



ST. MARY'S UNIVERSITY

SCHOOL OF GRADUATE STUDIES

**INSTITUTE OF AGRICULTURAL AND DEVELOPMENT STUDIES MASTERS
PROGRAM IN SOCIAL WORK**

**EXPERIENCE OF FAMILY VULNERABILITY AND RESILIENCE AMONG WOMEN
AFFECTED BY LEPROSY: IN THE CASE OF KOLFIE KERANIYO SUB CITY
WOREDA ONE.**

BY: MESELECH DESTA

**A THESIS IS SUBMITTED TO SAINT MARY UNIVERSITY SCHOOL OF
GRADUATE STUDIES INSTITUTED OF AGRICULTURAL AND DEVELOPMENT
STUDIES IN PARTIALFULFILLMENT OF THE REQUIREMENTS FOR
MASTERSPROGRAM IN SOCIAL WORK**

July, 2023

ADDIS ABABA, ETHIOPIA



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SCHOOL OF GRADUATE STUDIES
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**A RESEARCH PROPOSAL SUBMITTED TO ST. MARY'S UNIVERSITY
SCHOOL OF GRADUATE STUDIES INSTITUTED OF AGRICULTURAL
AND DEVELOPMENT STUDIES MASTERS PROGRAM IN SOCIAL
WORK.**

**July, 2023
ADDIS ABABA, ETHIOPIA**

Declaration

I, Meselech Dasta, declare this research paper is my original work. I have carried out this research independently with the guidance and support of my advisor Dr.Habtamu Mokennen and that all the materials in the research paper have been dully acknowledged. The matter embodied in this project work has not been submitted earlier for award of any degree or diploma to the best of my knowledge and belief.

Name

St. Mary's University, Addis Ababa

Signature

Date

Advisor Approval sheet

I hereby certify that I have supervised, read, and evaluated this thesis/dissertation titled, “Experience Of Family Vulnerability And Resilience Among Women Affected By Leprosy: In The Case of Kolfe Keraniyo Sub City Woreda One.”, by Meselech Desta under my guidance. I recommend the thesis be submitted for an oral defense.

Dr. Habtamu Mekonnen (PhD) _____

Advisor’s name

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Examiner's Approval sheet

As members of the board of examiners, we examined this thesis entitled. "Experience Of Family Vulnerability And Resilience Among Women Affected By Leprosy: In The Case Of KolfeKeraniyo Sub City Woreda One.", by MeselechDesta We hereby certify that the thesis is accepted for fulfilling the requirements for the award of the Degree of Master of Social Work in St. Marry University.

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Acknowledgment

First of all, my heartily thanks go to the Almighty God for his gracious provision of knowledge, wisdom, inspiration and diligence required for the successful completion of this paper and for bringing my dreams into reality. I am also greatly indebted to my advisor Dr. HabtamuMekonen for his countless guidance, assistance and invaluable advice.

I would also like to extend my thanks to kolfiekeraniyo sub city Woreda one Women children and Social Affairs office Staffs. That was cooperative and helpful throughout my engagement. Last, but not least, my warmest appreciation and thanks go to my beloved family members who have always been encouraging and supporting me.

Acronyms/Abbreviations

FGD: Focus Group Discussion

NTD: Neglected Tropical Disease

NGO's: None Governmental Organizations

PAL; People affected by leprosy

Table of Contents

Declaration.....	I
Advisor Approval sheet	II
Examiner’s Approval sheet.....	III
Acknowledgment	IV
Acronyms/Abbreviations	vi
<i>Abstract</i>	xi
CHAPTER ONE	1
1. Introduction	1
1.1 Back ground of the study.....	1
1.2. Statement of the problem	4
1.3. Research Question	5
1.4. Objective of the study.....	6
1.4.1. General Objective	6
1.4.2. Specific Objective	6
1.5. Scope of the Study	6
1.6 Significance of the Study.....	6
1.7 limitation of the study.....	7
1.8. Operational definition.....	7
HAPTER TWO.....	8
REVIEW OF RELATED LITERATURE	8
2. Theoretical literature	8
2.1. Introduction	8
2.1.1. What is Leprosy?.....	8
2.1.2. Leprosy in the Ethiopian context	10
2.1.3 Family Resilience against Leprosy-Related Discrimination.....	10
2.1.4. Risk Factor and Vulnerability of leprosy	11
2.1.4.1. Psychological risk and Vulnerability leprosy	11
2.1.4.2. Economic risk and vulnerability leprosy-	12
2.1.4.3. Martial Relationship Risk and Leprosy.....	13
2.1.4.4. Social risk and vulnerability leprosy-	13
2.3 Empirical Literature.....	14
2.2.1The effects of leprosy on women	15
CHAPTER THREE	17

RESEARCH METHODOLOGY	17
3.1. Introduction	17
3.2. Research Design	17
3.3. Sampling Technique.....	18
3.4. Sample Size	18
3.5. Methods of Data Collection and Source of Data	19
3.5.1. Primary Source of Data.....	19
3.5.2. Secondary Sources of Data	20
3.6. Method of Data Analysis.....	21
3.7. Ethical Considerations.....	21
CHAPTER FOUR.....	23
FINDINGS OF THE STUDY	23
4.1. Introduction	23
4.2. Background of the Respondents.....	23
4.3. Perceived causes of leprosy.....	25
4.3.1 Leprosy its physiological effects.....	26
4.3.2 The psychological effect of leprosy.....	26
4.3.3 The Economic vulnerability of leprosy affected.....	27
4.3.4 The social effects of leprosy.....	28
4.4. Family Resilience (Coping) Mechanisms of women affected by Leprosy	29
CHAPTER FIVE	31
SUMMARY OF MAJOR FINDINGS, CONCLUSION AND RECOMMENDATIONS	31
5. Introduction	31
5.1. Summary of Major Findings.....	31
5.2. Conclusion.....	32
5.3. Recommendation.....	33
5.4. Future Research Direction	34
References	35
Annexes	37

List of figure

page

figure2. 1. Conceptual framework 16

Abstract

The purpose of this study was to explore the experience of family vulnerability and resilience among women affected by leprosy and to investigate the risk factors of vulnerability for families living with women with leprosy. The study followed a qualitative approach and the research design adopted for this study was descriptive research. To achieve the objective of the study 15 participants were selected. The participants were selected through a purposive sampling. For the purpose of the study open ended questionnaire, were used to obtain both primary and secondary data from Kolfie Keraniyo sub city woreda one. In-depth Interview focus group discussion and observation were employed to collect the data and descriptive analysis was used to analyze the data. The findings of the study showed, families lived with leprosy come across loss of sensation, wound, deformity and negative reaction to their disability. They also encountered anxiety and depression. Socially, they have problems of interaction, stigma, discrimination and marital relationship. In conclusion, the mental, financial and social needs of sickness sufferers especially women casualties in Kolfie Keraniyo sub city woreda one were comparable to those of sickness sufferers in other sub city. Desires for self-acceptance, social acknowledgment and Individuals with sickness see their life and the way in which they conceptualized the infection is unequivocal variables for their levels of mental wellbeing. Participants used different coping mechanisms such as hiding their health status, using traditional treatment, migration, going to spiritual places, institutional support and begging. Hence, stakeholders including the government intervention strategies have to address the welfare of the leprosy affected families.

