The experience of persons affected by leprosy; specific to the implication of leprosy on their lives: the case of Amhara regional state, Dessie town.

By

Metsehet Demelash

A Thesis Submitted to Addis Ababa University Graduate School of Social Work in Partial Fulfillment of the Requirements for the Degree of Masters of Arts in Social Work.

Addis Ababa University

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October, 2016

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Thesis Approval

This is to certify that the thesis prepared by Metsehet Demelash, entitled *The experience of persons affected by leprosy; specific to the implication of leprosy on their lives: the case of Amhara regional state, Dessie town* and submitted in partial fulfillment of the requirements for the Degree of Master of Arts (Social Work) fulfills with the regulation of the University and meets the accepted standards with respect to originality and quality.

APPROVED BY THE EXAMINING BOARD

Examiner _____ Signature _____ Date _____

Examiner _____ Signature _____ Date _____

Advisor _____ Signature _____ Date _____

Acknowledgement

This thesis owes its existence to the help, support and inspiration of several people. Firstly, I would like to pass my gratitude to my advisor Dr. Tenagne Alemu for the constructive comments in the study. I would also like to say a heartfelt thank you to my father and mother for always believing in me and encouraging me to follow my dreams. I am also indebted to Ato Hulemenaw Delelegn for hisadvices and ideas for my research. In addition Addisu, Markos,Messfin, Rahel,and seblethank you so much for all the moral and material supports.

My husband Edilegnaw thank you very much for the love, care and support you have showed me while I was doing this research.

I would like to pass my gratitude to the participants of the study for their time and willingness to participate in the study. Especially I would like to thank W/o Alem Geleta thechairperson of Dessie area ex-leprosy patients association for her integrity during my stay in the data collection.

Last but not least I would like to thank my friends Aminet, Eyerus, Hiwote, Mignot and Seble for making my three years of stay at Addis Ababa a memorable one. See you all on top!!!

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Abstract

With twelve in-depth interview participants and ten focus group discussants the study has made an effort to explore the experience of persons affected by leprosy. For this effort a qualitative method with case study approach as a specific method have been employed. Persons affected by leprosy with leprosy related visible deformities has been participants of In-depth interview and focus group discussions. In-depth interviews, observation, focus group discussions and document reviews were utilized to collect data. Thematic analysis was used to analysis the data that has been collected from field. The findings include the following points. Persons affected by leprosy have limitation in activities which involves their hands and feet due the deformities and loss of sensation on their hands and feet. Persons affected by leprosy face a problem to endure their marriage as well as in getting married because their families, in-laws' and the adjacent community discriminated against them. The study depict they are free to became members of local informal organization like Idder, Ekub and Mahiber however, they have limited roles. The study also reveals persons affected by leprosy faced income lose, they lose their employment and face restriction in getting employed. Besides, persons affected by leprosy use different coping strategies to win out the challenge.

Key words: leprosy. Stigma, physical impairment,social participation,marital relationship and employment.

Annexes 1

List of aberrations/ acronyms

AASW	Australian association of social workers
ENAELPs	Ethiopian national association of ex-leprosy patients
FMOH	Federal ministry of health
GLRA	German TB and leprosy relief association
ILEP	International Federation of Anti-Leprosy Associations
MDT	Multidrug therapy
PALs	Persons affected by leprosy
WHO	World health organization

CHAPTER ONE

1.1. INTRODUCTION

Becoming a social work student in the practice with health care concentration has been the major inspiration to select this research topic. The other reason is the researcher's experience with persons affected by leprosy during the field placement. In addition the director of the institution that the researcher engaged during the field placement has motivated the researcher a lot while she was telling some of her experiences. The director worked with persons affected by leprosy over fourteen years.

1.2. Background of the study

Leprosy is a chronic bacterial disease that mainly affects the skin and nerves. At an early stage leprosy may manifest itself only in mild skin lesions. But if left untreated, these lesions can become much more noticeable. At the same time, nerves may be damaged leading to impairments of eyes, hands and feet. Even while being treated, persons affected by leprosy may have various skin conditions and deformity. This is due to immunological reactions that may occur before, during or after treatment (The Nippon Foundation, 2011).

Although Leprosy is easily treated with antibiotics, it is a disease dreaded as contagious, disfiguring and without cure. Many people diagnosed with the disease, those who have been cured, or even family members face rejection and social exclusion (The Nippon Foundation, 2011).

Leprosy when diagnosed early and treated adequately can be cured with no adverse effect. However if left untreated it may cause several disabilities which often cause severe emotional

distress to patients and their families and may also seriously disturb their social life (Simon Haambozie, 1995).

First, (2003) clarified leprosy has a multidimensional effect on individuals and the community as well, for example it exposes people to permanent disability. In addition WHO, (2012) estimates 2-3 million peoples have leprosy related disability.

The study carried out in china shows that the problems caused by leprosy are not merely health-related in nature. The impairments and related social stigma (sometimes stigma alone without impairment) can lead to many social and economic problems for patients and sometimes also for their families, such as unemployment, poverty, community dislocation and destitution, which is neglected in most leprosy control programs(Chen & Wan, 2005).

Sileshi Baye, (2015) Ethiopia is categorized among the few African countries to have achieved the WHO elimination targets (less than 1 case for every 10,000 population). The highest proportion of childhood leprosy and a considerable number of new cases could witness the level of transmission of the disease and the existence of new infections within the country. In addition high proportion of patients with grade-2 disability (9.3 per 100) indicates a significant delay in the diagnosis and treatment.

Stigma is a central feature of the social impact of leprosy. Social stigma and discrimination attached to leprosy has been described as worse than the disease itself by leprosy patients. The far-reaching and unfavorable impact of leprosy stigma leads to avoidance of healthcare services, deterioration of personal health and socio-economic status and reduced quality and effectiveness of public health programs in controlling the disease (Nsagha, 2011).

The Nippon Foundation (2011) reported that at different times and places, the way leprosy patients and their families have been treated by governments, communities, schools, companies, hospitals and other organizations, including religious institutions, has constituted a serious violation of their human rights. Enforced isolation, limited or no access to social services, discrimination in the job market, obstacles in the way of getting an education, and problems finding a place to live are just some of the ways in which persons affected by leprosy have suffered. This Strip off them of their dignity in the process.

According to Edward (2010) Persons with stigmatizing conditions like leprosy experiences problem in their marriages or difficulties in getting married. In addition they face problem in their working environment or in getting employed at the first place. Their community interaction, such as social relationships and friendships are also affected.

The Future forecasts of the global leprosy burden show that 5 million new cases would arise between 2000 and 2020. The forecast also shows that in 2020 there would be 1 million people with leprosy related disability. In addition to physical impairments and activity restrictions, they are likely to suffer from social stigma and discrimination leading to economic loss. Consequently, of the other leprosy related issues, social stigma and discrimination is considered as an important 'environmental factor' that contributes to leprosy related disability (Brakel, 2012).

From the above stated studies one can understand that in researching the experience of persons affected by leprosy, it is sound to understand the implication leprosy on social participation, marital relationship, and employment experience and addition the coping mechanisms of persons affected by leprosy in light of stigma and discrimination.

Although, Stigma and discrimination itself is a complex issue with the capacity to affect all facets of life of persons affected by leprosy this study delimited to the implication of leprosy on social participation, marital relationship and employment experience of persons affected by leprosy. This is because the researcher wants to have comprehensive information on the subject. Moreover, due to the existence of Boru Meda hospital in Dessie town there are reasonable number of displaced leprosy patients in the town, so that the researcher become initiated to conduct study in Dessie town.

1.3 statement of the problem

Leprosy is one of the world's oldest and most dreaded diseases that has tortured humans throughout history. It has been synonymous with stigma and discrimination due to the hideous deformities it produced, mystery around its transmission and lack of any effective remedy till recently. In addition to the physical effects of the diseases, patients have also suffered severe social stigma and ostracism from their families, communities, and even health professionals to such an extent that leprosy has been known since ancient times as "the death before death" (Kumar,2013).

According to Nsagha (2011) even though leprosy can be cured clinically, the effect that leprosy has on persons affected by leprosy remain unresolved due to the stigma and discrimination associated with the impairments of eyes, hands and feet and various skin condition caused by the disease.

The above stated author also documented that the number of persons affected by leprosy living with the burden of stigma and discrimination is counted in millions. The stigma and discrimination can lead to persons affected by leprosy being rejected and excluded from the

society. Social stigma and discrimination associated with leprosy has been described as worse than the disease itself by the patients themselves.

Brackel (2003) reported the area of life affected by leprosy related stigma includes interpersonal relationship, marriage, employment, leisure activities and attendance at social and religious function. Despite enormous cultural diversity, leprosy related stigma and discrimination is global phenomena. People have left their families and even spouses and children, fearing the consequence of the fact that they had leprosy.

Joy Raffert (2005) documented that Stigma and discrimination cause problems for the treatment of leprosy. Often, to prevent discrimination, patients try to hide their disease by not immediately seeking medical help even though they get signs of leprosy .When they are forced to face it, they may develop significant disabilities and deformities.

The above stated author also reported PLAs may lose their employment because of their disease, the disabilities associated with leprosy and negative attitudes of employers (discrimination). When this happens, they lose the means of support for their families. Thus there can be severe financial burdens to bear.

The study in Cameron carried out by Nsagha (2011) shows that PALs are abandoned by their spouses because they are diagnosed with leprosy or they have deformity related to leprosy. On the other hand some of the PALs left their spouse because they are diagnosed with leprosy.

Social contact with leprosy patients was mostly avoided by majority of participants because of physical imperfections. This is because of the belief that “patients with “clawed” hands and feet are still infectious and as a result many people refused to have bodily contact with them” (p. 5).

ENAELPs (2012) reported that due to the established societal misconception and low public awareness leprosy affected people in Ethiopia are highly discriminated and neglected from basic socioeconomic services and life opportunities. Consequently, more than 95 percent of leprosy affected people are living under extreme poverty and leading the worst life.

ENAELP's (2001) reported most PALs in Dessie town are migrants from rural areas and they were predominantly agrarian before the onset of the disease, then they shifted to small income generating activity and begging. Begging is the major source of income for more than 27 percent of the settlers.

Persons affected by leprosy are deprived of employment opportunities and they mostly don't get better acceptance from employers. In addition persons affected by leprosy and their families are forced to hide themselves and where they came from, otherwise they will be denied to an opportunity compete even if they meet the criteria. All these results low level of employment among persons affected by leprosy and their families. (ENAELP's, 2001)

According to Sileshi B. (2015) Ethiopia is categorized among the few African countries to have achieved the WHO elimination targets (less than 1 case for every 10,000 population). But the highest proportion of childhood leprosy and a considerable number of new cases could witness the level of transmission of the disease and the existence of new infections within the country. In addition high proportion of patients with grade-2 disability (9.3 per 100) indicates a significant delay in the diagnosis and treatment.

Kumar (2015) documented that to decrease the disease burden in leprosy endemic countries, WHO suggested addressing issues of stigma and discrimination is one of a new global strategy to eliminate cases presenting with disabilities.

The above stated studies carried out abroad and in Ethiopia shows that leprosy elimination effort is yet to be completed. In addition Stigma and discrimination is major hurdle for leprosy eradication activities besides, it affects the living situation persons affected by leprosy.

At the best of researcher's knowledge the implication of leprosy on social participation, martial relationship, employment and the challenges related to the physical consequences of leprosy in light of stigma and discrimination is not much researched in the country in general and in the study area in particular.

The researcher identifies the implication of leprosy on social participation, marital relationships, employment specific to stigma and discrimination and challenges related to the physical consequences of leprosy as knowledge gap. Consequently, the findings of this study encountered this gap and provide essential inputs for the future leprosy related activities and studies.

1.4 Objective of the study

General objective

The overall objective of this study is to explore the implication of leprosy on social participation, martial relationship, employment and the challenges related to the physical consequences of leprosy in light of stigma and discrimination.

Specific objectives

- To explore the challenges of persons affected by leprosy related to its physical consequences.

- To explore if leprosy affects the marital relationships of persons affected by leprosy.
- To explore if persons affected by leprosy experience restrictions in their social participation.
- To explore and describe if leprosy affects employments of persons affected by leprosy
- To explore the coping mechanism of persons affected by leprosy.

1.5 Research question

1. Does persons affected by leprosy face challenges inexecuting their daily routines related to their physical impairment?
2. Does leprosy affect marital relationships of persons affected by leprosy?
3. Does Persons affected by leprosy experience restrictions in their social participation?
4. Does leprosy affect employment of persons affected by leprosy?
5. How does persons affected by leprosy cope with their conditions?

1.6 Significance of the Study

This study find out the implication of leprosy on marital relationship, social participations and employment specific to stigma and discrimination. In addition this study provides information on challenges of leprosy affected people related their physical condition. This gives a chance for rehabilitation workers, social workers, clinicians, planners and policy makers in the a study area make evidence based decisions, which are essential to improve the quality of care, psychosocial support, and treatment of the persons affected by leprosy and their families.

Moreover, it provides up-to-date information for those who are interested in doing research in the area.

1.7 Delimitation of the Study

This study is geographically delimited to Dessie town, south wollo zone in Amhara regional state Ethiopia. The study is also be bounded to deal only with how persons affected by leprosy experience challenges related to the physical consequence of leprosy and participation restriction in regard to marital relationship, social participations and the implication of leprosy on employment.

1.8 Operational Definition

- Employment- activities used by persons affected by leprosy as income generating mechanism.
- Grade 2 disability - refers visible deformity or damage present and severe visional problem due to leprosy.
- Level of deformity/Disability grade: The degree/extent of physical impairment observed on hand, feet and eye.
- Marital relationship – it includes experiences that persons affected by leprosy have in getting married or after getting married.
- New Cases of Leprosy: number of new cases of leprosy that never treated before and registered during the specified period of time
- Persons affected by leprosy – refers people who are currently on leprosy treatment with visible skin conditions / people who been diagnosed with leprosy and have grad 2 disability and participants of this study.

