውን በአለርት ሆስፒታል ከተከታተሉ ቡኃላ ወደ መጡበት አካባቢ ለመመለስ የለባቸውን ችግር በሚዳስሰው ጥናት ላይ ለመሳተፍ ተስማምቻለው፡፡ በዚህ ጥናት ውስጥ በመሳተፌ በአጭር ጊዜ ውስጥ የማገኘው ልዩ ትቅም አንደሌለም ተረድቻለው፡፡

በዚህ ጥናት የመሳተፍ ወይም ያለመሳተፍ መብት እንዳለኝም አውቄአለው፡፡ በጥናቱ ላይ መሳተፍ ከጀመርኩ ቡኃላ ማቋረጥ ብፈልግ ምንም አይነት ተጽህኖ እንደማይደረግብኝ ተረድቻልው፡፡እኔን የተመለከቱ መረጃዎች በሚስጥር እንደሚያዙም ተረድቻለው፡፡ የጥናቱ ውጤት መረጃ ማግኘት ብፈልግ ማግኘት እንደምችልም ተነግሮኛል፡፡ግልጽ ላልሆነልኝ ጉዳይ ሙሉ ማብራሪያ ተሰጥቶኛል፡፡ ከላይ በተጠቀሰውም መሰረት በጥናቱ ውስጥ ለመሳተፍ ተስማምቻለው፡፡

የተሳታፊው ስም ---------- ፊርማ ----------

የተመራማሪው ስም ---------- ፊርማ ----------

የእማኙ ስም ---------- ፊርማ ----------

ቀን ----------

Annex V: In-depth Interview Guide for the rural PAL
Back ground information

Name _____ Code _____

1. Age _____

2. Sex M _____ F _____

3. Educational status

A) Not Read and Write B) Read and Write C) Grade 1 to 8 D) Grade 9 to 12

E) Others Specify,_____

4. Occupation

a) Farming b) trade c) Student d) daily work e) Unemployed

f) Other specify, _____

5. Religion

a) Orthodox b) protestant c) catholic d) Muslim e) others specify _____

6. Marital status

a) Single b) Married c) Widowed d) Separated e) Divorced

f) Others Specify, _____

7. Do you have children? a) Yes b) No

8. Community of origin before coming to ALERT Hospital _____

9. How many years you stayed here after you decided not to return to your community? ----------

B. **The challenges and coping mechanisms of people affected by leprosy**

1. What is the health related challenges (probe; reaction, loss of sensation, deformity, disability, lack of early diagnosis, shortage of proper treatment, prevention of disability and rehabilitation service) which affect you not to reintegrate within your community of origin after treated at ALERT Hospital?

2. What type of psychological problems (probe: self-stigma, depression (suicide attempt, hopelessness, isolation, anxiety etc...) you are encountered with which affects you not to reintegrate within the community of your origin after treated at ALERT Hospital?

3. How do you see your family members, relatives, friends and other community members' attitude towards people affected by leprosy in your community of origin (probe: is there stigma, discrimination and status difference on the rural PAL)?

4. How it affects you not to reintegrate within your community of origin?

5. What is the effect of leprosy in your daily life, marriage, work, academic performance and social participation?

6. How it affects you not to reintegrate within your community of origin after treated at ALERT Hospital?

7. Is there use of derogatory words in your community of origin for people affected by leprosy?

8. If "yes" please specify? What is their implication?

9. How do you see the effect of derogatory words in your locality not to reintegrate within the community of your origin after treated at ALERT Hospital?

10. What was the effect of the physical environment (probe: weather, topography and infrastructure) not to reintegrate within your community of origin after treated at ALERT Hospital?

11. How leprosy affects you economically (Probe: How it affects your productivity, income generation, property ownership and to lose your permanent assets like land and cattle?)?

12. What was its role not to reintegrate with the community of your origin after treated at ALERT Hospital?

13. How do you cope up the bio psychosocial and economic challenges due to leprosy which prohibits you not to reintegrate within your community of origin?