Key words: Vulnerability, Resilience, Leprosy, Social exclusion, Social Marginalization, stigma and discrimination.

CHAPTER ONE

1. Introduction

This chapter deals with background of the study, statement of the problem, objectives of the study, significance of the study, delimitation of the study, and organization of the study. The details of each theme are presented here under.

1.1 Back ground of the study.

Leprosy is one of the most stigmatized diseases known to day leprosy patients may confront the impacts of disgrace and diverse shapes of segregation, such as dismissal, manhandle, separate, or misfortune of work, driving to diminished self-esteem and misfortune of regard from their communities .Interpersonal connections, social status, portability, and nobility endure and may cause uneasiness, discouragement, passionate push, segregation, and suicide or endeavored suicide. Products passes on found ladies to be more influenced by disease and its disgrace than men Shame may disturb existing imbalances due to age, sex, and social course frequently, the social and mental complications due to disease stay indeed after the restorative treatment is wrapped up. The psychosocial results an individual has got to bear after being analyzed by disease are often heaving urethane the physical results which will happen Leprosy is a chronic infectious disease that mainly affects skin and peripheral nerves and rarely other organ systems. It is not particularly age or gender specific disease. The behavior of individuals also helps the transmission cycle to continue, as many people are unwilling to seek medical care even after being diagnosed because of misconceptions, stigma and superstitions (Sileshi, 2015).

Women encounter numerous issues when enduring from disease, since the characteristics are exceptionally damaging to the body and are astute, hence putting them as a terrifying creature for women. leprosy is continuously related with traumatic occasions, misery and uneasiness which can cause psycho-emotional issues, psychological, economic and social effect Martial relationship, typically experienced by leprosy women all through their lives, so they sometimes find it troublesome to be the most excellent in their lives(Sileshi,2015). .

Leprosy has a long history in Ethiopia. Encompasses a long history in Ethiopia Chronicled prove demonstrates that the malady was in Ethiopia some time recently 16th century (Duff, 2005; Mesele 2005). Agreeing to Mesele (2005) the Portuguese diplomatic teacher, Chaplain

Francisco Alva's, had rendered the primary data around the illness within the nation in 1520. Mesele accepted that the malady might have happened in Ethiopia through the long far off exchange and other social connections.

Scott (2006) contended that sickness emphatically impacts the behaviors of individuals influenced by leprosy. The infection can influence a patient's conduct for the rest of their life. The tall rate of, self – destructive endeavorshighlights the patients' concept of the mental clutter as a result of sickness.

Leprosy is a disease that has been characterized for centuries by immense social stigma. Given the fact that stigmatization occurs for both males and females affected by leprosy, a number of interesting questions arise. Does stigmatization tend to equalize status differentials between men and women, as both may become outcasts from "normal" society? .Or does the lower social status of females, typical of many cultures; result in greater suffering for women? And to what extent do status differences between men and women contribute to differentials in the detection and treatment of the disease (Nasrudin et al.,2018).

Resilience can be understood as a dynamic and complex process (as well as outcome) of successfully adapting to difficult or challenging life experiences, especially through mental, emotional and behavioral flexibility and adjustment to external and internal demands Many factors can contribute to how well or poorly people adapt to adversity, including how they perceive and engage with the environment, their social resources and their use of coping strategies. Many of these “protective” or adaptive factors can be learned and strengthened, such as emotional regulation, self-efficacy, support seeking behavior, communication skills, and problem solving abilities and engaging in a supportive environment. In the face of stressors, these protective factors are said to modify the individual's or groups' response to adversity, thereby reducing the likelihood of negative outcomes(Scott 2006).

The psychological, economic and social problems of women affected by leprosy is inter women with the misconception of the large community about the cause of leprosy and the socio cultural factors related to gender roles and responsibilities that inhibit women from accessing and controlling resources including decision on their personal health care and services. The misconception around the causes of leprosy: that it is hereditary or is a curse of God exposed victims of leprosy including women to stigma and discrimination. The low status of women, lack of access to information and education about leprosy, the household chores of women or work load has its own negative bearing on women affected by leprosy.

Women living with leprosy is highly vulnerable by psychological, economic and social problems of women affected by leprosy is interwoven with the misconception of the large community about the cause of leprosy and the socio cultural factors related to gender roles and responsibilities that inhibit women from accessing and controlling resources including decision on their personal health care and services(Mesele, 2005).

Based on the experience of the sufferer, leprosy can be a very heavy burden, on family because it accepts physical, psychological and social consequences based on the severity of the disease. Some sufferers then try to balance physical and social stresses, but women with leprosy do not yet have enough ability to meet the demands of society, so the adaptation strategy chosen tends to be mal-adaptive even though it is very much needed to improve their mental health.(Nasrudin et al., 2018)

Hence, women influenced by sickness don't deliver time and due consideration for restorative checkup and opportune treatment. If ladies don't go to wellbeing offices and get analyzed, they would be helpless to incapacities. Incapacity incorporates a solid mental impact on ladies influenced by disease because it leads to need self-confidence and regard of their personality as ladies and moms. Women affected by sickness too confront a challenge to urge work; and even if they get employed they don't get rise to opportunity and are separated. Besides, socially a lady influenced by disease needs self-esteem to urge included in several social undertakings such as Idir, wedding and distinctive social occasions with the other community individuals openly (Rahel H, 2016).