- Social Participation –refers leprosy affected peoples involvement in community based organization such as “Idir” and “Ekub”, social festivals and occasions like “Mahiber”, wedding, and mourning and social gatherings.

1. 9 Limitation of the Study

Besides to the significance, the study also has its own limitations. Even though much can be studied about the implication of leprosy on the lives of persons affected by leprosy this study make an effort to explore only the experience of persons affected by leprosy on marriage , social participation and employment and the challenges of their physical impairments in executing daily household activities. But this study didn’t assess contributing factor contribute for the challenges face by persons affected by leprosy besides leprosy and leprosy related physical impairments.

CHAPTER TWO

2. REVIEW OF RELATED LITERATURE

This chapter is organized in five sections. The first section dedicated to the general over view of leprosy i.e. Definition of leprosy, the cause and transmit ion of leprosy and the treatment of leprosy. The second section is arrange for the over view of leprosy in Ethiopia and this section organized in to three sub sections, beliefs towards leprosy in Ethiopia, social participation of leprosy affected people in Ethiopia. And the third section covers the implication of leprosy on leprosy affected people and organized into three subsections, challenges of leprosy affected people related to the physical consequence of leprosy, the implication of leprosy in marriage, implication of leprosy in employment of leprosy affected people. Stigma and stigma in leprosy is covered in the fourth section and the final section is dedicated to theoretical orientation.

2.1 General over view of leprosy

The term Leprosy originates from the Latin word 'leprosus' it means defilement. Leprosy, also known as Hansen's disease, is a chronic, granulomatous infection caused by Mycobacterium leprae, an acid-fast bacterium (Guidelines for the Control of Leprosy in the Northern Territory, 2010).

Mycobacterium leprea (the causative agent of leprosy) was discovered by the Norwegian, Gerhard A Hansen, in 1873. Mainly leprosy affects the skin, mucous membranes of the nose, and peripheral nerves. Leprosy was recognized in the ancient civilizations of China, Egypt and India. The first-known written indication of leprosy is dated 600 BC. Throughout history, people afflicted have often been ostracized by their communities and families and has been prevalent worldwide.

According to Messele (2005) in 1847, two Norwegian dermatologists Daniel Cornelius Danielssen and Carl Wilhelm Boeck set out the first scientific illustration and descriptions of different forms of leprosy. These are tuberculoid and lepromatous, the tuberculoid form of leprosy resulted from a well acquired immunity of a host and characterized by presences of single or few patches on buttocks, face, and lateral aspects of limbs and scapulae. And it leads to the distraction to nerve tissues and sensory loss and paralyses of hands, foots and face. On the other hand lepromatous leprosy results from weaker acquired immunity of the host which allows multiplication of leprosy bacilli which finally leads to the distraction of eyes, nose, testes and larynx.

A patient with leprosy is an individual who has not completed a course of treatment and has one or more of the three cardinal signs; hypo pigmented or reddish skin lesions with loss of sensation; involvement of the peripheral nerves as demonstrated by their thickening and associated loss of sensation; skin smear positive for acid-fast bacilli. Any one of these signs has been regarded as sufficient for diagnosis of leprosy, so that the sensitivity is high (Guidelines for the Control of Leprosy in the Northern Territory, 2010).

At an early stage, leprosy may manifest itself only in mild skin lesions, but if left untreated, these lesions can become much more noticeable. At the same time, nerves may be damaged leading to impairments of eyes, hands and feet. Even while being treated, leprosy-affected people may have various skin conditions due to immunological reactions that may occur before, during or after treatment (Guidelines for the Control of Leprosy in the Northern Territory, 2010).

Untreated leprosy patients discharging bacilli are the main source of infection. The route of transmission of leprosy is uncertain. However, air-borne spread of droplets containing the

bacilli expelled by untreated leprosy infected persons and inhaled by healthy persons is believed to be the most important route of transmission. Leprosy patients are no longer infectious to others after being administered the first dose of the treatment regimen (Guidelines for the Control of Leprosy in the Northern Territory, 2010).

Although, leprosy was treated differently in the past, the first breakthrough occurred in the 1940s with the development of the drug dapsone, which arrested the disease. But the duration of the treatment was many years and even a lifetime, making it difficult for patients to follow it and besides, in the early 1960s, M. leprae started to develop resistance to dapsone, the world's only known anti-leprosy drug at that time (FMOH Tuberculosis, Leprosy and TB/HIV Prevention and Control Program manual fourth edition).

In the early 1960s, rifampicin and clofazimine, the other two components of recommended multidrug therapy (MDT), were discovered; And WHO recommended Multi drug therapy as effective way of leprosy treatment in 1981. Since 1995, WHO provides free MDT for all patients in the world .Transmission of leprosy is interrupted after the very first dose of MDT (FMOH Tuberculosis, Leprosy and TB/HIV Prevention and Control Program manual fourth edition, 2010).

Multi drug therapy is the use of a combination of two or three anti-leprosy drugs to treat leprosy. There are two types Multi drug therapy regimens, the firs regimen is Pauci-bacillary Multi drug therapy consists of Rifampicin and Dapsone for a total duration of 6 months. And the second regimen is Multi-bacillary Multi drug therapy consists of Rifampicin, Dapsone and Clofazimine for 12-month duration (FMOH Tuberculosis, Leprosy and TB/HIV Prevention and Control Program manual fourth edition, 2010).

Leprosy affects persons in all age groups and both sexes. The age group mainly affected is between 15 and 45 years. Factors related to poverty increase the risk of developing the disease. Under normal circumstances, only a very small proportion (less than 5%) of all individuals who are infected by the leprosy bacilli will develop the disease during their lifetime this is because majority of people immunological defense kills all the bacilli (the causative agent of leprosy) (FMOH Tuberculosis, Leprosy and TB/HIV Prevention and Control Program manual fourth edition, 2010).

2.2Overview of Leprosy in Ethiopia

2.2.1 Leprosy in Ethiopia

Mesele (2005), documented that leprosy might be the most ancient disease in Ethiopia.it arise in relation to the long distance trade and other cultural relations with leprosy-ridden Regions of the world.

German leprosy and tuberculosis relief association GLRA (2015) report shows that in Ethiopia from 1983 to 2014 there are 541,892 new leprosy cases were detected. Of the above new cases, 13,219 were cases with grade 2 disability. The document also shows 3,758 new leprosy cases were detected in 2014 and 384 of the cases were come up with grade 2 disability.

Kindu (2013) and Sileshi (2015) reported that although leprosy was treated in different ways in Ethiopia, from 1983 onwards government launches multidrug therapy as acceptable way of leprosy treatment. Consequently, tremendous change has been registered regarding the prevalence of leprosy thus Ethiopia accomplished WHOs elimination of leprosy from public health problem.

The above stated authors clarifies the statistics could not signify the prevalence of the problems in the country. It represents only those who were actually diagnosed in the health centers. There might be many cases that were not detected particularly in rural areas where there is a limited basic health care service which contribute to the case. On the other hand, because of low level of awareness on the causes, transmission and treatment of the disease, people might not go to the health centers even if the health services are accessible to the community.

2.2.2 Beliefs towards leprosy in Ethiopia

The early notions of leprosy in Ethiopia were wrought by religious and traditional attitudes towards the cause and cure of the disease. Mesele (2005) see the religious view in two domains, the first is the Muslim dominated areas, which highly ostracized leprosy patients. And the Ethiopian orthodox dominant areas, although there were high social ostracism especially in marriage case, leprosy patients were treated with special veneration and sympathy.

The traditional views that highly influence the outlook towards leprosy were society's believe about the cause of leprosy for instance shock from the devil, adultery by moonlight, intercourse during menstruation or even hereditary. In addition there were popular beliefs about the cure of leprosy including miraculous and herbal cure (Mesele, 2005).

2.2.3 Social participation of persons affected by leprosy in Ethiopia

Documents that the researcher reviewed indicated indicates in the earlier time leprosy affected people experienced social participation restriction mainly in marriage state and church affair's. Leprosy affected people mostly treated by society in sympathetic and charity manner. In addition there are documents that indicate leprosy affected people are experiencing social participation and thus they are tending to have their own groups.

Mesele (2005) documented that Christian society have had sympathetic approach towards leprosy patients. Besides there were significant ostracism in the case of marriage. In addition leprosy affected people were not allowed to participate in church and state affairs. On the other hand leprosy affected people were settle near districts of courts and they receive permanent charity from the rulers. There was no segregation of persons affected by leprosy till 1901.

The above stated author also documented that the first leprosy leprosarium was established in 1901.The permanent segregation of leprosy patients were the result of missionary activity and the awareness of the infectious nature of the disease. The early proponents of segregation were driven by fear of contagion of leprosy.

The establishment of leprosarium can be marked as new relationship among leprosy affected people and the rest of Ethiopian society. The relation can be characterized as the dwellers nearby leprosarium were maintained restricted interaction or even attempts to banish the leprosarium. On the other hand government follows strict segregation policies and leprosy affected people were forced to leave their land of birth and joined different leprosy colonies. By then Leprosy affected people forced to lose their means of support. They also experienced denying of property ownership (Messele, 2005).

The same author documented that the last decade of 20th century as the end of leprosarium and the beginning of reintegration of persons affected by leprosy into their corresponding society. But even today persons affected by leprosyhave limited social participation.

Melake (2008) and Yohans (2014) reported that leprosy affected people are isolated from participating in formal or informal community gatherings. Thus they are tending to form their

Owen gatherings. They are also neglected from participating in various social engagements like Idder, cultural and religious festivity.

2.3. Implication of leprosy on leprosy affected people

2.3.1. The challenges of PALs related to the physical consequence of leprosy

Leprosy complications can cause gross deformities of the face and limbs of affected individuals as well as crippling disabilities involving sight, touch, and manual dexterity. This could intensify stigma and discrimination and leads to social and economic isolation of leprosy affected persons (Mimi, 2015).

The above stated author reported that all participants were concerned about negative comments from others because of their different appearance, skin patches, physical deformity, and disabilities. They themselves, as well as their families and community members regards their different appearance as something negative, labeling it, and marking/characterizing them by it. This may have a negative implication on their lives, limiting and restricting their social participation, making it difficult to assert their rights and satisfy their basic needs. The participant also reported facing social exclusion due to stigma.

The study conducted in Brazil and Cameron also reveals that physical deformity causes stigmatization and dismissal from work on leprosy affected persons. Social contact with leprosy patients was mostly avoided by majority of participants. This is because of the belief that patients with clawed hands and feet and other deformities were still infectious and as a result many people refuse body contact with PAL(Nsagha, 2011).

2.3.2 The implication of leprosy on marital relationships of PALs

Mesele (2005) reported that being leprosy affected person or even have association with them may cause difficulties in getting married or cause separation or divorce. Let alone leprosy affected persons themselves, having leprosy affected family member meant marital isolation for the whole member of that family.

The study in Cameron carried out by Nsagha(2011), shows that PALs are abandoned by their spouses because of they are diagnosed with leprosy and they have deformity and disability. And some of the PALs left their spouse because they are diagnosed with leprosy.

Study conducted in Nigeria and South Africa shows that Long period of hospitalization and stigmatizing deformity related to leprosy is identified as most important Couse of divorce among affected people (Awofeso, 1995 & Scott, 2000).

The unmarried persons affected by leprosy stated that their disease was a hurdle in their marriage. Their parents were worried if they will able to get married even after the cure of the disease (Kumar, 2011).

Kindu (2013) reported In Ethiopia research results shows that that the stigma of leprosy does have an impact on marriage for leprosy-affected individuals and also on the marriage prospects of relatives. Either the society does not allow marriage with these people and their families due to the community believes that leprosy is curse of God and societal fear of contagion or being infected.

2.3.3 Implication of leprosy on employment of PALs

Leprosy related disability and, the chronic symptoms of untreated leprosy often afflict individuals in their most productive age of life. It bound them from fulfilling their normal roles

in society. It is mostly reflected on persons who engaged in physical-based employment (Yohans, 2015).

Joy Rafferty (2005) reported that leprosy affected people lose their employment because of their disease, the disabilities associated with leprosy and negative attitudes of employers (discrimination). When this happens, they lose the means of supporting their families and often the respect of their communities. Thus there can be severe financial burdens to bear.

ENAELPs (2012) reported that due to the established societal misconception and low public awareness leprosy affected people in Ethiopia are highly discriminated and neglected from basic socioeconomic services and life opportunities. Consequently, more than 95 percent of leprosy affected people are living under extreme poverty and leading the worst life.

ENAELPs(2001) reported most PAL in Addis Ababa are migrants from rural areas and they were predominantly agrarian before the onset of the disease, then they shifted to small income generating activity and begging because they lost their properties back home as they can't engage in farming due to leprosy related physical impairment . Begging is the major source of income for more than 27 percent of the settlers.

Holding the same idea Yohans (2015) reported that Leprosy patient had large tracts of land and other prosperities in their birth place. Most of them are left what they have there and migrated far from their home of origin. It is mainly due to, fear of stigma. Most of them prefer to be dependent on others, instead of facing rejection and exclusion in their own community.

In addition Yohans (2015) reported leprosy affected people are known to be highly disadvantaged in the job market .It is uncommon to see equal job opportunity given to those people affected by leprosy and those who are not affected. In this reared, leprosy affected people often suffer from unjust treatment while they are applying for a job.

2.4 Stigma and stigma in leprosy

Stigma is a Greek word that in its origins referred to a kind of tattoo mark that was cut or burned into the skin of criminals, slaves or traitors, to visibly identify them as blemished or morally polluted people. These individuals were to be avoided, particularly in public places (Frist, 2003).

The word was later applied to other personal attributes that are considered shameful or discrediting. In relation to health, stigma was defined by Erving Goff man as an attribute that signifies an individual as different from 'normal' people and, further, that the person is of a less desirable kind in the extreme, a person who is bad or weak (Frist, 2003).