14. Are there other factors that make you not to succeed to reintegrate within your community of origin after treated at ALERT Hospital?

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

THANK YOU! For Your participation!

Annex VI: In-depth Interview Guide for the rural PAL Amharic Version

ቅጽ6:ከገጠር ለመጡ የስጋ ደዌ ተጎጂዎች የተዘጋጀ መጠይቅ

ሀ. መሰረታዊ መረጃ

ስም ———————————————— መለያ————————————

1.እድሜ ————

2.ጾታ ወ -———— ሴ————

3.የትምህርት ደረጃ

ሀ.ማንበብና መጻፍ የማይችል/ትችል ለ.ማንበብና መጻፍ የሚችል/ትችል

ሐ.ከ1-8ኛ ክፍል መ.ከ9-12ኛ ክፍል ሠ. ሌላ————————————

4.ስራ

ሀ.ግብርና ለ.ንግድ ሐ.ተማሪ መ.የቀን ሰራተኛ ሠ.ስራ የሌለው/ላት ረ.ሌላ————————

5.አይማኖት

ሀ.ኦርቶዶክስ ለ.ፕሮቴስታንት ሐ.ካቶሊክ መ.ሙስሊም ሠ.ሌላ————————

6.የጋብቻ ሁኔታ

ሀ.ያላገባ ለ.ያገባ ሐ.ባል/ሚስት የሞተበት/ባት
መ.የተለያየ/ች ሠ.የተፋታ/ች ረ.ሌላ————————————

7. ልጆች አሉህ/ሽህ? ሀ.አዎ ለ.የሉኝም

8.የመጡበት አካባቢ. ————————————

9. ወደ መጡበት አካባቢ. ላለመመለስ ከወሰኑ ወዲህ ምን ያህል አመት ሆኖት? ----------

ለ.ከገጠር የሚመጡ የስጋ ደዌ ተጎጂዎች ወደ መጡበት አካባቢ. ለመመለስ የሚያጋጥሙአቸው ችግሮች አንዲሁም የሚወስዱአቸው መፍትሄዎች

1. በአለርት ሆስፒታል ህክምናዎትን ከተከታተሉ ቡኃላ ወደመጡበት አካባቢ. ለመመለስ እንዳይችሉ ያደረጎህ የጤና ችግሮች ምን ምን ናቸው?

2. በአለርት ሆስፒታል ህክምናዎትን ከተከታተሉ ቡኃላ ወደ መጡበት አካባቢ. ለመመለስ እንዳይችሉ ያደረጎህ የስነልቦናዊ ችግሮች ምን ምን ናቸው?

3. የቤተሰብ፣ ዘመድ፣ጓደኛ እንዲሁም ማህበረሰቡ ስለ ስጋ ደዌ ተጎጂዎች ያላቸውን ግንዛቤ እንዴት ያዩታል?

4. በአለርት ሆስፒታል ህክምናዎን ከተከታተሉ ቡኃላ ወደ መጡበት አካባቢ ለመመለስ እንዳይችሉ ምን ያህል አስተዋጽዎ ነበረው?

5. ስጋ ደዌ በቀን ተቀን ህይወትዎ፣በጋበቻ ህይወትዎ፣በስራዎ፣በትምህርትዎ እንዲሁም በማህበራዊ ተሳተፎ ላይ ምን ተጽህኖ አሳድሮቦታል?

6. በአለርት ሆስፒታል ህክምናቸዎን ከተከታተሉ ቡኃላ ወደ መጡበት አካባቢ ለመመለስ እንዳይችሉ ምን ያህል አስተዋጽዎ ነበረው?

7. በአካባቢዎ ለስጋ ደዌ ተጎጂዎች የሚሰጡ የተለዩ መጠሪያዎች አሉ?

8. መልስዎ አዎ ከሆነ ቢነግሩን ተጽህኖአቸውስ ምን የህል ነው?

9. ስያሜዎቹ በአለርት ሆስፒታል ህክምናዎን ከተከታተሉ ቡኃላ ወደ መጡበት አካባቢ ለመመለስ እንዳይችሉ ምን ያህል አስተዋጽዎ ነበራቸው?