The other finding of the study is the need of rise to opportunity on the work advertises for people with incapacities in common and sickness patients in specific. The respondents have uncovered that they frequently confront unjustifiable treatment when applying for a work. With respect to the shame and societal isolation caused by the illness, the finding of the ponder appears that, nearly all sickness influenced people are constrained to stow away themselves from their relatives, so as not to be stigmatized and not to disrespect their families in their communities, and relocate to regions exceptionally distant from their birth places ideally to sickness colony settlements (Rahel H, 2016). Moreover, socially a woman affected by leprosy lacks self-esteem to get involved in different social affairs such as Idir, wedding and different social gatherings with the other community members freely.

1.2. Statement of the problem

A baseline needs assessment study on persons affected by leprosy and their family members in Addis Ababa was conducted in 2011. It focused, socio-economic situation, attitude, self-esteem. The study is one of its kinds and can be considered as a baseline assessment and a pioneer for it has extensively raised many critical issues of the victims. It has specifically focused on the area around All Africa TB Leprosy Rehabilitation and Training Center (ALERT) where leprosy patients dominantly live. As the study involved leprosy patients, their families and those people living in their surroundings who are not affected by leprosy, it is very comprehensive in describing the issue and the situation of the victims (Menberu.2011).

In Ethiopia different researches have been done on leprosy and people affected by leprosy like a research by Richard Pankhurst (2014), the history of leprosy in Ethiopia up to 1935, MeseleTerecha (2005), Leprosy, and Society in Ethiopia, DesalegnTerecha (2014), the pleasing unspoken voices and SileshiBaye (2015), leprosy in Ethiopia. The research by Pankhurst and Mesele have many commonalities to mention, both of them give emphasis in the history of leprosy in the world and in Ethiopia, the effects of derogatory words, religious values and laws to mold the misconceptions towards PAL. The study by Pankhurst in 1984 and Mesele in 2005 also mentioned in their respective researches that the Ethiopian outlook to the disease can be seen in the country's traditional code the FethaNagast literally (Law of the Kings). The law declared that a person affected by leprosy could not serve as a priest and a patriarch.

Mesele's(2005) also discussed the emergence, development and expansion of people affected by leprosy settlements and the transformation of those deprived members in Ethiopia. The research added a social history of leprosy sufferers in the 20th century Ethiopia, explains that problems related to marriage were long lasting and profound factors to aggravate social exclusion of leprosy sufferers. The property ownership of people affected by leprosy has been influenced by the society taking over the property of the leprosy sufferers by pushing them in to leprosaria according to the finding. Particular concerns of sickness patients incorporate the illness result, future security, and misfortune or alter of work. In expansion, patients feel blameworthy, restrained and insufficient. The person affected by leprosy experiences a so called psychological vulnerability, not only due to the stigma associated with the disease, but also due to the consequences of the disease and the treatment itself The study primarily help

to make a difference the women casualties enduring from disease by appearing the circumstance they are in and showing activity focuses that would offer assistance to progress their circumstance. GOs (policy makers, program developers at different levels), NGO, IOs.

A research study In addition, tropical disease (NTD) services such as leprosy programmers states that, with the use of drugs and with leprosy reactions, people affected by the disease can develop transformations in the perception of their body image. They also point out these people's difficulties in continuing daily life and work activities, which can lead them to isolate themselves socially. In the same direction, another survey refers to women with leprosy and the impacts produced by transformations in their physical body, affecting self-esteem and affective relationships. This consider pointed to explore the encounters of ladies influenced by disease with respect to conjugal life and sexuality, comparing these to the encounters of ladies with other physical incapacities and to those of able bodied ladies in South-East Nepal. This consider centered on ladies, since ladies are frequently more seriously influenced by disease and it's (Annat T.2016).

Thus, the present study investigates endeavors to address the circumstance of family and women in leprosy and fill the gap on psychological, economic and social effect Martial relationship women's in leprosy confront as a result of social stigma and marginalization the information, education and communication of women affected by leprosy..

1.3. Research Question

- ✓ How do families experience living with leprosy? How family and societal perception affects their life?
- ✓ What are the risk factors of vulnerability for families living with women affected by leprosy?
- ✓ What are the risk mediating resources for families living with women affected by leprosy?
- ✓ What coping strategies do families of women with leprosy use?

1.4. Objective of the study.

1.4.1. General Objective

The general objective of the study was to explore experience of family vulnerability and resilience among women affected by leprosy in kolfiekeraniyo sub city woreda one.

1.4.2. Specific Objective

- ✓ To explore families experience living with leprosy how family and societal perception affects their life.
- ✓ To investigate the risk factors of vulnerability for families living with women affected by leprosy.
- ✓ To assess the risk mediating resources for families living with women affected by leprosy.
- ✓ To analyses coping strategies do families of women with leprosy use

1.5. Scope of the Study

This study was conceptually scoped, by mental, social and economic and martial relationship and coping of family experience issues of women influenced by Leprosy and methodologically it is qualitative type research was utilized. Geographically delimited to KolfieKeraniyo sub city Woreda one.

1.6 Significance of the Study

The study primarily help to make a difference the women casualties enduring from disease by appearing the circumstance they are in and showing activity focuses that would offer assistance to progress their circumstance. GOs (policy makers, program developers at different levels), NGO, IOs, researchers. Practitioners, Community based organization and Family based organization etc. The discoveries of the think about will advantage arrangement creators and organizers serving as a marker of the crevice that has got to be worked on. Other than, it is advantageous for executing accomplices both government and nongovernment organizations for it uncovers the real life of women in leprosy confront and addresses the issues in like manner. The truth that the study highlights the significance of counting wants of this area of the society in all improvement endeavors and the significance of hearing their voices are extra importance.

1.7 limitation of the study

This study was conducted using qualitative approach particularly case study. h. Therefore, this research also shares this limitation, which means the result of it cannot be generalized. Most of the women affected by leprosy live by begging. I was also unable to use the tape recorder in the data collection process because of the late response from the respondent to have ethical clearance and to facilitate the permitted budget for the study. I was also unable to review patient cards and case stories. Finally, I was not able to include other health professionals working with the rural PAL in the study such as dermatologist, ophthalmologist, surgeon, prosthesis orthotic technicians, physiotherapists.

1.8. Operational definition

Leprosy: - a chronic, mildly infectious disease caused by mycobacterium affecting the peripheral nervous system, skin, and nasal mucosa and variously characterized by ulcerations, tubercular nodules, and loss of sensation that sometimes leads to traumatic amputation of the anesthetized part.