ILEP (2011) explain the impact of stigma on the lives of people who have health problems, such as leprosy and identified four domains in which stigma impacts on the lives of people: emotions, thoughts, behavior and relationships. These domains are interconnected and manifest themselves in different degrees, at different moments, and in different contexts. The first domain contains feelings such as "fear, grief, depression, shame, guilt, anxiety, low self-esteem, hopelessness and anger, or inability to express such feelings". The second domain describes the impact on thoughts in particular the "negative and pessimistic thoughts and beliefs about self, the world and the future" Emotions and thoughts influence the way people react and behave and can result in lack of confidence, avoidance, withdrawal from social life, and self-isolation. These elements are part of the third domain: behavior. Finally, the strength of the person's social support network and the attitudes of people in the network are important in the experience of stigma. The impact on the final domain, relationships, is described as "rejection, forced isolation and restricted social participation.

CHAPTER THREE

3.METHODOLOGY

3.1. Study Design

This study intended to uncover the experience of persons affected by leprosy. To this end the selected study design is exploratory type of qualitative case study.

In order to have comprehensive information on the study subject it is very important to use a qualitative methods. In addition, qualitative method enable the researcher to integrate participants' experience and perspective about the study subject. Accordingly, this study utilized qualitative method because; the focus is to uncover the experiences of persons affected by leprosy. Yin (2011) summarize the above stated ideas as follows "Qualitative method allows the researcher to collect, integrate, and present data from variety of sources, and it also allows to explore the views and perspectives of participants about their own performance of every day role in social, institutional and environmental contexts they lived in (p. 83)."

Exploratory type of research remain valuable instrument to grasp large data especially when the study aims to become familiar with issue least dealt out Kreuger & Neuman, (2006). Thus, exploratory approach is utilized in this study because the researcher only intends to uncover detail information about the study subject.

Case study allows investigator to retain the holistic and meaningful characteristics of contemporary phenomena and real life event desire to understand complex social phenomenon Yin, (2003). In this study the researcher decide on using case study approach consequently, it gave a wide opportunity to explore the unique and multidimensional experience of the targeted population of this study.

3.1.1 Study Paradigm

The way an individual views the world depends on the persons' paradigm. Hence, the world is how we view it not like as it is. For that reason it is vital to make clear about the philosophical assumption of the researcher.

The researcher believes there is no social problem that is entirely exists rather; it is a people's conceptions and interpretations of representations in particular contexts. So that the researcher believes researches on human experiences need to relay on participants' own meanings and explanation. Accordingly the researcher chose to investigate the questions prepared to guide this study by using qualitative methods. Thus In-depth interview and focus group discussion has been selected as best methods of data collection to dig out participants' experience.

3.1.2 Sampling procedure and Study participant

3.1.2.1 Sampling procedure

In this study the target population was 220 (male=125 & female=85) persons affected by leprosy who are members of Dessie area ex-leprosy patients association located in Amhara regional state south wollo zone, Dessie town. However, In order to understand and illuminate the case, there was a need to select information-rich cases.

In qualitative research having samples that will yield the most relevant and plentiful data is the main reason for selecting the specific study unit. Accordingly, the samples are chosen in a deliberate manner known as purposive sampling.

Patton (1990) states, the relevance of using Purposive sampling technique in such studies as follows "it allows cases election involves explicitly and thoughtfully picking cases that are

congruent with the study purpose and that will yield data on major study questions (p.197)". Therefore, in this study participants selected by using purposive sampling technique.

To select the in-depth interview and focus group discussion participants the researcher communicates the objective of this study and inclusion criteria with pre-identified community gatekeepers and Dessie area ex-leprosy patients' association officials.

From the above mentioned 220 target population, 133 members were excluded since they cannot meet the inclusion criteria set by the researcher.

Accordingly, the researcher manage to locate 83 potential participants and among them (12) twelve in-depth interview participants and (8) eight focus group discussions participants were selected.

3.1.2.2 Study participants and inclusion criteria

Study participants

The participants of this study were 20 persons affected by leprosy who are members of Dessie area ex-leprosy patient's association located in Dessie town. Among them, 12 persons affected by leprosy were in-depth interview participants and the rest were participated in two focus group discussions.

Inclusion criteria

- Having leprosy related grade 2 disability
- Having visible leprosy related skin condition
- Being above 18 years old
- Being volunteer to participate in this study

In order to make sure the research participants are drawn from different social strata; gender, marital status, religion, source of income and educational status has taken in to consideration in addition to the inclusion criteria.

3.2 description of the study area

This study conducted in Dessie city administration located in the south wollo zone Amhara regional state. Dessie town has ten sub-cities and six rural Kebeles. In 2008, Dessie town has a total population 203,095, of whom 102,783 male and 116,039 females (Dessie city administration socio-economic annual plan, 2008).

This area is selected purposely because of the existence of relatively high number of leprosy affected people due to the presences of Boru Meda hospital during the preliminary assessment.

3.3. Data collection techniques

3.3.1. Observation

Critically observed and recorded Observation provides firsthand information and enables in-depth views into the issue under investigation. Accordingly, the researcher implemented observation to have information about the physical conditions (disability status) of the participant. Observation checklist has been prepared to cover the themes to be observed during the fieldwork. Based on the checklist that was prepared during proposal development the researcher has observed the physical conditions of the participants. The researcher was taking notes at times of waiting for in-depth interview.

During the interviews the researcher manages to made observation on the disability status of the participants thus, the researcher recorded the disability status of participants in addition to the information gathered through in-depth interview.

The researcher also be able to observe participants while they are performing household activities before and after the interview, accordingly participants' regular performance has been recorded.

3.3.2. In-depth interview

Interviewing is by far the most commonly used method of data gathering for qualitative studies due to the reason that it enables the researcher to get in-depth information about the experience of the informants. "It enables the researcher to clarify meanings of participants' action and behavior through informal conversation, and chatting with participant or through posing semi structured and structured open ended questions (Heather &Martyn, 2004)".

In this study the researcher utilized In-depth interview to gather data form the participant. The researcher engaged with participants by posing questions in a neutral manner, listening attentively to participants' responses, and asking follow-up questions and ask explanation on responses needed clarification.

Semi structured interview guides has been prepared to cover the main themes of the research question during in-depth interview with participants.

All interviews were conducted using Amharic language and were recorded making hand-written notes and by audiotaping. Consequently, the researcher accomplished obtaining and recording everything the participant understood about the research topic. In depth interviews was

done from March 28, 2016 to April 20, 2016. Duration of Interviews with the participants has taken from 39 minutes to 119 minutes.

3.3.3 Focus Group Discussion

Focus group discussions (FGDs) allow group interaction in which participants are able to discuss each other's ideas that provide better insight to the issue under investigation which is not easily attainable through individual interview. This method offer the researcher opportunities to study the ways in which individuals collectively make sense of a phenomenon and construct meanings around it (Bryman, 2004). Thus, two focus group discussions were conducted five persons affected by leprosy were participated in each focus group discussions. Two of whom were participated in individual in-depth interview. In order to monitor the focus group discussion structured open ended guide has been prepared and the researcher participate by facilitate the discussion. The focus group discussions were held in offices obtained from Dessie area ex-leprosy patients association on April 10 and 14. The discussions were conducted in Amharic was audio taped and took an average 150 minutes.

3.3.4 Document review

To collect secondary data different printed and electronic documents which are related and relevant to the study has been reviewed.Published and unpublished materials including books, magazines, journal articles, electronic materials and progress reports are documents that have been reviewed.

3.4 Source of data

This study utilized both primary and secondary source of information. Primary data collected through in-depth interview and focus group discussion with 22 purposely selected

persons affected by leprosy. On the other hand, secondary data obtained from Published and unpublished materials including books, magazines, journal articles, electronic materials and progress reports.

3.5 The Process of Data Collection

The process of data collection had initially started after the approval of the proposal by the School of Social Work. After that the researcher has taken the support letter to Dessie area ex-leprosy patients association. After that the researcher gave the letter from the school to the chairperson of the association's. From chairperson, the researcher gets the number of persons affected by leprosy who are members of the association. And those who met the inclusion criteria have been identified. Currently working on the project and the days they are available in the courts. On March 18, 2016 the researcher started the data collection from the key informants and ended on April 20, 2016.

3.6 Data analysis

The aim of data analysis in qualitative study is decreasing and organizing the data in to specific themes in order to explore participants experience in social and historical contexts out of the data. Thus findings can be interpreted in a meaningful way. In addition Data collection and analysis must be a simultaneous process in qualitative research (Creswell, 2009).

In this study data generated from the in-depth interview, observation, focus group discussion and document review analyzed thematically by Compacting extensive and diverse raw data into a concise structure then major issues generated by the participants were detected and identified. In addition the identified themes were linked to each other.

Alhojailan (2012) states the relevance of thematic analysis in qualitative study as follows:

> *Thematic Analysis is considered as the most appropriate for any study that seeks to discover human experience by using participants own interpretation. It is capable to detect and identify factors or variables that influence any issue generated by the participants Alhojailan, (2012, p. 6).*

In order to scrutinize, categorize, and organize the masses of raw data acquired during the data collection phase the researcher employed various processes. Side by side with the voice recording of the interviewee, nonverbal clues (silences, laughter, coughs, and crying) were recorded on the field notebook. Immediately after the interview, the researcher listens each recording over and over again and read field note. Accordingly, the researcher manages to capture the stories properly.

Next, the recorded interviews were transcribed into written forms (Amharic) and the transcriptions were translated to English. Next, significant statements and phrases connected to the issue being studies are extracted from each transcript. Meanings are then formulated from the significant statements. Then the meanings are organized into themes, and these themes evolve into theme clusters, and eventually, into theme categories that are related to research questions. A color coded system has been used to highlight specific themes/categories to perform a preliminary analysis.

Then, the researcher writes description of the lived experience of participants. This description presented in the findings section.

3.7 Trustworthiness

Building trustworthiness in qualitative study aims to carry out the study based on explicit evidence and conduct the study in a manner that other peoples can review, examine, understand and inspect both the finding and the conclusion of the study and the evidences used to support the finding and the conclusion of the study. In addition, avoiding unexplained bias and deliberate distortion is another important reason for building trust worthiness (Yin, 2010).

Although, participants selected by using pre-identified criteria and consult with gatekeepers (elite informants), to avoid inaccurate or insufficient data or misled , the researcher used her judgment based up on the best available evidence to choose subjects who know enough, can recall enough, and are able to responded precisely to questions asked.

In addition, to avoid deliberate distortion, each participant who is approached given an opportunities to refuse to participate in the interview and encouraged to be frank from the outset of each session so as to ensure that the data collection sessions involve only those who are genuinely willing to take part and prepared to offer data freely.

On the other hand, to avoid the influence of the context under which the data are gathered, physical and social environments will be taken in to consideration.

3.8 Ethical consideration

The researcher believe that there should be ethical issues that needs to be considered for instance privacy, confidentiality, informed consent and informants should not be misled.

Heather & Martyn(2004A) documented six special ethical responsibilities of social workers engaged in research as follows; protecting the privacy and dignity of research

participants, obtaining informed consent for participation, protecting research participants from unwarranted discomfort, distress, harm, danger or deprivation, ensuring anonymity and/or confidentiality of research participants and data, reporting research and evaluation results accurately and objectively and storing research material securely and for the required period (Heather & Martyn, 2004).

To this end Consent forms prepared and provided for the participant to get their consent for participation. In addition the objective of the study as well as their right to continue or withdraw their consent before or during the study was explained. And appropriate setting or environments has been selected to avoid discomfort during the interview. In line with that the researcher has explained verbally to the participants and key that an audio tape is going to be used to ease the process of data analysis. Anonymity and confidentiality was protected by not using the name of the participants

The information gathered from the participant utilized for the original purpose and will be discarded appropriately after the completion of the study.

CHAPTER FOUR

4. DATA PRESENTATION

The finding section encompasses five different sections and it begins by providing a brief description of participants' profiles and then proceeds to its main task of presenting the findings of this research.

4.1 socio demographic background of study participant

The first section is Socio-demographic back ground of the study participants this part presents descriptions of the demographic and other characteristics of in-depth interview informants and focus group discussion participants' of this research .

All of the entire in-depth interview informants are persons affected by leprosy and have leprosy related grade2 disabilities. To meet the inclusion criteria the disabilities were graded using the grading system of the WHO, which includes those who have visible impairments in eyes, hands, and feet. In terms of sex, five of the informants were female and seven of others were male. Their ages ranged from 36-78years old. In terms of marital status, one was widowed, seven were married. Four were divorced. In terms of educational status, one of the informants completed grade 10, one dropped at grade 3, one dropped at grade 6, and the rest of informants' were illiterate. Regarding to sources of income three of the informants engaged in begging and one lived by support from the neighbor community and the rest eight engaged in income generating activities. The informants lived in the area from 12 – 50 years.

When we see participants access to social service all participants reviles they have access to health service they get the service they needed from Boru Meda hospital and

*Buwanbuha*health center. And they confirmed there are governmental primary and secondary schools around.

When we see the housing conditions of the participants, all participants confirmed they have their own houses which have three rooms and they mentioned German TB and leprosy relief association built their houses. And all participants have accesses to tap water, electricity and communal toilet.