10. የመጡበት አካባቢ የአየር ሁኔታ፣መልካ ምድር እና የመሰረተ ልማት ሁኔታ በአለርት ሆስፒታል ህክምናዎን ከተከታተሉ ቡኃላ ወደ መጡበት አካባቢ ለመመለስ እንዳይችሉ ምን ያህል አስተዋጽዎ ነበረው?

11. ስጋ ደዌ ምን ያህል አኮኖሚዊ ጉዳት አስከትሎብኛል ብለው ያምናሉ?

12. በአለርት ሆስፒታል ህክምናዎትን ከተከታተሉ ቡኃላ ወደ መጡበት አካባቢ ለመመለስ እንዳይችሉ ምን ያህል ሚና ነበራቸው?

13. የጤና፣የስነልቦና፣ማህበራዊ እና ኢኮኖሚያዊ ችግሮችዎን ለመቋቋም የሚወስዱአቸው መፍትሄዎች?

14. በአለርት ሆስፒታል ህክምናዎትን ከተከታተሉ ቡኃላ ወደ መጡበት አካባቢ ለመመለስ እንዳይችሉ ያደረግዎትን ሌሎች ምክኒያቶች ቢገልጹልን?

15. ሌላ ተጨማሪ አስተያየት ካሎት ቢገልጹልን?

ለተሳትፎዎት አመሰገናለው!

Annex VII: Key Informant Interview Guide

Name _____

Profession _____

Position _____

Year of experience _____

1. What is the health related, psychological, social and economic challenges of leprosy on people affected by leprosy coming from rural areas not to reintegrate within their community of origin?

2. Have you ever encountered with clients whom faced a challenge to return back the original community, after treated at ALERT Hospital? a) Yes b) No

3. If "yes" What was his/her justification?

4. What are/were his/her survival strategy to cope up the bio psychosocial and economic challenges that make him/her not to reintegrate within his/her community of origin?

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

THANK YOU! Your participation is appreciated.

Annex VIII: Key Informant Interview Guide Amharic version

ቅጽ8:ስለ ጥናቱ የተሻለ መረጃ ላላቸው ተሳታፊዎች የተዘጋጀ መጠይቅ

ሙሉ ስም _____

የሰለጠኑበት ሙያ _____

ኃላፊነት _____

የስራ ልምድ _____

1. ከገጠሪቱ ኢትዮጵያ የሚመጡ የስጋ ደዌ ተጎጂዎች በአለርት ሆስፒታል ህክምናቸውን ከተከታተሉ ቡኃላ ወደ መጡበት አካባቢ ለመመለስ የማያስችሉአቸውን የጤና፣ የማህበራዊ፣ ስነልቦናዊ እና ኢኮኖሚያዊ ችግሮች ምንምን ናቸው?

2. ህክምናቸውን ከተከታተሉ ቡኃላ ወደ መጡበት አካባቢ ለመመለስ የተቸገሩ ተገልጋዮች አጋጥመዎት የውቃሉ? ሀ.አዎ ለ.የለም

3. መልስዎ አዎ ከሆነ የሚያቀርቡት ምክኒያት ምን ነበር?

4.ወደ መጡበት አካባቢ ለመመለስ የማያስችሉአቸውን የጤና፣የማህበራዊ፣ስነልቦናዊ እና ኢኮኖሚያዊ ችግሮች እነዴት ነበር ለመቋቋም የሚሞክሩት?

5. ሌላ ተጨማሪ አስተያየት ካሎት ቢገልጹልን?

ለተሳትፎዎት አመሰግናለው!

Annex IX: Focus group discussion guide for the rural PAL

1. What are the health related factors that affects you not to reintegrate within your community of origin after treated at ALERT Hospital?

2. What type of psychological problems you encountered with which affects you not to reintegrate within the community of your origin after treated at ALERT Hospital?

3. How do you see your family members, relatives, friends and other community members' attitude towards people affected by leprosy?