Social exclusion: -refers to tendency of vulnerability of people to be excluded socially and economically due to the inability of a society to treat all groups with equality

Social Marginalization:-is discrimination based on the basis of caste, gender, age, HIV status, occupation, ethnicity , religion, sexual orientation color leading to stigma, discrimination, sustained exclusion and something violence, overlooked development challenges or themes such as chat addiction and mental health problems.

Stigma-is an attitude of identifying and labeling people, based on presumed thought through out to be unacceptable qualities or deviant. .

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

HAPTER TWO

REVIEW OF RELATED LITERATURE

2. Theoreticalliterature

2.1. Introduction

The chapter comprises the empirical and theoretical components of the literatures. In regard to the empirical literature, general overview of leprosy is tried to be dealt with. This, what is Leprosy, leprosy in Ethiopia context, family resilience against leprosy-related discrimination, risk factor and vulnerability of leprosy are discussed.

2.1.1. What is Leprosy?

Leprosy, also known as Hansen's disease, is a chronic infectious disease caused by the bacterium *Mycobacterium leprosy*. It primarily affects the skin and nerves and can lead to severe disabilities if left untreated. The disease has been known for thousands of years and has been a subject of study and curiosity throughout history (WHO, 1995).

According to the World Health Organization (WHO), leprosy is still considered a public health problem in some countries, particularly in parts of Africa, Asia, and Latin America. As of 2019, over 200,000 new cases were reported globally, indicating the ongoing significance of the disease.

The transmission of leprosy is not fully understood, but it is believed to occur through respiratory droplets from infected individuals and prolonged close contact. It has a long incubation period, ranging from months to years, which makes it difficult to trace the exact source of infection. However, research has shown that the risk of transmission is comparatively low, and around 95% of people have natural immunity to the disease.

Leprosy primarily affects the skin and peripheral nervous system, leading to characteristic skin lesions and nerve damage. The initial symptoms may include pale or slightly red patches on the skin that are numb to touch. As the disease progresses, it can cause disfigurement, loss of sensation, muscle weakness, and even disability if left untreated (Menberu et al., 2011).

.The diagnosis of leprosy is primarily based on clinical symptoms, such as skin lesions and nerve impairment, as well as laboratory tests to detect the presence of the bacteria. Early

diagnosis and treatment with multidrug therapy (MDT) are crucial in preventing the progression of the disease and minimizing disabilities (ibid).

Fortunately, leprosy is curable with the use of antibiotics, specifically a combination of rifampicin, dapsone, and clofazimine for a recommended duration of six to twelve months. MDT has been provided free of charge by the WHO since 1995, contributing to a significant reduction in the global burden of leprosy (WHO,1995).In addition to medical treatment, social support and rehabilitation are essential components of leprosy control programs. Efforts are made to reduce stigma and discrimination associated with the disease, as historically, leprosy sufferers often faced isolation and societal exclusion. In conclusion, leprosy is a chronic infectious disease caused by Mycobacterium that affects the skin and nerves. While it remains a public health concern in some areas, significant progress has been made in its diagnosis, treatment, and prevention. Continued efforts are needed to eliminate leprosy and support those affected by it.

A persistent, gently irresistible infection caused by mycobacterium leprosy influencing the fringe apprehensive framework, skin, and nasal mucosa and differently characterized by ulcerations, tubercular knobs, and misfortune of sensation that some of the time leads to traumatic removal of the anesthetized portion Distinctive theories as to the birth put of disease as a malady have been made. A few scholars consider upper Nile and others accept waterway Indus and Israel as the support of disease. In reality, the supreme prove for the event of the infection is seen within the skeleton of Egyptians within the 2nd century BC and preserved bodies of the 5th A.D. (Menberu et al., 2011).

Concurring to Mesele (2005) verifiable writing of disease came within the 2nd half of the 20th century especially on hypothesizing the birth put or root of sickness as a malady. After different verifiable scenes the primary objective prove for the predominance of disease in Egypt came as it were from archaeological findings, which revealed four sick skulls buried within the Egyptian desert spring of Dakhleh ,in 200 B.C. The moment indubitable archeological prove, with clear pockmarks of mangling sickness was found from the burial ground of Coptic Christians at El-Bigha, in Upper Egypt dated 500A.D. India and the Indus stream valley have moreover been credited by others as birth put of sickness. Besides, the Persians who had created solid socio-economic relations with Indians and had selected them in their armed forces had such involvement as well.

In general, more than single historical episodes such as wars, trade and pilgrimages are given for other long term factors for the dissemination of leprosy among different regions and peoples. (Mesele,2005) .Leprosy presently occurs markedly in territories of Asia, Africa, and central and South America. However, the disease is observed to be severe and widely spread in Africa. As the baseline need assessment study carried out in 2001 revealed, the distribution and prevalence of leprosy is neither uniform nor random. The distribution and prevalence of leprosy are observed to be higher in males than females apart from certain African countries, where higher rates have been reported among females. However, it is the female who suffer more from the effects of leprosy than men due to the low natural immunity, resulting from pregnancy and their low social status. ((Menberuetal., 2011).

2.1.2. Leprosy in the Ethiopian context

Historical records and inquires about uncover that sickness is ages ancient in Ethiopia and it is accepted to have initially spread from neighboring countries-Nubia, Egypt and nations around the Ruddy Ocean since of Ethiopia's solid exchange relations with these ranges. (Pattern, 2001) A book on chronicled considers of chosen locales 1901-2001“Leprosy, Leprosaria and society in Ethiopia” by Mesele (2005) moreover uncovered that by ethicalness of its long standing exchange and other social relations with the disease ridden locales of the world i.e. Egypt, the Situate, the Greco-Roman world and the Middle eastern promontory, disease might have been one of the foremost old infections in Ethiopia. At the minute, more than ten thousands of sickness influenced citizens counting their families and relatives live in sickness settlements. Thousands are including up each year with 7-14% of inability rate among recently analyzed cases alone which reach up to 5000 yearly. The number of unused cases within the twenty a long time appears to appear no.

Leprosy is considered as hereditary and a curse of God. Even marriage with leprosy affected people was prohibited legally in the former Ethiopian family law. There were also poems written to depict the social disparity of the victims from others. In this particular book, the misconception about the disease inhibited the victims from going to hospital but rather resort to traditional medicine. (Desalegn, 2014)

2.1.3 Family Resilience against Leprosy-Related Discrimination

Resilience can be understood as a dynamic and complex process (as well as outcome) of successfully adapting to difficult or challenging life experiences, especially through mental, emotional and behavioral flexibility and adjustment to external and internal demands Many

factors can contribute to how well or poorly people adapt to adversity, including how they perceive and engage with the environment, their social resources and their use of coping strategies. Many of these “protective” or adaptive factors can be learned and strengthened, such as emotional regulation, self-efficacy, support seeking behavior, communication skills, problem solving abilities and engaging in a supportive environment. In the face of stressors, these protective factors are said to modify the individual’s or groups’ response to adversity, thereby reducing the likelihood of negative outcomes (Pattern, 2001).