Table 1: Description of in-depth interview InformantProfile

Respondents' code	Sex	Age	Age during the onset of the disease	Marital status	Educational background	Source of income prior to the onset of the disease	Current source of income	Level of deformity
Respondent 1	M	68	20	divorced	Illiterate	Farming/animal husbandry	Mill hands	Claw in right hand, Loss of toes and skin fragment
Respondent 2	M	66	15	Widowed	Grade 3	------	Pity tread	Loss of fingers in both hands loss of toes
Respondent 3	M	60	21	Married	Read& write	Farming	Mill hands	Facial deformity and Claw in left hand
Respondent 4	F	40	17	Married	Grade 6	Maid	Gulit	Facial deformity, lost sensation in both hands

								and loss of right eye
Respondent 5	F	70	30	Divorced	Illiterate	Farming / house wife	Support from neighbor	Facial deformity and loss of toes in both legs
Respondent 6	M	60	10	Married	Illiterate		Animal husbandry/ urban gardening	Facial deformity and loss of toes in both legs
Respondent 7	M	70	21	Married	Illiterate	Farming	Gulit and family support	Claws in both hands and loss of toes
Respondent 8	M	44	19	Married	Grade 10	Farming	Mill house employee & farming	loss of toes in both legs and claw in right hand
Respondent 9	M	69	25	Divorced	Illiterate	Construction machinery operator	Begging	Loss of fingers in both hands and loss of toes in both legs and facial deformity
Respondent 10	F	60	28	Married	Illiterate	Daily labor	Begging	loss of toes in both legs and facial deformity
Respondent 11	F	36	24	Married	Read and wright	Waitress	Daily labor	loss of toes in

								both legs
Respondent 12	F	78	30	Divorced	Illiterate	Farming/ housewife	Begging	Loss of fingers in both hands and loss of toes in both legs and facial deformity

On the other hand focus group discussion participants were persons affected and have leprosy related disabilities. And they all are living in the study area. Two of them are female and the rest eight are male. Related to educational status one of them have diploma, five of them are grade 5- 10, two of them read and write and one of them was illiterate.

Participants' code	Age	Sex	Marital status	Educational back ground	Source of income	Level of deformity
Participant 1	73	M	Married	Grade 10	Pension and family support	Claws in both hand and loss of toes in both legs
Participant 2	68	M	Married	Diploma	Government employee	Facial deformity
Participant 3	46	F	Married	Grade 8	Daily labor/Gulit	loss of toes in both legs
Participant 4	50	M	Married	Read and write	Daily labor	Facial deformity Claws in both hand
Participant 5	53	M	Married	Grade 5	Gulit	Facial deformity loss of left eye
Participant 6	44	M	married	Grade 10	Mill house employee	loss of toes in both legs and claw in right hand
Participant 7	70	M	widowed	Illiterate	Gulit	Claw in both hands
Participant 8	40	F	Married	Grade 6	Gulit	Facial deformity, lost sensation in both hands and loss of

						right eye
Participant9	60	M	Married	Read and write	Mill house employee	Facial deformity and Claw in left hand
Participant10	63	M	Married	Read and write	Daily labor	Facial deformity Claws in both hand

Table 2: Description of focus group discussion InformantProfile

4.2Challenges of executing daily household activities while having leprosy related physical impairments.

This major theme emerged from participants' experience related with executing daily household activities. And it presents experiences of participant related to restrictions they face in performing daily house hold activities. Subthemes included under this major theme are burn injury and wound /blister/

4.2.1 Burn injuries

As per the data obtained from all in-depth interviewees and focus group discussion participants of this study, the huge implication of leprosy is that, the fact that it left them with various types of physical impairments. Impairments give rise to limitations of activities involving the use of hands and feet.

It was stated by almost all participants, leprosy cause substantial damages and loss of sensations in their hands. Which exposes them to injure themselves during daily household activities for instances, cooking. Loss of sensation in their hands affect their ability to feel heat and pain therefore, they got burn from direct contact with hot liquids or surfaces or open fire.

Respondent 4 is 40 years old, she is originally from Sekota. She came to Dessie in search of treatment. She became the victim of leprosy at age of 17. The disease damaged her right eye and face, and claws her hand. Related to burn injury she told the researcher:

I have loss of sensation and claws in my hands. Consequently, cocking without having burn is the hardest thing among the daily household activities. I told you already I have been a maid prior to my hands claws gotten worse. I got burn over and over again during me baking Enjera. I couldn't keep safe distance from the flame hence, I haven't felt the heat or pain in my hands. That cost me my finger. If it would have been today, I thought, I will be fine. Now I learn different ways to protect my hand. "

The other in-depth interviewee, Respondent 2 who is 66 and originally from Delanta he came to Dessie 43 years ago in search of treatment. And now he is widowed living by himself. He retail plastic shoes in open market (GULIT) for living. He told the researcher, he have lost all his entire finger due to leprosy and lost sensations (the researcher also observed he has no finger at all) as a result; he got burn for several times from direct contact with hot water or surfaces of hot casserole or open fire. Nonetheless, he learned doing things differently through time and able to cook without burning himself. He states:

Even if I lost all my fingers in both hands, I have to cook and feed myself ever since my wife died long time ago. Consequently, I have to hold utensils, and sharp objects by using my palms. The hardest of all this is using hot water and fire without hurting myself. I have hired a woman who bakes Enjera 50 birr per month because I couldn't do it without burning my hand. But then again, I still have to cook the sauce. I sometimes couldn't avoid burn although, cover my hand with strip of cloth and inspect my hands recurrently. As I told you already, I have to use warm water to soak and clean my hands and feet to avoid further dryness and wound. Sometimes it is hard to see if the water is safe to use or burning me because I can't feel heat because of loss of sensation in my hand. However, I don't want to feel like I am not able to do things thus, I learned to

perform tasks without injuring myself like other people and somehow I think I succeeded."

All Participants of focus group discussions also share the experience of respondent2. They reveal exposing themselves for heat and fire is extremely dangerous for the reason that, unlike other people they can't sense the hotness or coldness of objects unless they see or think about the possibility of danger while they cook or use warm water. And yet, they learn to cook while they have multiple deformities in their hands, and mitigate the possibility of injuring themselves

4.2.2 Blisters/wounds

The data obtained from in-depth interviews and focus group discussions reveals they have limitations doing household activities. For the reason that, repeated rubbing of the anesthetic skin on their hands and feet against hard surfaces of tools causes wound and blister. Although, this cause repetitive pressure and pain on the skin they are unable to feel it due to the loss of sensation related to leprosy. Eventually, they develop blisters and wounds. Though, almost all of in-depth interviewees and focus group participants argued they learn to manage injuries on performing daily household activities.

Related to this respondent 4 told the researcher she got blister while she is cooking:

It happens a lot when I try to chop of onion, cabbage and potato with unpadded knife. As I told you already, my hand lost sensation of roughness or pain due to leprosy. Accordingly, my hand rubs back and forward over a hard and sharp surface of the knife. I don't even feel the friction between my hand and the knife thus, there is no way I

possibly will know I am hurting myself. Eventually, I see my hands and I come to know I am developing blisters."

Other in-depth interviewee respondent 8, he is age 44 and mill hand originally from north Gondar. He came to Dessie in search of treatment. He has lost his toes and loss of sensation in his feet due to leprosy. He has multiple wound and ulceration in his feet because he developed injuries from hard objects that trapped inside shoes or sharp objects that have pierced through the sole. Respondent 8 told the researcher,

As you see I have lost all my toes and lost sensation in my feet. Initially walkingaround without hurting myself was difficult, let alone executing household activities. I got wound from thorn and stone trapped inside my shoes. I couldn't feel and remove it soon thus it stabbed my feet. When I takeoff my shoes I found out I was bleeding. Through time, I learn to walk using special footwear, and avoid injuries and controlled ulceration in my feet. Most importantly I can walk around, look after my sheep, fixing fence, and other household activities like everybody else as long as I check my feet recurrently and avoid injuries. I would like to think I can do everything as normal people do. That makes me happy and sometimes I forget I have deformities."

4.3 participants' experience of marital relationship regarding leprosy related stigma and discrimination

This major theme emerged from participants' experience regarding challenges/divorce on their marriage due to leprosy and restrictions/discrimination they used to experience in getting married. The finding depict leprosy cause substantial challenges in their marriage mainly divorce

and it also cause restriction in getting married unless they marry their ‘own kind’. Four Subthemes and nine codes are included under this major theme.

4.3.1 Divorce due to fear of leprosy transmission

This subtheme includes participants’ experience of divorce due to their spouse, in-laws and families fear of catching leprosy from them. Code included under this subtheme is fear of catching leprosy.

The finding shows all in-depth interviewees’ and focus group discussion participants’ who was married prior to the onset of the disease asked divorce by their spouse because their illness happened to be leprosy.

Three focus group discussions participants told the researcher persons affected by leprosy who were married prior to the onset of the disease face problem in sustaining their marriage. They forced to divorce their spouses and leave their home and children because they requested either by their spouses and in-laws’ or by their own family.

Two respondents support the above stated ideas; they told the researcher they were married and have children prior to the disease. However, when their spouse and their own family found their disease is “TILIQU BESHITA” (leprosy), they forced them to divorce and leave their children either with their husband or their family.

Respondent 1 is age 68; he was originally from Delanta and came to Dessie 48 years back in search of treatment. He was married and a father of two prior to the onset of the disease. However, when he went home after 1 year of hospitalization, his wife asked him to divorce her and took their children with her. Regarding their divorce he told the researcher:

She brought elders home and asked me to divorce her (offffff….. Long deep breath) she asked me never to see my children. Surprisingly, my own families supported her and told me that, I can't have a family anymore. I disputed a lot but it was unfruitful. What could you do??!! Even my own families' were not by my side let alone my wife and in-laws. Then after, I had no choice but leave behind my house and came back to Dessie. However, God never let me down after I came to Dessie I found a woman of my 'own kind' and got married and have three children with her.

When the researcher asks respondent1 the reason for the divorce, he replied:

My wife, families and in-laws were terrified of catching leprosy from me. They both blamed me for letting my own children have my disease and unfortunate fate. I told them I got treatment and I am not contagious anymore but they didn't listen to me. Who cares for a 'leper'?!!

Three Focus group discussion participants supported respondent1's idea, the spouses and in-laws' ask divorce as soon as they knew their spouses and in-laws' had leprosy since they think the disease can be transmitted by living together for a long period of time. To magnify this Focus group participants7 told the researcher: *our spouse, in-laws, and families don't listen to us even if we told them we got treatment and we are not contagious anymore. They avoided any contact with us.*

Respondent 5 share the above idea. She told the researcher that she was married and a mother of two while she knew she had TILIKU BESHITA (leprosy). And soon after, her husband spokes to her family and her elder brother came to her home to finalize the divorce. Regarding to the divorce she said:

My brother told me living together is dangerous for my children and my husband. They will catch the disease. He said it is not God's will for me to live with my family. He took me with him and put me alone in one room. The room use to be byer. My family does not allow me to touch my children. They told my children I am beast and stay away from me. I live for two years like that and until I heard about Boru Meda hospital and came to Dessie."

Focus group discussion participants agreed on fear of leprosy transmission is initiating divorce among persons affected by leprosy who are married prior to the onset of the disease. Focus group discussion participant5 explain the situation as:

There is a fear the 'healthy' spouse and family member think the disease is highly communicable, of course it is communicable but, it's transmission ends as soon as we starts the medication it is curable and it is not going to jump on them. However, 'healthy' spouses and in-laws have a tendency to ignore this fact. This cause persons affected by leprosy lives in this area (Dessie town) including me to experience divorce and leave behind our family and home town.

The researcher understands persons affected by leprosy face divorce due to families, spouses and in-laws are terrified of catching leprosy from them.

4.3.2 Divorce due to spouses' and in-laws' fear of discrimination and insult by adjacent community

This sub theme includes participants experience on divorce due to their spouses, and in-laws' fear of discrimination and insult by adjacent community. Codes included under this subtheme are fear of discrimination and fear of insult.

The finding shows ‘healthy’ spouse, in-laws and family members ask divorce due to the fear that the adjacent community will discriminate and insult them for having ‘leper husband’ or ‘leper family member’. Related to this Two Participants of Focus group discussion and two in-depth interview respondents told the researcher their spouses and in-laws ask them divorce because they afraid of to be said ‘leper’. And they are worried about the fate of the entire family. Regarding this Respondent 1 told the researcher,

> *My wife with whom I had two children left me and took my children with her. She asked me whether I want her to be said leper and amputated. Otherwise, I should divorce her and left my children with her and never back in their lives.*

Focus group discussion participant 7 told the researcher his wife left him as soon as he found out he had TLIKU BESHITA /leprosy/.To explain this he said:

> *Because the neighbors and family members considered the disease as incurable and disabling, she couldn’t bear the rumor. As a result she left me. She said everybody treats her as if she is a ‘leper’ merely for the reason that she is married to me.*

4.3.3. Restriction in getting married due to fear that leprosy is hereditary

This subtheme emerged related to participants’ experience of restriction in getting married due to the community fear that leprosy is hereditary. Code included in this theme is belief that leprosy is hereditary disease.

The finding depicts persons affected by leprosy experienced challenges in getting married due to the community's belief that leprosy is hereditary. Thus, people married to leprosy affected partner will bear a child who has the same disease. However, this is proved to be wrong according to the health/medical perspective.

Almost all participants told the researcher that they experienced big problem in getting married for the reason that, in their respective community there is a deep investigation of the family tree of marriage partners. And this investigation includes whether the family are free from hereditary disease (leprosy assumed by the community as a hereditary disease).

Respondent 2 is age 66. He came to Dessie in search of treatment. He got treatment and back to his home town 30 years back, he tried to get married and failed. Regarding this he told the researcher: nobody gives him to marry his daughter because they are afraid of mixing their lineages with 'leper'. He says:

> *Once my brother found a girl for me in our locality and my uncle with elders went to her family to betroth. The girl's family refused the marriage. They check on me and found out I had leprosy they called it KUMTINA. They don't want to be called seeds of 'leper' or mix their lineage with 'leper'. Eventually, I understand the 'healthy' people don't allow me to marry even if the disease doesn't exist in my family. Thus, I left my family and home town and came to Dessie. I never went back or seen my family since then. Nonetheless, Allah never let me down. After I come back to Dessie I met girl who is my 'own kind' and we got married, have two children.*

Respondent3 magnifies restriction in getting married because of spouses' and families' fear that leprosy is hereditary disease as*:*

I never saw persons affected by leprosy and healthy people getting married because the community believed leprosy is hereditary disease which is very wrong. Leprosy is not hereditary the doctors and nurses told us it is not hereditary and it is curable.