4. What are the causes for that?

5. How it affects you not to succeed to reintegrate with in your community of origin?

6. What is the effect of leprosy in your daily life, marriage; work, education and social participation?

7. How it affects your reintegration with your community of origin after the treated at ALERT Hospital?

8. What was the effect of the physical environment not to reintegrate within your community of origin after treated at ALERT Hospital?

9. How leprosy affects you economically?

10. How was its impact for not to reintegrated within your community of origin?

11. What are/were your strategies to cope up the bio psychosocial and economic challenges in your community of origin?

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

THANK YOU! For Your participation!

Annex X: Focus group discussion guide for the rural PAL Amharic Version
ቅጽ10፡ከገጠር ከሚመጡ የስጋ ደዌ ተጎጂዎች ጋር ለሚደረግ የአትኩሮት ቡድን ውይይት መምሪያ

1. በአለርት ሆስፒታል ህክምናዎትን ከተከታተሉ ቡኃላ ወደ መጡበት አካባቢ ለመመለስ እንዳይችሉ ያደረጎህ የጤና ችግሮች ምን ምን ናቸው?

2. በአለርት ሆስፒታል ህክምናዎትን ከተከታተሉ ቡኃላ ወደ መጡበት አካባቢ ለመመለስ እንዳይችሉ ያደረጎህ የስነልቦናዊ ችግሮች ምን ምን ናቸው?

3. የቤተሰብ፣ዘመድ፣ጓደኛ እንዲሁም ማህበረሰቡ ስለ ስጋ ደዌ ተጎጂዎች ያላቸውን ግንዛቤ እንዴት ያዩታል?

4. ለዛ ምክኒያቱ ምንድን ነው?

5. በአለርት ሆስፒታል ህክምናዎን ከተከታተሉ ቡኃላ ወደ መጡበት አካባቢ ለመመለስ እንዳይችሉ ምን ያህል አስተዋጽዎ ነበረው?

6. ስጋ ደዌ በቀን ተቀን ህይወትዎ፣ በጋብቻ ህይወትዎ፣ በስራዎ፣ በትምህርትዎ እንዲሁም በማህበራዊ ተሳተፎዎ ላይ ምን ተጽህኖ አሳድሮቦታል?

7.በአለርት ሆስፒታል ህክምናቸውን ከተከታተሉ ቡኃላ ወደ መጡበት አካባቢ ለመመለስ እንዳይችሉ ምን ያህል አስተዋጽዎ ነበረው?.

8. የመጡበት አካባቢ የአየር ሁኔታ፣መልካ ምድር እና የመሰረተ ልማት ሁኔታ በአለርት ሆስፒታል ህክምናዎን ከተከታተሉ ቡኃላ ወደ መጡበት አካባቢ ለመመለስ እንዳይችሉ ምን ያህል አስተዋጽዎ ነበረው?

9. ስጋ ደዌ ምን ያህል አኮኖሚዊ ጉዳት አስከትሎብኛል ብለው ያምናሉ?

10. ስጋ ደዌ ያደረሰበዎት አኮኖሚዊ ጉዳት ወደ መጡበት አካባቢ ለመመለስ እንዳይችሉ ምን ያህል አስተዋጽዎ ነበረው?

11. የጤና፣የስነልቦናዊ፣የማህበራዊ፣የኢኮኖሚያዊ እና የአካባቢያዊ ችግሮችዎን ለመቋቋም የሚወስዱአቸውመፍትሄዎች?

12. በአለርት ሆስፒታል ህክምናዎትን ከተከታተሉ ቡኃላ ወደ መጡበት አካባቢ ለመመለስ እንዳይችሉ ያደረግዎትን ሌሎች ምክኒያቶች ካሉ ቢገልጹልን?

ለተሳትፎዎት አመሰግናለው!

Annex XI: Observation check list guide

1. How much leprosy affected physically rural people who are unable to reintegrate within their community?

2. What do the psychological situation of rural PAL who is not able to return to their community look like?

3. How does rural PAL unable to reintegrate within their community interact in the hospital?

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