Evidence-based approaches to building resilience within families have been described including where a family member has health and disability problems , or is stigmatized and in resource-poor settings Versions of these approaches are now also conducted as brief interventions , addressing family stress, conflict, cohesion, adaptation, working through adversity, beliefs and spirituality, and broader communication beyond the family. Unfortunately, most of them are highly resource intensive, with even the brief interventions requiring multiple counseling sessions with each family over many months. In addition, most are not designed for neglected tropical disease (NTD) services such as leprosy programmers. The key challenge is how to make these highly strategic interventions more suited to the realities of treatment, rehabilitation and other services, and thereby more accessible to people in leprosy-endemic countries. The improvement in quality of life noted for people affected, but not for their family members, in suggests that the attention provided to them through the project may have had substantial benefit for them, but as noted above, was insufficient to improve the quality of life of their family members. It is self-evident that improving the resilience of families in extreme poverty requires more of a long-term, multifaceted and systemic intervention. This is an important lesson for future research.

2.1.4. Risk Factor and Vulnerability of leprosy

Investigation was to characterize important risk factors associated with leprosy incidence in household contacts in order to support monitoring programs with the use of screening procedures Psychological risk and Vulnerability leprosy Economic risk and vulnerability leprosy,, Martial relationship risk and leprosy Social risk and vulnerability leprosy, that might identify individuals at a high risk, improving early diagnosis and treatment.

2.1.4.1. Psychological risk and Vulnerability leprosy

Scott (2006) contended that sickness emphatically impacts the behaviors of individuals influenced by leprosy. The infection can influence a patient’s conduct for the rest of their life.

The tall rate of, self- destructive endeavors highlights the patients' concept of the mental clutter as a result of sickness. Assortment of feelings are escalation experienced by disease sufferers. Pain shows up to be the primary and most common response those disease sufferers appear after a determination of disease. In some cases the dismalness gets to be incessant and the frequency of psychiatric clutters is subsequently demonstrated. Isolation and hardship of the normal benefits of domestic situations lead to uneasiness. They appear to have powerless egos and need autonomy in feeling, considering and activity. Disease has long-term results related to disability and shame. This incorporates a major effect on mental wellbeing. This study aims to consolidate current evidence regarding the mental health impact of leprosy on affected persons and their family members.

In addition, determinants influencing mental health outcomes among leprosy-affected persons and effective interventions are examined. A keyword-based search was conducted in PubMed, Web of Science, Scopus, PsycINFO, Infolep and InfoNTD; additional literature was also considered. Articles presenting primary data involving leprosy-affected persons or their family members experiencing mental conditions were included. Independent extraction of articles was executed using predefined data fields. Articles were sorted according to relevance. In total, 65 studies were included in this systematic review. Multiple psychiatric morbidities have been identified among leprosy-affected persons, including depression, anxiety disorders and suicide (attempts). Additional factors were found that may impact mental health. Moreover, studies found that demographic factors, lifestyle and disease-specific factors and stigma and discrimination impact mental health.

Depressive symptoms and low self-esteem were identified among children of leprosy-affected persons. In addition, interventions were identified that could improve the mental wellbeing of leprosy patients. Depressive disorders and anxiety disorders were found to be very common among persons affected by leprosy. Feelings such as fear, shame and low self-esteem are also experienced by those affected, and their children. Further research is necessary to ensure that mental health impact is included when determining the burden of disease for leprosy, and to relieve this burden (Pattern, 2001).

2.1.4.2. Economic risk and vulnerability leprosy-

Scott (2006) expressed that when the wage era of the disease sufferer influenced, their family experienced financial issues frequently denying them of their day by day necessities. Generally, alter in business leads to tolerating less requesting coming about in a drop in

income that leads to financial issues. As individuals influenced by sickness are segregated from participating within the financial exercises, they gotten to be disconnected and lose self-confidence. Frustrations with work, at last constrain patients into liquor abuse, asking and appropriation of a parcel of time and cash was required amid the determination and treatment handle of sickness, the postponed sickness would moreover impede the labor capability of patients as well, and these put a overwhelming burden for the disease patients. The patient is a special group and need more concern. Our goal was to assess the economic burden of leprosy places heavy economic burden patients and governmental policies and programs could substantially alleviate this. Measures to implement more active surveillance and early diagnosis would benefit both populations, while labor protection and medical insurance are urgently needed for migrant patients and easier access to medical services and social aids could substantially decrease the burden of leprosy for resident patients.

2.1.4.3. Marital Relationship Risk and Leprosy

Marital relationship affect relationships, to the extent that even divorce is not uncommon in marriages in which one spouse develops leprosy Given the fear of contagion that surrounds leprosy, it is likely that divorce is only the tip of the iceberg and that many problems in marital and sexual relationships go unnoticed. Investigate the experiences of women affected by leprosy regarding marital life and sexuality, comparing these to the experiences of women with other physical disabilities and to those of able-bodied women in the stigma surrounding leprosy can be a major burden and affects many dimensions of a person's life, including intimate relationships. We aimed to investigate the experiences of women affected by leprosy regarding marital life and sexuality, comparing these to the experiences of women with other physical disabilities and to those of able-bodied women.(Yonas, 2014)

2.1.4.4. Social risk and vulnerability leprosy-

Regardless of religious and cultural variations among different societies, leprosy has commonly been associated with sin, impurity and rejection incurred from God as a punishment.