The researcher understand spouses' and families' wrong belief about leprosy is a hereditary disease cause discrimination and limits marriage between almost all participants who were single prior to the onset of the disease and 'healthy' marriage partners .

4.3.4 Restriction in getting married due to the communities' fear of leprosy transmission

In this sub theme emerged related to participants' experience of restriction in getting married due to communities' fear of leprosy transmission. Code included in this subtheme is fear of leprosy transmission from leprosy affected person to his/her spouse.

The finding shows people fear catching leprosy so that they avoid intimacy with them. And the fear turn out to be grave in the case of having marital relationship with persons affected by leprosy. Regarding this two participants ratifies although they ended up getting married to non-leprosy affected spouse, they never thought getting married to 'healthy spouses' and everyone around them were not supporting the marriage. Respondent8 explain the situation as:

I never tried to get married with healthy women. Everyone around me including my families told me I can't marry healthy woman for the reason that the disease is transmissible. However, the doctors told me after I got the treatment I am no longer infectious. Eventually, I left my home town and came back to Dessie. Once government beat off non leprosy affected people from Boru Meda leprosarium and I met healthy

woman has nowhere to go. To avoid compulsory displacement she became member of leprosy patients association. And I asked her to marry me and we decided to get married. People around even my 'own kind' warned her about the disease. The whole world told her she would loss her hands and legs and becomes a 'leper' but it was God's will she stayed with me and we have four children.

Focus group discussions participants agreed on persons affected by leprosy experience restriction in getting married due to the fear of transmission of leprosy. They told the researcher people think the disease is not curable and the person affected by leprosy is continued to be contagious even after the treatment. However, the doctor told them treated persons are no longer contagious. Related to this focus group discussion participant who is married to non-leprosy affected spouse explained:

My wife used to be a janitor in Boru Meda hospital when we first met. She accepted me and we got married. However, her family found out that I had leprosy, they forced her to leave me. When she refused to do then they told her that she is no longer the family member. And we never heard from them since then.

4.3.5 Restriction in getting married due to spouses' and family's fear of discrimination by adjacent community

This subtheme presents participant experience on restriction in getting married to healthy marriage partner due to 'healthy' people are afraid of discrimination and insult. Codes included in this subtheme are fear of discrimination and fear of insult.

The finding reveals participants experience restriction in getting married because their spouse and in-laws are afraid of discrimination and insult by the adjacent community.

Two in-depth interview respondents and three participants of focus group discussion explain 'Healthy' people do not want to marry Persons affected by leprosy due to fear of said to be descendants of 'leper' as a result, community do not allow the whole family to mix via marriage. To elaborate this focus group discussion participant3 said:

> *To tell you the truth maybe you will live with your leprosy affected family member which you can't do anything about but, there is no way you could allow your 'healthy' family members choose marriage partner who has leprosy. And risk your whole family members to be said 'mixed with leper'. The out group insults the whole family member as the one who can't find marriage partner. Let me tell you one story that a close family member of mine face a while back. He and his parent had leprosy….. He works veryhard thus; he had his own house and millhouse. He decides to marry 'healthy' girl. The decision was between him and the girl then they informed her families. A little earlier to the wedding day, her parent canceled the wedding, although she doesn't want to. Her family said they don't want to be said they mix their lineage with leper. Thus it hurts the moral of the whole family.*

In-depth interview participant agreed on people do not want marry persons affected by leprosy because of the fear that the neighboring community call them 'leper'. Respondent11 is age36. She was single prior to the onset of the disease. She explained the situation as:

> *Even if healthy person want to marry us (persons affected by leprosy) the rest of the family do not allow the marriage because they afraid the sarcasm and rumor/insult/.*

If 'healthy' men marry me the neighboring community thinks of him and his family as 'leper', this will hurt the fate of other family members. Thus, 'healthy people don't want to marry us (persons affected by leprosy).

4.4 participants experience related to their social participation

This major theme emerged from participants' experience related to their participation in social events like wedding, mourning and religious festivals and membership in local informal association like *Idir, Mahiber and Ekub.* Two Subthemes and four codes are included under this major theme.

4.4.1 Participants' membership in local informal organization

This subtheme emerged from participants' experience of membership in local informal organizations. Codes included under this subtheme are participants' membership of Mahiber, Idir, and Ekub. And limitation of roles in Mahiber, Idir and Ekub.

The finding shows participants are members of *Idir, Mahiber and Ekub.* They did not face restriction in getting membership. However, two participants (respondent9 and respondent10) told the researcher that they are not members in any local informal organizations because of economic problems.

Regarding the roles they (participants) played in those local informal organizations most (ten) of the respondent agreed on they had limited roles due to different reasons. The first reason is other members don't consider persons affected by leprosy are capable of doing tasks because of their deformities. Elaborating this idea respondent5 explain the situation with a very tiresome voice as: *the neighbor community with whom we form Idir and Mahiber don't like us to take part in tasks because they think we are not capable because of our deformity.*

Nevertheless, three male and two female respondents told the researcher although, they don't experience restriction in becoming member of Mahiber and Idir but they have limited role because they are unable to execute tasks. Due to this they choose to stay at home. Respondent12 explain the situation as:

> *I choose not go out because I have difficulties to walk long distance. So I have limited roles in our Idir. I simply send the contribution and stay at home. There is penalty if Idir members are absent in mourn or monthly meeting however, they/Idir leaders/ are kind they exempt me from the penalty.*

Inconsistent to that the other participants complaining about the restricted roles in informal local organizations two respondents told the researcher they don't experience restriction in becoming members of Idir and Mahiber and they used to be among the leaders. Respondent7 said:

> *I used to be the chairperson/Idir dagna / and when I finished my term after serving more than ten years they prized me for my service. So we /leprosy affected people/ are not restricted from having significant roles in Idir, Ekub and Mahiber as long as we are capable as healthy people.*

Adding an example on this Focus group discussion participant2 said:

> *We/ leprosy affected people/ restrict ourselves from being significant in Idir, Mahiber and Ekub. We make ourselves busy thinking about what other people will say. We feel embarrassment about our self and allow others to humiliate us. I think that is how we became stranger in front of Idir and Mahiber members.*

The researcher understand that participants are able to be members in local informal organization however, they play limited roles due to two reasons, the first one is other members of informal organizations don't believe persons affected by leprosy are capable of executing tasks because of their deformities. On the other hand, some of the participants choose not to take roles due to their physical impairments.

4.4.2 Participants' engagement in social events

This subtheme developed from participants' experience related to their engagement and roles in social events. Codes included in this subtheme are invitation to wedding and religious festivals, attending funerals, and roles in executing tasks in wedding and mourning.

All participants confirmed that they are engaged in social events like wedding, mourn and religious festivals. However, their participation is limited.

All female respondents told the researcher although, the community in the adjacent area invites them on wedding ceremonies they were never allowed to participate in the preparation of foods and beverages while all the 'healthy' women requested to do.

Three female respondents explain restriction in social engagements as, the adjacent community doesn't allow them to contribute in preparation of food and beverage prior to the wedding day which all neighbor women supposed to take part. This is because; the community discriminates against them because persons affected by leprosy presumed as incapable of performing activities like any other person. To magnify the situation Respondent4 told the researcher:

The neighboring community invited me forweddings. I never went empty handed I always buy something as gift for the groom and bride because I don't want them to see

me as a minor. However, most of the time I try to help with activities like cooking, they don't seem happy, they(the community) give me other tasks which a nine years old girl can do. That makes me very sad. And now I stopped asking to help them.

Most participants of focus group discussions support the above in-depth interview participants' idea. They confirmed that persons affected by leprosy participated in social events however; the community invites them simply to attend the event not to take part as 'healthy' people do. To elaborate this focus group discussion participant1 says:

In times of wedding they invite us (persons affected by leprosy) in to the ceremony/to eat/ but they want us to sit tight. They (healthy people) do not feel comfortable to eat or drink with material I washed using deformed hand.

On the other hand, according to some respondents (respondent3, 2, focus group discussion participant3) the adjacent community allows leprosy affected people to engage in all social events but sometimes there are things the community doesn't let them do because of sympathy. Explaining about the sympathy of the community for persons affected by leprosy Respondent2

As you see I have deformities' in my hands and if I say I have to serve the food and beverages in wedding ceremonies it would be rude because I ended up ruining the program. Consequently, people don't ask help from me and other person who have hand deformities like me because they feel sympathetic for us.

Two focus group discussion participants agreed on the above idea. According to them persons affected by leprosy got invitation for different social events and they take part in it like

'healthy' people as long as they are capable of the task. To add examples on communities' sympathy for persons affected by leprosy focus group discussion participant3 says:

> *We (persons affected by leprosy) are allowed to participate in all events. We attend weddings, mourns, Mahiber, Tezikar. For instance, all Idir members supposed to contribute Enjera if our Idir member or one of their families dies. All Idir members' including us (persons affected by leprosy) goes to funerals and home with the rest of the family. However, I and others who have substantial deformity don't contribute Enjera instead we give ten birr. This is not because they don't like to eat our food rather;Idir members understand we have problems to cook.*

Participant12 didn't agree with the above idea, she told the researcher the neighboring community with whom she has Idir, doesn't let her to contribute *Enjera* because they don't like to eat her food. She explains the situation with frustrated sound as:

> *Why would I lie to you?!! I never contributed Enjera for feasts in mourn because people don't eat it. Even if healthy people don't say in front of me I saw them throw it out. This is because this dreadful disease amputated my fingers and legs.*

The researcher understands that all participants confirmed they are able to participate in different social events with adjacent community. However, their role in the event is limited due to two reasons. Most of the participants confirmed the first reason which is the adjacent community members don't like / stigmatize/ persons affected by leprosy to take part in activities which needs close contacts. As respondent5 explained it: *I will be ashamed to participate like other people do in the companion of healthy people because I feel when other people are disgust with what I touched.*

On the other hand, some of the participants don't agree with the above idea, they confirmed the adjacent community allows them to participate in all social events. And leprosy affected people have limited role in social events only because they have difficulties in executing tasks due to their deformity.

4.5 The implication of leprosy on employment experience of participants

This major theme emerged from participants' experience of challenges in their employment, getting employed and other income generating activities and limitations they face due to leprosy. This major theme incorporated three sub themes

4.5.1 Loss of income due to loss of properties

This subtheme emerged from participants' experience on loss of income due to loss of properties because of leprosy. The finding shows that leprosy affected people face loss of income because they lost their cattle and land ownerships.

Participants gave two reasons for their loss of properties first, the cattle got vanished and the land reallocated for another dwellers since they leave their home town because they can't bear leprosy related discrimination. On the other hand, leprosy affected people be wiped out of their land since they can't perform farming activities due to leprosy related physical impairment consequently, the land reallocated for another dwellers.

Most participants told the researcher formerly they are from diverse places and they came to Dessie in search of treatment. Consequently, they lost their property ownerships which was their sole sources of income thus, they loss their source of revenue.

Five in-depth interviewees told the researcher, they used to be farmer and they support their families merely by farming their land. However, after the onset of the disease they lost their land. Related to these three in-depth interview participants (respondent 1, 5, 6) told the researcher they lost possessions of land and cattle because of their spouse, in-laws, and families forced them to leave their home town. Respondent1 explain the situation with saddened face and sound as:

> *Farming was my only means of support however, after I caught leprosy my wife in-laws and even my own families forced me to leave my home. They said the neighbor community will insult and stigmatize against the whole family because of me. Thus, I had no choice but leave my family and my home. Consequently, I lost my land and cattle so I lost everything I have which I spent my energy for years.*

Focus group discussion participants agreed on. Persons affected by leprosy lost their property because they leave their home due to fear of stigma and discrimination. Focus group discussion participant5 explained the situation as:

> *Persons affected by leprosy abandoned their land and cattle because they can't stand the disgrace from family and neighboring community, they(family members and neighboring community) don't count me as human and they belittle me so I chose to leave without accumulating my property. Meanwhile, I came back home but it was too late the land was reallocated.*

In addition, two respondents (respondent7 and 8) told the researcher they lost the possession because the local government transfer the land to the local residents as a result they became mill hands. Respondent8 the then farmer explained it as:

After this disease impaired my hands and legs I got difficulties' in ploughing digging and any other farming activities thus, I decide to come to Dessie to have treatment and not to engage in farming activities. Consequently, I gave my land to my cousin and we agreed to share the proceeds. I used to support myself with it. However, in 1983 the new government reallocate the land to the local residents.

Findings from focus group discussions also show that persons affected by leprosy experienced loss of income because of the local government reallocates their land. Three focus group discussions participants (4, 5 and 10) explain that they gave their land and cattle for trustees meanwhile they come to Dessie in search of treatment. And after years they found out their land has been transferred to other dwellers. Focus group discussion participant4 explain about this:

When this disease disfigure my face and disseminated I decided to come to Boru Meda hospital (Dessie) so I gave my property to trustees. And after years, I went to my home town and I found out government reallocated the land. Although, I managed to sell some of the cattle, it was nothing if you compared with what I supposed to get.

4.5.2 Restrictions in getting employed due to leprosy related physical impairments and discrimination

The finding depicts participants face restriction in getting employed for two reasons. First, people don't want leprosy affected people to hire and for some persons affected people, the physical effects of leprosy prevent the continuance of physically based employment, which is the main type of employment found amongst the participant.