It has also been commonly seen as hereditary disease. It deserves a reputation as "the death before death" and "the disease of the soul". These societal misconceptions have mainly been traced in their origin from "the age old" prevalence, mysterious pathology, hideous physical deformities of the disease and its chronic nature, in which the infection is not followed by immediate death but rather sever physical deformities and mutilations. Traditions in China,

India and Japan have similar traditional conceptions in associating leprosy with sin, impurity and affected people were isolated, excluded from society, and stigmatized. The stigma due to leprosy represents a social stigma, associated with a strong feeling that a leprosy patient is shameful and not to be accepted normally by society. It is also called a leprosy-related stigma, leprostigma, and the stigma of leprosy. Person who is strongly disliked and avoided by other people because of something bad that he or she has done: She claimed that the rumors had made her a social. Desalegn, (2014)

2.3 Empirical Literature

Social prohibition could be a concept centering on entire individual who is cut off from diverse point of the social bond that joined to the society. It is reflected in a combination of - a need of regulating integration and moo degree of social interest, fabric hardship, and deficiently gets to social rights (Gijisberg and Vrooman, 2007). Hence, the sickness influenced people are the marginalized and stigmatized gather that has multidimensional avoidance. (Yonas, 2014) The conviction that disease is innate is profound established. But for few individuals who had the chance to get it the nature of the maladies from different sources, anything the instructive level of the person, the conviction that sickness innate is still far reaching. Since of such deep-rooted concepts around sickness, people living with disease are stigmatized and disconnected from all intelligent in society. The disease debilitated person, be that as it may, faces still another issue. The society accepts that: Leprosy has deep rooted stigma in the society, it is absolutely feared and caused migration of thousands of Ethiopian leaving behind their beloved ones and birth places. The society holds misconception that it is hereditary, calamity of God, curse, etc. This exposed persons affected by leprosy to loss social dignity. Begging has been accepted by the leprosy affected people themselves and the society for years. (Desalegn, 2014) Among communicable infections, leprosy is the driving cause of lasting physical inability. Tall incapacity review in a recently analyzed sickness quiet speaks to a delay in determination which May be due to the quiet displaying himself at the wellbeing office late within the course of the illness or due to misdiagnosis at the wellbeing office as a result of destitute competence of wellbeing specialists in recognizing the signs and side effects of disease. In Ethiopia, the national information appears that rates of incapacity review II among recently analyzed cases of sickness have astoundingly diminished (70% in 1986/7 to 6.9% in 2012). But the territorial breakdown information appears that the normal five a long time inability review II in recently analyzed cases is more noteworthy than 10% in most of the locales but a far distance, Oromia

2.2.1 The effects of leprosy on women

The case of women affected by leprosy is not different from other people affected by leprosy. In any case, the impact has seriously influenced ladies due to the moo status given to them within the community. The burden of ladies influenced by sickness is multiplied due the sexual orientation or control relationship between male and female within the community made the ladies subordinate, and separates them from get to and control of assets. Need of cash to go to wellbeing offices or get treatment is portion of the impact of sexual orientation. Other than, for leprosy women it is troublesome to completely lock in within the family chores due to the serious physical join of the illness. (Desalegn, 2014)

In developing countries, woman holds subjugated and dependent status. In creating nations, lady holds oppressed and subordinate status. When she gets to be debilitated she loses the small positive status she may have all together. In this way, she gets to be completely confined, stationary and restricted to the house. It is much more troublesome for her than it is for a male with inability to take an interest in open exercises or gatherings, unless extraordinary endeavors are made to assist her do so. For her, there's no incapacity remittance, no natural alteration, practically no get to instruction or preparing and so to business, and no opportunity to gotten to be included in self-help developments. (Alemu, 2012)

As far as marriage problem is concerned, the situation of disabled women including women in leprosy cases in developing countries is much more difficult, as marriages are mostly arranged. Stereotyped concepts, prejudices and negative attitude about disability are so deep-rooted that they greatly influence these arrangements. The marital opportunities of females with disability are limited. For example, the blind women are downward to in marriage than blind men. This happens due to people's perception of persons with disability and gender relations, particularly as they are manifested in the roles of a housewife (Boylan, 2008).

2.6. Conceptual framework:

A persistent, gently irresistible infection caused by mycobacterium leprosy influencing the fringe apprehensive framework, skin, and nasal mucosa and differently characterized by ulcerations, tubercular knobs, and misfortune of sensation that some of the time leads to traumatic removal of the anesthetized portion Distinctive theories as to the birth put of

disease as a malady have been made experience of family vulnerability and resilience among women affected by leprosy.