Most of the participant states employer avoids them from getting employed because of their physical impairment. They explain the situation is worse for leprosy affected people who has wounds in their hands and face. Respondent4 explain the situation with tears on her face as:

> *I have to earn money to stay alive after I flee from my parents' house so I worked as a domestic worker, washing clothes, and cooking. And eventually, my hands became fully claw and develop facial deformitiessince then nobody wants me to work in their house. People avoid me and ridicule me. Thus, I chose to sell charcoal on the roadsides.*

To add another case, Responden9 is 69 years old, this man developed visible deformities related to leprosy, wounds on his hands and feet, and as a result of this he was unable to get work. His income suffered as a result of the stigma of both his potential employers and colleagues as a result he engaged in begging to sustain his life. Respondent9 the then construction machinery operator explain the situation with expression of grief in face as:

> *Prior to the onset of the disease I used to be construction machinery operator. But now I have deformities in my hands and legs due to leprosy thus, when I apply for a job, they label me saying I look as somebody who is looking for charity. They did not look at my application they stare at my body. You should understand me I am not saying I should have the former job. I know I am not capable because of the impairments in my hands and legs but I can do something easy like security guard. However, nobody wants me to hire so now I stopped trying and engaged in begging.*

Focus group discussion participants (focus group discussion participant 5, 7, 8) also agreed on leprosy affected people face restriction in getting income , they claim persons affected by leprosy are engaged in *Gulit* trade however, people don't feel comfortable to buy foodstuff

because they don't like persons affected by leprosy. Focus group discussion participant5 is age 53 he is engaged in *Gulit* trade for living. He sells anion, potato and tomato. He claims some people don't like to buy from him because they disgust with what he touched. To elaborate the situation focus group discussion participant5 continued as:

I have facial deformity thus, some people don't buy vegetables from me because they believed that a person with clawed hands and feet and facial deformities are still infectious.

4.5.3 Income loss due to physical effects of leprosy and discrimination

The finding depicts leprosy affected persons affected by leprosy lose their employment because of functional disabilities associated with leprosy and or because of negative attitudes of employers or the community.

A handful of participants, who were construction machinery operator, farmer, maid, and daily labor deprived of employment owing to their deformity and discrimination. Related to this respondent9 explains he is a 69-year old divorced man, diagnosed with leprosy 30 years back and whose livelihood had changed from construction machinery operator to begging. Respondent9 magnify his situation as*:*

> *After the disease impaired my hands and legs I realized my life as a construction machinery operator is over. Initially I was highly motivated to gain access to easy job. However, after I got serious wound, No body allowed me to work I was in complete destitution, without food, water and shelter. And to sustain my life I had to beg.*

Focus group discussion participants also reveal the disease itself and the presence of visible deformity led people refused to hire them. In addition thein-depth interview also revealed

that the participant developed physical problems inhibiting their income generation. Respondent11 is 36 years old female waitress at local café explained the situation as:

> *I developed loss of sensation in my hands initially and then I got a wound. The disease has affected my hands. I cannot hold things properly with my hands then I stopped working. I can do only easy work now. Thus, I choose Gulit trade my husband help me however the disease impaired his legs,he is stronger than me.*

The finding also reveals persons affected by leprosy who used to be farmers couldn't sustain the farming because of the physical impairments related to this respondent6 a 60 years male explained the situation as*:*

> *The ulcer on my foot deteriorated and finally I had to have an amputation this deprived me of the chance to participate in farming. Nevertheless, I engaged in urban gardening and animal husbandry it is somehow easy for me. Although, the income is fall down I can sustain my life.*

4.6 coping mechanisms

This major theme emerges from participants' ways of handling challenges of leprosy. Five subthemes are incorporated in this major them.

4.6.1 Coping strategies related to challenges of leprosy related physical impairments

All participant of this study mentioned they have leprosy related physical impairments and loss of sensations on their hands and feet consequently, they expose themselves for burn

injuries and wounds. However, they claim they didn't let this challenge totally avoid them from exciting daily tasks because they used different strategies to deal with their situation. Related to burn injuries and wounds the in-depth interview revealed using long tools and appliances with protective (molded) handles at home and at place of work is a strategy to win out the challenges of executing daily routines. To magnify this respondent2 explained as:

> I *already told you I cooked but I use long and padded spoon and utensils to avoid burn from direct contact with hot metal objects*.

And all focus group discussion participants also share in-depth interview participants' idea. The common implications of leprosy among participants is loss of sensations due to nerve damage and this put persons affected by leprosy in danger of injuring themselves when they are in their daily routines. Woundsfrom rubbing their anesthetic skin against hard objects are other injury they face during executing daily routines. However, they explain they use stripes of cloth to cover their hands and padded hard objects to avoid friction and wound. In addition,Looking for injuries, redness, blisters and impending ulcers in hands and feet on daily basis is essential to mitigate further impairments. Focus group discussion participant3, 46 years old female explained the situation as*:*

> *We/persons affected by leprosy/ use stripes of cloth to cover the surface of hard objects like knife, axe, and what have you! Other ways it will rub our anesthetic skin and wounded our hands. In addition, I inspect my hands and feet daily to see if I had injuries while I execute daily activities.*

On the other hand the finding of this study also reveals persons affected by leprosy also have impairments on their feet's easily get ulceration while walking around. Consequently, they

use special footwear made by Boru Meda orthopedic workshops. Related to this respondent 10 told the researcher the disease impaired his feet and he is mill hand and he explain the coping strategies to mitigate further injuries on his feet as :

> *To mitigate injuries on my anesthetic feet I use special footwear which is comfortable and soft enough to avoid friction and ulceration. As I told you already I didn't feel no matter what injures happened on my feet consequently, I have to check my feet recurrently and this help me to avoid injuries from sharp and hard objects trapped under my shoes.*

Most participants of this study also mentions due to the injuries in daily routines persons affected by leprosy have dry skin and wounds in their hands and feet consequently, to avoid further physical impairments they soak their hands and feet with cold water. To explain this

Respondent 2 who have lost his fingers and toes told the researcher:

> *My skin cracks and ulcerates most of the time however; I manage to avoid further amputation by socking my hands and feet over thirteen minutes and massaging with Vaseline on a daily base.*

4.6.2Coping strategies related to leprosy related stigma and discriminationon marital relationship

Thefindingreveals all participants of this study face problems in their marriage and in getting married merely because of their illness happened to be leprosy. All participants who were single prior to the onset of the disease told the researcher they leave their home town and moved to Dessie town to escape the problem in gettingmarried. They explain they chose to leave their home town and move to Dessie because they have a chance to live with their 'own kind.

Respondent 2 explained he tried to marry a girl in his home town after he released from the hospital however, the bride's family forbade the marriage as soon as the found out he had leprosy. He clarified how he copes with his situation as:

> *when I heard the bride's family did not allow the marriage I came to know I have no fate in my home town to have family and when I was in Boru Meda hospital I happened to know there is a leprosy affected community around. Consequently, I decided to live my home town and came back to Dessie and I met my 'own kind' have two children with her.*

The finding also shows participant who were married experienced problems in their marriage they all asked divorce by their spouses and in-laws and they cope with the situation by leave their home town and married to another spouse affected by leprosy. To present an example respondent 5 who was married and a mother of two prior to the onset of the disease explain the situation as:

> *After the divorce and my family and my ex-husband restricted me from contacting my children I decided to leave my home and family and come to Dessie where I met another man who is leprosy affected and we married.*

4.6.3Coping strategies related to leprosy related stigma and discriminationonsocial participations

The finding shows persons affected by leprosy have limited roles in social events because of the neighboring community discriminate against while they are trying to take part in different social events. And some of the respondents used abstaining request to participate in social events

as coping strategy to avoid rejection by the community. To magnify this respondent4 explain the situation with shattered sound as:

> *The community invited me to wedding programs however; they didn't want me to join the other women who work on the food and beverage. People seem to be disgusted to eat what I touched I noticed it on different occasions and recently I saved myself from humiliation by stop asking to help.*

On the other hand, the finding also reveals participants who face rejection from family members and neighbors use moving places where persons affected by leprosy are concentrated. Respondent4 explain the situation as:

> *I feel very bad when friends and family members stares at me and rejected any contact with me consequently, I choose to leave my home town /labella/ and come back to Dessie and started life here with other persons affected by leprosy. Here no one stares at me and rejects me because the community is my 'own kind'.*

Explaining about the disease and be friendly is another coping strategies to avoid stigma and discrimination on different social events. Focus group discussion participant3 explained this as:

> *People afraid having contact with us/person affected by leprosy/ I tried to explain I got the treatment and completely cured I am not contagious. Besides I tried to be friendly and not offended by people's outlook towards me (disfigured hands and feet). And I tried to stay calm and positive when 'healthy' people use arrogant discourses like 'komata' means mutilated. As a result my neighbors feel comfortable around me and the likes me.*

4.6.4Coping strategies related to leprosy related stigma and discriminationemployment the finding demonstrated stigmatizing attitudes and discrimination is a common experience for people affected by leprosy. While, tangentially, participants had to tell the more drastic incidents of discrimination from the past, in the present negative attitudes in society were still felt and experienced and affect their employments. Nonetheless, most of the participants manage to engage in small business /*Gulit*/. Focus group discussion participant 7 explains the coping mechanisms as:

> *It certainly cannot be denied that people have a bad feeling about us and, no question, they are afraid and distance themselves and consequently, refused to buy foodstuffs from us /persons affected by leprosy/. However, we manage to sustain our source of income by changing our commodity from foodstuffs to plastic shoos and charcoal. 'Healthy' people seem to be comfortable to buy packed commodities and non-foodstuffs from us/leprosy affected people so we use this opportunity.*

The finding also reveals participants use 'healthy' family members to sell commodities when people refused to buy from them.

Most participants described that their income had deteriorated after their illness, since they could not continue work as before. Because they have Activity limitations due to leprosy related physical impairments. However some participants change into more suitable line of work to cope with the situation.to magnify this respondent7 who was farmer prior to the onset of the disease and quite farming and engaged in *Gulit* because of leprosy related physical impairments explains situation as:

Farming was my sole source of income however, I can't continue as a farmer after the disease harmed my hands and feet's. Nonetheless, I didn't give up I started small business on the roadsides it is not much but it sustain my life and kept me out of streets.

On the contrary some participants reveals they tried to engaged in suitable line of work but they faced meagre opportunities due to rejection at work as a result they engaged in begging to sustain their life. To illuminate this Respondent9 who was construction machinery operator told the researcher with crying sound as:

I wasn't thinking to have my old job back however I thought I can have some easy jobs like security guards but everybody I asked to hire me rejected me. Where can you work with a sick foot? Nowhere!! But I have to have money to sustain my life so I engaged in begging.

CHAPTER FIVE

5.1 DISCUSSION

Under this chapter the researcher have discussed about the findings of this research with the other Researchers' findings in the literature review based on the four research questions.

5.1 Challenges of executing daily household activities while having leprosy related physical impairments.

The findings of this studies reveals persons affected by leprosy have limitation in activities which involves their hands and feet due to the deformities and loss of sensation on their

hands and feet which is secondary to leprosy. Consequently, they exposed themselves for burn injuries while conducting daily routines. The finding confirms the loss of sensation in their hands affect their ability to feel heat and pain therefore, they got burn from direct contact with hot liquids or surfaces or open fire while conducting daily household activities. Likewise, Brakel (2012) reported persons affected by leprosy face limitations of activities involving the use of hand due to loss of sensation they put themselves at risk of burns and injury because of anesthetic nerves in their hands, and these injuries later developed ulcers which led to amputations and further activity limitation .

5.2 participants' experience of divorcedue to leprosy related stigma and discrimination

The finding of this study reveals persons affected by leprosy face a problem to endure their marriage they forced by their spouses, in-laws or even by their own families to divorce their other half and leave their home town. The finding depict two reasons for the divorce, first healthy spouses and family members' fear of leprosy transmission from persons affected by leprosy , the next reason was the spouses and family members fear the adjacent community will discriminate and insult them for having leprosy affected spouse. In line with this, a study conducted in Cameron indicated that persons affected by leprosy face divorce or separation from their spouse due to leprosy (Nsagha, 2011). Related to this One of the studies in India reported that one- third of leprosy patients were left by their spouses either because of fear of contagion or discrimination (Marahatta 2015).In addition studies indicated persons affected by leprosy requested divorce either due to the fear of contagion or being infected or the class strata and social order established between the leprosy affected and the community (ENAELP, 2002, Mesele, 2005, Yohans, 2015).

5.3 Restriction in getting married

The finding depicts persons affected by leprosy experienced challenges in getting married due to the community's belief that leprosy is hereditary. Thus, people married to leprosy affected partner will bear a child who has the same disease. Holding the same idea Mesele (2005) reported that being leprosy affected person or even have association with them cause difficulties in getting married. Let alone leprosy affected persons themselves, having leprosy affected family member meant marital isolation for the whole member of that family because of the fear that leprosy is a hereditary disease.

In the findings, it was also showed that persons affected by leprosy experience restriction in getting married due to the fear of transmission of leprosy because of people think the disease is not curable and the person affected by leprosy is continued to be contagious even after the treatment. However, the doctor told them treated persons are no longer contagious. Likewise Kindu (2013) reported that in Ethiopia research results shows that the stigma of leprosy does have an impact on marriage for leprosy affected individuals and also on the marriage prospects of relatives. The society does not allow marriage with persons affected by leprosy and their families due to the communities' believes that leprosy is curse of God and societal fear of contagion or being infected.

The finding shows peoples' fear of discrimination and insult by the adjacent community is also a reason for restriction in getting married among persons affected by leprosy. It was stated by the participant Healthy' people do not want to marry Persons affected by leprosy due to fear of said to be descendants of 'leper' as a result, community do not allow the whole family to mix via marriage. In line with this studies showed that marriage with persons affected by leprosy is highly avoided because of having 'leprous' spouse cost the whole family marriage fate and social

classes thus persons affected by leprosy left their home in order not to be in the way so his/her siblings had a chance to get married. (Messele 2005, Tanny 2007, Melake, 2008).

5.4 Participants experience related to their social participation

Related to social participation of persons affected by leprosy the finding point out they didn't face restriction to be members in local informal organization however, they play limited roles because other members of informal organizations don't believe persons affected by leprosy are capable of executing tasks because of their deformities. Likewise Sen (2002) reported that persons affected by leprosy are not considered as capable to overcome the social function as others. Thus, they are isolated from take part in community based organizations, formal and non-formal community.

Having the same idea, Melake (2008) reported that persons affected by leprosy engaged in local informal organization with other healthy people however, they have not significant roles in leadership of those informal organizations.

On the other hand the finding depict some of the participant choose not to take roles in local informal organizations due to their physical impairments. This is in agreement with the study of Mimi (2015) who reported that some of the persons affected by leprosy decided to stay away from people and their social groups because of their physical impairment.

In the finding it also showed that persons affected by leprosy are engaged in social events like wedding, mourn and religious festivals. However, their role is limited because there are things the community doesn't let persons affected by leprosy do because of the community feel sympathetic for them because of their deformities.

The finding also shows the community didn't want persons affected by leprosy to contribute in activities which need close contacts so that people discriminate against them. Persons affected by leprosy invited in to different social events simply to attend the event not to take part as 'healthy' people do. These findings are in agreement with the work of Nsagha (2011) who found that interactions that did not involve physical contact with lepers were generally welcomed however, the roles of persons affected by leprosy in social events were shunned because of physical imperfections. Most non- leprous the community believed that patients with clawed hands and feet and other deformities were still infectious and as such many refuse body contact with them. Having the same idea Yohans (2015) also reported leprosy affected people are highly excluded from various social engagements like wedding, and *Idder* and other social occasions.

5.5 The implication of leprosy on employment experience of participants

The finding shows persons affected by leprosy face loss of income due to loss of properties. It was mentioned that the cattle got vanished and the land reallocated for another dwellers since they leave their home town because of two reasons first, they can't perform farming activities due to leprosy related physical impairment and they can't bear leprosy related discrimination. similar to this finding ENAELP's, (2001), report shows most PAL in Addis Ababa are migrants from rural areas and they were predominantly agrarian before the onset of the disease, then they shifted to small income generating activity and begging because they lost their properties back home as they can't engage in farming due to leprosy related physical impairment. In addition Yohans (2015) reported Leprosy patient had large tracts of land and other prosperities in their birth place. Most of them are left what they have there and migrated far

from their home of origin. It is mainly due to, fear of stigma. Most of them prefer to be dependent on others, instead of facing rejection and exclusion in their own community.

The finding depicts participants face restriction in getting employed for two reasons. First, people don't want leprosy affected people to hire and for some persons affected people, the physical effects of leprosy prevent the continuance of physically based employment. Similar with this Ajibade (2010) mentioned that persons affected by leprosy experience restriction in getting employed due to physical impact of leprosy because it make impossible to continue in their former occupation.

In this finding it is also showed leprosy affected people lose their employment because of functional disabilities associated with leprosy and or because of negative attitudes of employers or the community. Ajibade (2010) also reported that persons affected by leprosy experience unsympathetic abandonment or rejection in the labor market. Likewise, report shows persons affected by leprosy are deprived of employment opportunities and they mostly don't get better acceptance from employers. In addition persons affected by leprosy and their families are forced to hide themselves and where they came from, otherwise they will be denied to an opportunity compete even if they meet the criteria (ENAELP's, 2001). Yohans (2015) also reported leprosy affected people are known to be highly disadvantaged in the job market they often suffer from unjust treatment while they are applying for a job.

The finding also illustrates persons affected by leprosy lose their employment because of functional disabilities associated with leprosy and or because of negative attitudes of employers or the community. In line with this Scott (2000) mentioned Employers may dismiss an employee affected by leprosy out of fear of getting the disease and of losing customers in their businesses. Another reason for dismissing is that people with impairments due to leprosy may not be able to

perform well on the job. Having the same idea, Rafferty (2005) mentioned that leprosy affected people lose their employment because of their disease, the disabilities associated with leprosy and negative attitudes of employers.

5.6 Coping strategies

Associated to challenges of leprosy related physical impairments, in the findings it was revealed that the loss of sensations on the hands and feet's of persons affected by leprosy exposed them for burn injuries and wounds. However, to deal with their situation they use long tools and appliances with protective (molded) handles at home and at place of work. In addition looking for injuries, redness, blisters and impending ulcers in hands and feet on daily basis is essential to mitigate further impairments Likewise, WHO (2009) reported that inspect insensitive hands and feet daily and frequently after work; both at home and at work place, for signs of impending ulcers. It is also stated that Handle hot and sharp objects by using gloves, cloth, insulated handles is a mechanism to win out burn and injury while executing daily routine.

The finding also shows persons affected by leprosy cope with injuries in anesthetic feet while executing daily routine by special footwear made by orthopedic specialists. Likewise using Shoe which fit well, neither tight nor loose. Usually one size bigger than the required size with broad front so that it has plenty of space for clawed toes is essential to prevent injuries in the feet WHO (2009).

Due to the loss of sensation on hands and feet persons affected by leprosy have dry skin and wounds consequently; to elude further physical impairments they soak their hands and feet with cold water. Similar to this finding WHO (2009) also point out to manage dry skin and wounds persons affected by leprosy Soak dry hands and feet in a bucket of water for 20 – 30

minutes more until any hard and dry skin becomes soft. Container should have enough water to cover hands/feet.

In the finding it is also stated that to escape the problem in getting married persons affected by leprosy leave their home town and move to Dessie so that they can have a chance to live with their ‘own kind. Similarly persons affected by leprosy who experienced problems in their marriage, leave their home town and married another spouse who are their ‘own kind’.

The finding also shows to avoid rejection by the community persons affected by leprosy abstained request to participate in social events and explain about the disease and be friendly.

The finding also reveals participants use ‘healthy’ family members to sell commodities when people refused to buy from them. In addition in order to avoid engaged in beggary participant change the job before the onset on the disease and engaged into more suitable line of work.

CHAPTER SIX

CONCLUSION AND IMPLICATION TO SOCIAL WORK

6.1. Conclusion

With twenty participants the study has made an effort to explore and had found out thechallenges of persons affected by leprosy related to the physical consequences of leprosy (physical impairment) and the implication of leprosy on social participation, martial relationship and employment in light of stigma and discrimination.

Based on the findings of this research it is possible toconclude that persons affected by leprosy have limitation in activities which involves their hands and feet due the deformities and loss of sensation on their hands and feet consequently, they exposed themselves for burn and wounds while conducting daily routines.

Relying on the findings of thisstudy it is concluded that persons affected by leprosy face a problem to endure their marriage as well as in getting married because their families, in-laws' and the adjacent community discriminated against them.

Related to the social participations of persons affected by leprosy the study depict they are free to became members of local informal organization like *Idder,Ekub* and *Mahiber* however they have limited roles because of they choose not because of physical impairments, the community did not let them out of sympathy, and the community discriminated against them.

According to the findings of the study it's concluded that persons affected by leprosy face income lose because of loss of property, loss of their old job because of leprosy related physical impairments. In addition they face lose their employment and restriction in getting employed

because of functional disabilities associated with leprosy and or because the community discriminate against them.

The study also shows different coping strategies used by persons affected by leprosy in order to win out challenges of leprosy.

6.2. Social Work Implication

6.2.1 Implication for practice

Social workers can and should advocate the full participation and equal opportunity of persons affected by leprosy and also raising awareness among the society in order to relieve the misconceptions and discriminatory actions against persons affected. In addition raising public awareness, educating persons affected by leprosy and their families about the disease how it is caused, transmitted, prevented and cured is another area of intervention.

And social workers should engage in Facilitation of multidisciplinary provision of health education and self-care at community level to prevent or minimize further disability of people affected by leprosy.

Social worker should engage in program designing in order to provide bio psycho social and economic rehabilitation for persons affected by leprosy.

At the point when a person faces stigma they are likely to be vulnerable and needing acceptance, encouragement and emotional support. In a busy medical setting, individuals find it difficult to express their concerns. So that social workers social workers can play significant role in the provision of counseling services for persons affected by leprosy.

6.2.2 Implication for research

Beside this research make an effort to explore the experiences of persons affected by leprosy it was conducted in single site with limited numbers of participant therefore a macro level study that incorporates large samples would help to arrive at different result, which might help to introduce a better intervention plan.

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APPENDICES A

Addis Ababa University

College of social science

Graduate school of social work

Informed consent form

Study project: "The experience of persons affected by leprosy; specific to the implication of leprosy on their lives: the case of Amhara regional state, Dessie town"

The overall objective of this study is; to explore the implication of leprosy on social participation, martial relationship, employment and the challenges related to the physical consequences of leprosy in light of stigma and discrimination.

My name is Metsehet Demelash Wondim and I am graduate student at Addis Ababa university graduate school of social work. Currently I am conducting thesis project titled "The experience of persons affected by leprosy; specific to the implication of leprosy on their lives: the case of Amhara regional state, Dessie town" for the partial fulfillment of master of social work (MSW).

Participation in this study is entirely voluntary and you can choose not to participate in the interview or withdraw your consent any time at the middle of the interview. I would like to ask you questions that will not take long time if you kindly allow me, to tape-record your answers so that I can change it in to written forms and use it as an input in this study. I would very much appreciate your participation. The tape-recording will be discarded appropriately after the completion of the study. Your answers will be confidential and I will not record your name so that your answers will be anonymous. If you are agreed to participate in this study, may I have your signature?

Respondents agree to interview _____ date _____/____/_____

APPENNDICE B

Addis Ababa University

College of Social Sciences

Graduate School of Social Work

Interview guide I

The following Questions are designed in order to conduct interview with persons affected by leprosy for the thesis project titled "The experience of persons affected by leprosy; specific to the implication of leprosy on their lives: the case of Amhara regional state, Dessie town".

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

Part 1. Questions relatedto participants' Socio-demographic & Economic conditions.

1. Current address
2. Gender (question number 1&2 fill out by interviewer without asking participants)
3. What is your age now?
4. What is your religion?
5. What is your educational status? 1. Illiterate 2. Read and write 3. Primary school 4. Secondary school
6. Could you tell me your family size?
7. How long have you lived in this community?

8. Where is your birth place?
9. How much is your estimated monthly income?

Part 2 Questions related to housing

10. Did you own the house you live in? If yes how do you acquire it?
11. What is the legal condition of your house?
12. Number of rooms of the house?
13. Do you have electricity in the Dowling?
14. What is your source to access water?
15. Does your house have private toilet facility/communal/?

Part 3 Questions related to participants' access to Socialservice and food security

16. Is the health service available in your sounding? / Form where usually do you get health service?
17. Is their primary school in your surrounding (year 7)?
18. How many times a day the household members getting a meal?
19. Is your total household income adequate to feed your family?(question 19,20 is not for participants earn their income from begging)
20. How do you manage it?

Part 4 questions related to participants' health status

21. How old were you when you had leprosy?
22. How did you come to know you had leprosy?
23. What do you think about the cause of leprosy disease?
24. What were our villagers/ family members/ spouses believes regarding the cause of leprosy?

25. Where were you going first for treating leprosy?
26. How long you been on treatment?

Part 4questions related to participants physical condition

27. Do you have physical impairment on your body because of leprosy?
28. If yes for the above question what is the extent of your physical impairment (visible deformity or damage present and severe visional problem due to leprosy)?
29. Would your physical condition cause difficulties in your daily routine? How?
30. How do you manage it?

Part 5Questions related to participants' marital and family relationships

31. Were you married/ have you had children before the onset of the disease?
32. If you married/had children are you living currently with them?
33. If not what was the reason?
34. How is your relationship with them/ have you visited them?
35. If no why?
36. What is your current marital status?
37. If single would leprosy be problem for getting married? Would you explain how?
38. If married is your partner affected by leprosy or have physical impairment?
39. If yes is that a coincidence?
40. If you divorced, what is the main reason for divorce?

Part 6 questions related to participants' social participation

41. How do you characterize your relation with your neighbors?
42. If not good why?
43. Is their community based organization or festivals/ rituals in your community?

44. If yes are you a member/ participant of community based organization/festivals/rituals?
45. Is other members PAL or non-PAL?
46. Could you tell me your position in the community organization/festival/rituals?
47. Have you ever experienced participation restriction because of your status? Would you explain how?
48. How do you manage it?

Part 7 Questions related to participants' employment

49. Does leprosy affected your employment? How?
50. How do you manage it?
51. What was your income source before the onset of the disease?
52. Have you changed your source of income after the onset of the disease?
53. If Yes why?
54. What is your current source of income to your household?
55. If daily labor (physical based employment) is your physical condition affected your physical based employment? / is your engagements in physical based employment aggravate your/physical condition?
56. How do you manage it?
57. If you are self-employed, does leprosy affected number customers? How?
58. How do you manage it?
59. Would employers refused to employ you because of your status while you fit for the work?
60. If yes why?
61. How do you manage it?

62. If begging why?

APPENDICE C

Addis Ababa University

College of Social Sciences

Graduate School of Social Work

Focus group discussion guide

The following Questions are designed in order to conduct focus group discussion with persons affected by leprosy for the thesis project titled "The experience of persons affected by leprosy; specific to the implication of leprosy on their lives: the case of Amhara regional state, Dessie town".

1. Do you experience challenges in daily activity due to the physical impairment related to leprosy? How?
2. Would leprosy related physical impairment because of stigma in daily routines? How?
3. Would leprosy be a problem to a person to get married? Why?
4. Would leprosy be a cause of divorce? How?
5. Would your status be a challenge to take part in major festivals/rituals and social activities? How?
6. Would your status be a challenge to participate in local community based organizations? How?