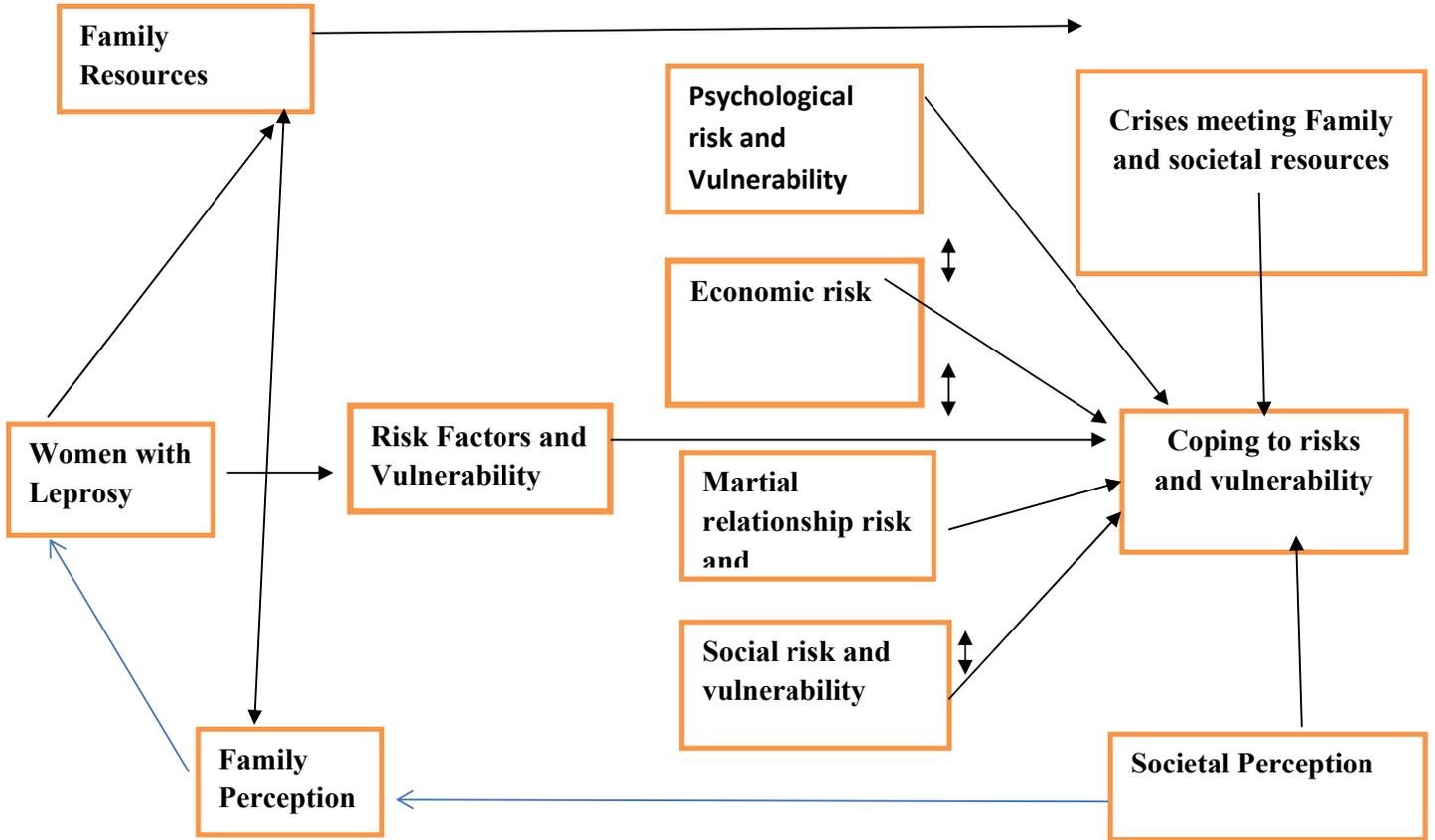


figure2. 1. Conceptual framework

Source own model (2023)

CHAPTER THREE

RESEARCH METHODOLOGY

3.1. Introduction

The chapter presents important components of the research methods, including research design, , sampling technique and sampling size. The chapter also presents methods of data collection, including primary and secondary data sources. Of the primary sources of data collection, in-depth interview, key informants interview, FGDs and observations were employed. With regard to secondary sources of data, analyses of different materials were conducted. Moreover, data collection tools, methods of data analysis and ethical considerations of the study are incorporated in the chapter.

3.2. Research Design

The study employed **descriptive qualitative research design** as it helps to put the detailed picture of the subject matter. Qualitative research tends to be more open and flexible in discovering new issues and help to have an in-depth understanding of a social phenomenon. It can also be seen as one where the stress is on the understanding of the social world through an examination and interpretation of that world by its participants (Kreuger&Neuman, 2006). In line with this, the researcher employed qualitative research approach as it provides the most appropriate way of investigating and answering the research questions in detail. Creswell (2007) stated that the research design development in qualitative method has direct association with the philosophical paradigm that the researcher follows. Congruently, the design of this study is selected as the researcher follows a **constructivist research philosophy**, arguing that viewing issues from the subjective experiences of people helps thoroughly understand the individual's feelings, beliefs, behaviors, opinions, lived experiences and extract meanings out of them. Accordingly, as the main objective of the study is examining the experience of family vulnerability and resilience among women affected by leprosy in kolfiekeraniyo sub city woreda one.

Based on the general purpose of the study, the researcher employed descriptive research, as it presents a picture of the specific details of a situation, social settings, relationships, issue or concern and begins with a well-defined subject and conducts research to describe it

accurately (Krueger and Neuman ,2006). Moreover, the physical environments and physical appearances of the study participants were described.

3.3. Sampling Technique

Among the types of sampling, non-probability sampling was employed to identify participants of the study because the researcher learned that it is difficult to determine the sample size of the potential research participants in advance except putting the tentative one as there is limited knowledge about the larger group from which the sample is anticipated to be taken. According to Neuman (2007), qualitative researchers select participants who have an ability to provide substantial contribution to the study. Krueger and Neuman (2006) also discussed that what matters in qualitative research is the relevance of the participant's rather than their representativeness what determines their selection for the study. Congruently What is more, the researcher's perspective, the research questions and objectives of the study also fit such type of sampling, as the objective of this research is not to generalize the result for the larger population; but rather to have detailed examination of the issue studied.

Among the types of non-probability sampling, purposive were employed. Judgmental purposive sampling is used when the purpose of the research is not to generalize to a larger population and when the aim is to gain a deeper understanding of situation. It is also the appropriate sampling strategy for special situations and uses judgment of the researcher in selecting cases with a specific purpose in mind. What is more, it is employed for the reason that the goal of purposive sampling is to select participants who are relevant to the research questions (Kreuger&Neuman, 2006).

3.4. Sample Size

The sample size of qualitative research method can be influenced by **data saturation**. That is, when gathering fresh data no longer reveals new properties (Creswell, 2014). Compatibly, Fusch and Ness (2015) revealed that in qualitative research, sampling is not a key rather; it is the richness of the data that is vital. It is furthered that saturation is achieved neither because of large sample size nor small sample size; rather richness and thickness of data get supreme consideration in data saturation. In view of that, rich refers to quality of data elaborated, exhaustive, intricate and deep data; and thick means quantity of data- a lot of data, the sample size of the study was15 for qualitative research large number is not appropriate.. Here, the experiencesexamined by employing a case study method as it helps to get holistic and expressive characteristics of real life events. What is more, the detail information obtained

from the key informants was supplemented to the study's findings obtained through other techniques of data collection, including interview, FGD, observation and document review. Accordingly, thick and rich data were collected and triangulated whereupon data saturation was achieved.

3.5. Methods of Data Collection and Source of Data

In order to build an in-depth picture of the case at hand, the researcher employed extensive data collection methods rather than relying on a single data. Yin (2003) discusses that qualitative researchers typically rely on different methods for gathering information, such as participating in the setting, observing directly, interviewing, focus group discussions, document review, audiovisual materials, archival records, and physical artifacts that are incorporated either in primary and secondary sources. Accordingly, both of the data sources were utilized in the study.

3.5.1. Primary Source of Data

Primary source of data are types of data sources that are collected for the first time, and are original in character. Participating in the setting, observing directly; interviewing, focus group discussions are categorized under the primary sources of data (Kothari, 2004). Accordingly, in-depth interviews, key informants interview, FGD and observations were employed in the study. Boyce and Neale (2006) defined in-depth interviewing as a qualitative research technique that involves conducting intensive individual interviews with a small number of respondents to explore their insights on a particular idea, program, or situation.

Moreover, it entails that the researcher start interview with a set of general open questions which are in line with the research questions. Up on this, interview guides were prepared followed by probes that further helped to unearth the details and underlying meanings about the subject matter. Accordingly, six (6) of the women were interviewed in-depth followed by probation after probation based on their responses.