APPENDICE D

OBSERVATION CHECKLIST

1 Upon the consent of the participant the researcher will observe their physical conditions.

2 The researcher will observe participant while they are performing household activities.

APPENDICE E

አዲስአበባዩኒቨርሲቲ

የሶሻልሳይንስኮሌጅ

የሶሻል-ወርክድህረ-ምረቃትምህርትቤት

መፅሔትደመላሽእባላለሁ፡፡በአዲስአበባዩኒቨርሲቲየሶሻል-ወርክድህረ-ምረቃትምህርትቤትየሁለተኛዲግሪተማሪሰሆንበአሁኑጊዜየሁለተኛድግሪማሟያየሚሆንጥናትበደሴከተማበሩአካባቢበሚገኙየስጋ-ደዌተጠቂወችላይእያካሄድኩእገኛለሁ፡፡

ይህጥናት**“የስጋ-ደዌተጠቂወችልምድ”**በሚልርእስየሚከናወንሲሆንአላማውምስጋደዌጋርየትያያዘየአካልጉዳትበስጋደዌተጠቂዎችየቀንከቀንከንወኔወችላይያለውተጽእኖ፤የስጋ-ደዌተጠቂወችጋብቻሁኔታላይያለውተጽእኖ፤የስጋ-ደዌተጠቂወችማህበራዊተሳትፎእንዲሁምየስራተሳትፏቸውንተሞክሮማጥናትነው፡፡

በመሆኑምለዚህጥናትየሚውልቃለ-መጠይቅየሚካሔድሲሆንእርስዎለዚህቃለ-መጠይቅፍቃደኛበመሆንዎምስጋናየከፍያለነው፡

፡

በዚህቃለ-መጠይቅላይመሳተፍሙሉበሙሉበፍቃደኝነትላይየተመሰረተነው፡፡ ያልተስማማወትንጥያቄአለመመለስወይምቃለመጠይቁንመቀጠልባልፈለጉጊዜማቋረጥይችላሉ፡፡

ቃለ-መጠይቁረዥምጊዜየማይወስድቢሆንም፤ የእርስዎተሳትፎእናሁሉንምጥያቄዎችመመለስዎለጥናቱአጅግመሰረታዊጠቀሜታይኖረዋል፡፡በቃለ-መጠይቁጊዜስምዎየማይመዘገብበመሆኑየሚሰጧቸውምላሾችእናሃሳብአስተያየትዎበሚስጥርየሚጠበቅይሆናል፡፡ከዚህቃለ-መጠይቅየሚገኙመረጃዎችለዚህጥናትአላማዎችብቻየሚውሉሲሆንእርስዎበዚህጥናትበመሳተፍዎምንምአይነትችግርአያጋጥምዎትም፡፡

በድጋሜስለተሳትፎዎእያመሰገንኩማንኛውምጥያቄወይምአስተያየትካለዎትመጠየቅይችላሉ፡፡

APPENDICE F

አዲስአበባዩኒቨርሲቲ

የማህበራዊሳይንስኮሌጅ

የሶሻልወርክድህረ-ምረቃትምህርትቤት

ቃለ-መጠይቅቅጽአንድ

የሚከተሉትጥያቄወችየተዘጋጁትከስጋ-ደዌተጠቂወች,ጋርለሚደረገውቃለ-መጠይቅሲሆንቃለ-መጠይቁየሚካሄደውበደሴከተማከሚኖሩስጋ-ደዌተጠቂወችልምድለማጥናትነው፡፡ጥናቱከአዲስአበባዩኒቨርሲቲድህረ-ምረቃተማሪለድህረ-ምረቃድግሪማሟያየሚውልይሆናል፡፡ቃለ-መጠይቁአምስትክፍሎችያሉትሲሆንስለተሳትፎዎአመሰግናለሁ፡፡

ክፍልአንድ፡በዚህክፍልየተካተቱጥያቄወችየተሳታፊወችንግለ-መረጃእንዲሁምማህበራዊእናኢኮኖሚያዊሁኔታወችየሚዳስሱይሆናል፡፡

1. አድራሻ ……
2. ጸታሴት…… ወንድ…….
3. እድሜ ……..
4. ሀይማኖት ……
5. የትምህርትሁኔታ 1. ያልተማረ 2.ማንበብእናመጻፍየሚችል 3. የመጀመሪያደረጃትምህርት 4 ሁለተኛደረጃእናከዚያበላይ
6. የቤተሰብብዛት ……..
7. በዚህአካባቢለምንያህልጊዜቆዩ ……..
8. እዚሁነውተወልደውያደጉት ? ……
9. ከትውልድቦታወወደዚህየመጡበትምክንያትምንይሆን?

10. በአማካይየወርገቢወምንያክልይሆናል?

ክፍልሁለት፡በዚህክፍልየተካተቱትጥያቄወችየስጋ-ደዌተጠቂየሆኑግለሰቦችንየመኖሪያቤትሁኔታየሚመለከቱናቸው፡፡

11. የሚኖሩበትቤትየግልወነው? እንዴትነበርያገኙት?

12. የሚኖሩበትቤትባለቤትነትወህጋዊነው?

13. ቤትወስንትክፍልነው?

14. የኤሌክትሪክአገልግሎትተጠቃሚነወት?

15. ንጹህየመጠጥውሀተጠቃሚነወት?

16. ቤትወየግልመጸዳጃአለዉ (የጋራ)?

ክፍልሶስት፡በክፍልሶስትውስጥየተካተቱትመጠይቆችየተሳታፊወችንማህበራዊአገልግሎትእናየምግብሽፋንይመለከታሉ፡፡

17. የህክምናአገልግሎትየሚያገኙትእንዴትነው?(ዘመናዊህክምናከሆነከየትነው?)

18. በሚኖሩበትአካባቢየመጀመሪያደረጃትምህርትተቋማትይገኛሉን?

19. እድሚያቸውለትምህርትየደረሱ (7 ዐመትበላይ) ልጆችአሉወት?(ስንትናቸው?)

20. በትምህርትገበታላይየሚገኙስንትልጆችአሉወት?

21. ሁሉምእድሚያቸውለትምህርትየደረሰልጆችወበትምህርትገበታቸውላይናቸውን?(ካልሆንለምን?)

22. እርስወእናቤተሰብወበቀንለምንያህልጊዜይመገባሉ?

23. የወርገቢወየቤተሰቡንየምግብወጪይሸፍናል? (በልመናለሚተዳደርይህጥያቄአይመለከትም)

24. ካልሸፈነእንዴትያመቻቻሉ ?

ክፍልአራት፡በዚህክፍልየተካተቱትጥያቄወችየተሳታፊወችንየጤናሁኔታየሚመለከቱናቸው፡፡

25. በስጋ-ደዌእነደተጠቁሲያውቁእድሜወስንትነበር?

26. የስጋ-ደዌበሽታእንዳመመወእንዴትእንዳወቁያስታውሳሉ?

27. በጊዜውየስጋ-ደዌበሽታበምንምክንያትእንደሚከሰትያውቁኖሯል? ምንነበርየሚያውቁትያስታውሳሉ?

28. የትዳርአጋርወ/ቤተሰብወ/ ጎረቤቶችወእናየመንደርሰወችስለስጋ-ደዌበሽታአምፁምክንያትየሚያስቡትምንነበር?

29. ለበሽታውህክምናለማግኘትበወቅቱለመጀመሪያጊዜወደየትነበርየሄዱት?

30. ለምንያክልጊዜየስጋ-ደዌህክምናተከታትላችኋል ?

31. በስጋ-ደዌምክንያትየመጣየጤናችግርበአሁኑሰአትአለብወት?

ክፍልአምስት፡በዚህክፍልውስጥየተካተቱትጥያቄወችየተሳታፊወችንበስጋ-ደዌየመጣአካልጉዳትንየሚመለከቱናቸው፡፡

32. በስጋ-ደዌበሽታየመጣየአካልጉዳትአለብወት ?የጉዳቱንመጠንእናአይነትይነግሩናል?

33. የቀንከቀንከዋኔወች (ማብሰል፤መመገብእናየመሳሰሉትን) ለመከወንየፈጠረብወትእክልይኖራል?

ካለእንዴትእንደሆነያብራሩልኛል?

34. እነዚህንእክሎችእንዴትይወጧቸዋል?

ክፍልስድስት፡በዚህክፍልውስጥየተካተቱትጥያቄወችየተሳታፊወችንየጋብቻእናየቤተሰብሁኔታይመለከታል፡፡

35. በስጋ-ደዌበሽታከመታመምወበፊትአግብተውነበር?

36. በአሁኑሰዐትከባለቤትወ / ከልጅወጋርነውየሚኖሩት?

37. አብረውየማይኖሩከሆንበምንምክንያትነው?

38. አሁንትጠያየቃላችሁ ? ቅርበታችሁስምንያህልነው?

39. የማትጠያየቁከሆነበምንምክንያትነበርመጠያየቅያቆማችሁት?

40. አሁንስአግብተዋል?

41. የትዳርአጋርወበስጋ-ደዌህመምታመውየውቃሉ? የአካልጉዳትስአላቸው?

42. የትዳርአጋርወንየመረጡትበኢጋጣሚነው?

43. ካላገቡበስጋ-ደዌመታመምሰወችጋብቻእናዳይመሰርቱእንቅፋትሊሆንይችላልን?

44. የፈቱከሆነእባክወትንለፍችወዋነኛምክንያትምንእነደነበርይነግሩኛል?

45. እንዴትነበርሁኔታውንየተወጡት ?

ክፍልሰባት፡በዚህክፍልየተካተቱትጥያቄወችየተሳታፊወችንየማህበራዊህይወትተሳትፎየተመለከተይሆናሉ፡፡

46. ከጎረቤትወጋርያለወትንቅርበትእንዴትይገልጹታል?

47. ያለወትቅርበትጥሩካልሆነለምን?

48. በሚኖሩበትአካባቢየሰፈርማህበር፤እቁብ፤እድርወ.ዘ.ተያሉመደበኛያልሆኑየማህበርተቋትአሉን?

49. በነዚህማህበራትአባልነወትይሳተፉሉ? ተሳትፎወስምንይመስላል?

50. ሌሎችአባላትየስጋ-ደዌተጠቂወችናቸውን?

51. በማህበራትውስጥያለወትየስራድርሻምንይመስላል?

52. በአነዚህተቋማትሲሳተፉየስጋ-ደዌተጠቂበመሆንወትሳቢያየደረሰብወትእክልይኖራል? እንዴትእንደሆነያብራሩልኝ?

53. ያጋጠመወትንሁኔታወች/እክሎችእንዴትእንደተወጧቸውቢነግሩኝ?

ክፍልስምንት፡በዚህክፍልከተካተቱጥያቄወችየተሳታፊወችንየስራተሳትፎሁኔታየሚመለከቱይሆናሉ፡፡

54. የስጋ-ደዌተጠቂመሆንወበስራሁኔታወላይየፈጠረውእክልይኖርይሆን? እንዴትእንደሆንቢያብራሩልኝ?

55. እነዚህንእክሎችእንዴትተወጧቸው?

56. በስጋ-ደዌበሽታከመታመምወበፊትየገቢምንጭወምንነበር?

57. ከታመሙበኋላየገቢምንጭወንቀይረዋል?

58. ለምንነበርየቀየሩት?

59. በአሁንሰዓትየቤተሰብወየገቢምንጭምንድንነው?

60. የቀንስራ/የጉልበትስራ / ከሆነበስጋ-ደዌምክንያትየመጣብወየአካልጉዳትእክልይፈጥርብወትይሆን?

እንዴትእንደሆንያስረዱኝ?

61. የነገሩኝንእክሎችእንዴትነውየሚወጧቸው?

62. በግልወስራ /አገልግሎት፤ንግድ/ ከሆነየሚተዳደሩትየስጋ-

ደዌተጠቂመሆንወወይንምየአካልጉዳትመኖሩደንበኞችወብዛትላይተጽእኖይፈጥርይሆን?

እንዴትእንደሆነያብራሩልኝ?

63. ደንበኞችወንለማብዛት /ችግሩንለመወጣት/ ምንአይነትዘዴወችንይጠቀማሉ?

64. (ተቀጥረውየሚሰሩከሆነ) የስጋ-ደዌህሙምበመሆንወምክንያትችግርገጥሞወትያውቃል? (ለስራውብቁሆነውሳለ)

65. ለምንእንደሆነጠይቀውያውቃሉ?

66. እንዴትነበርበሰዓቱየፈቱት?

67. በልመናየሚተዳደሩከሆነለምንወደልመናገቡ?

APPENDICE G

አዲስአበባዩንቨርሲቲ

የማህበራዊሳይንስኮሌጅ

የሶሻልወርክድህረ-ምረቃትምህርትቤት

ቃለ-መጠይቅቅጽ - ሁለት

የሚከተሉትጥያቄወችየተዘጋጁትከሚመለከታቸውየስራሃላፊወችጋርለሚካሄደውቃለ-መጠይቅነው፡፡ቃለ-መጠይቁበአዲስአበባዩኒቨርሲቲየማህበራዊሳይንስኮሌጅሶሻልወርክትምህርትቤትተማሪየሚከናወንሲሆን፣ይህቃለ-መጠይቅበደሴከተማየሚገኙየስጋ-ደዌተጠቂወችንልምድለማጥናትየሚያገለግልይሆናል፡፡

1. በስጋ-ደዌየተነሳየሚፈጠሩአካልጉዳቶችበስጋ-ደዌተጠቂወችየስራሁኔታላይእክልይፈጥራሉብለውያስባሉ? እንዴትእንደሆነቢያብራሩልኝ?
2. የስጋ-ደዌበሽታበሰወች (የስጋ-ደዌተጠቂለሆኑሰወች) የጋብቻሁኔታላይየሚያስከትለውእክልይኖርይሆን? ቢያብራሩልኝ?
3. የስጋ-ደዌበሽታለጋብቻመፍረስምክንያትሊሆንይችልይሆን ? እባክወንያብራሩልኝ?
4. በስጋ-ደዌበሽታታመውየነበረመሆኑለማህበራዊጉዳዮች /እድር/ እቁብ/ ሀዘን/ ሰርግላይባለወትተሳትፎያስከተለውተጽእኖይኖርይሆን? እባክወንያብራሩልኝ ?
5. ከስጋ-ደዌበሽታጋርበተገናኘያለብወትየአካልጉዳት /የስጋ-ደዌበሽታታመውየነበረመሆኑመገለል/ መድሎወይንምማንኛውምእይነትተጽእኖአስከትሎብወትያውቅይሆን? እባክወያብራሩልኝ?