3.5.2 Key Informant Interview

Key informants are people who know a lot, at least about their domain, and willing to share their knowledge with the researcher. In key informant interview the informants talk with the researcher for relatively longer hours about an issue (Bernard, 2006) cited in (Chekole, 2017). Accordingly, **three (3) key informants** were selected from Social and Labor Affairs Office and from the Office of Women, Children and Youth Affairs. The Key informant interviewees

were purposely recruited from the aforementioned government offices as the issue under the study is one of their sectorial concerns.

3.5.3 Focus Group Discussions

The FGD conducted with two groups of the **PAL comprising of 15 members**. The number of participants in each FGD was odd to reach in consensus. Inpatients and out patients passed through the challenge to reintegrate with their community of origin and finally not able to return included in the FGD. The discussants complete strangers and homogeneous (sex and background) to have better discussion and counter argue. The researcher had a moderator role to facilitate the discussion. As a moderator the researcher tried to involve all the participants in the discussion. The researcher also tried to balance the discussions and not to be dominated by some individuals and facilitated the group to reach into consensus on the discussion points.

3.5.4. Observation

Observation was the other data collection method employed as it helps to comprehend the contextual information of the research participants. In line with this, Corbetta (2003) unearths that observation is the technique for gathering non-verbal data in which the researcher is anticipated to delve in to the social and physical environments of the study participants. Creswell (2014) also affirmed that gathering field notes by using observation is important for complementing the data gathered through other tools. Likewise, Creswell (2007) described that context is essential to understand about the participants in addition to verbal interview. To this end, **observation checklists were developed** and gestures constituting emotions/feelings of the study participants, their physical appearances, and their social and physical environments were thoroughly considered and examined since the observation of the stated and so forth issues served to compliment and triangulate the information obtained through the other methods of data collection.

3.5.2. Secondary Sources of Data

Secondary sources of data are those which have already been collected by someone else and passed through different data analysis processes (Kothari, 2004). In view of that, analyses of reports were employed as a secondary source of information.

3.6. Method of Data Analysis

The central purpose of qualitative data analysis is to select, sort and organize the masses of data acquired during the data collection phase in such a way that the themes and interpretations that emerge from the process address the original research questions. In addition, **it is a way to look for the major themes and patterns in the data and then to break these down into sub themes and categories** as such distinctions become important and vice versa. Thus, we must continually move back and forth between initials and later interviews, identifying units of meaning, coding and interpreting the data as we go along (Grinnell & Richard, 1997). According to Braun and Clark (2006), thematic analysis is the most widely used in qualitative data analysis. They also indicate that thematic analysis is qualitative descriptive approach that is mainly as Creswell (2007) identified, the most common elements of qualitative data analysis includes, categorizing and theme. Up on this, the researcher attempted to reduce the collected data into manageable themes from field notes and tape recorder. Since coding involves a systematic recording of data, the researcher used codes to cover key themes, ideas and concepts that were collected from the study site. Categories and subcategories for codes were developed. Then detailed analyses were categorized according to their similarity and difference of ideas and information. In addition, thematic areas were identified and categorized based on the research questions. Then, the researcher gave headings for the identified and categorized themes.

3.7. Ethical Considerations

Consideration of ethical issues is crucial as the study deals with human beings. According to Kreuger&Neuman (2006), social work researchers should follow proper ethical guidelines even when the study participants are negligent or unaware of that for the fact that no one should be coerced or forced to participate in the study and participation has to be with the full consent of the participants. In line with this, Punch (1998) stated that recognition and consideration of ethical issues has become a bigger feature of the social science research literature since some qualitative research deals with the most sensitive, intimate and inner most matters in people's lives, and ethical issues inevitably accompany the collection of such information.

What is more, key informants were also provided informed consent without any hesitation. To this end, in order to get their consent, the purpose of the study was properly explained that the study output is used for educational purposes. In order to make them confident and create

a comfortable environment, the interview places were arranged based on their interest. Accordingly, the interview was held at their home and their workplaces. Besides, to ensure anonymity, the study participants were informed that their right names would not be written down. Accordingly, pseudonyms were employed. They were also informed that they have full right not to participate or else to stop the researcher at any time if they do not feel comfortable.

CHAPTER FOUR

FINDINGS OF THE STUDY

4.1. Introduction

The chapter presents the findings of the study that are gathered through in-depth interview, Focus Group Discussions (FGDs), key informant interview and observation as discussed in the method of the study. An in-depth interview and FGDs were conducted with six (6) women's. An in-depth interview was also held with key informant interviews of focal persons from Office of Women, Children and Youth Affairs as well as Office of Social and Labor Affairs in order to have context-based understandings about the experience of family vulnerability and resilience among women affected by leprosy. Furthermore, observation was made in order to obtain thick and rich data about the issue under study. As a qualitative research, patterns, categories or themes were built out of the raw data and the data were interpreted and triangulated in account of objectives of the study. Accordingly, the chapter compresses themes with their respective sub-themes. The first main theme is the demographic profile of participants of the study, which consists, pseudo names, marital status, religion, education level and family background. The second overarching theme is factors affect them, which encompasses two paramount sub-themes, including push and social, which further consists of six (5) subthemes, including living conditions, economic situation, devaluation of the significance of education, low wage in employment, deterioration of the quality of education, and cultural factors, and two (2) sub-themes, composed of differences in wage and success

4.2. Background of the Respondents

The overall objective of the study was to examine experience of family vulnerability and resilience among women affected by leprosy the case of kolfie keraniyo sub city woreda one. To achieve the objective, of the study incorporated fifteen women leprosy victims' respondents.

Respondents of the in-depth interview were fifteen in number all were women leprosy victims' ranging from 30-70 years of age. . With regard to their educational level five respondents were Grade 9 to 12; two respondents were not read and write, three respondents were read and write and the remaining five respondents were Grade 1 to 8. Regarding to

marital status four of them had single, six respondents were divorced, and the remaining five respondents were separated. Regarding Occupation eight respondents were daily work, four respondents were participating in trade and the remaining three respondents were Unemployed. Finally, regarding to children seven respondents were have child and the remaining eight respondents were haven't a child.

Table. 4.1 Back ground of the Respondent (Demographic Information of the participant)

Respondent	Age	Sex	Education	Job	Marital Status
1 st	50	F	0	Trade	Divorce
2 nd	53	F	5	Unemployed	Divorce
3 rd	38	F	7	Daily work	Single
4 th	39	F	6	Trade	Marriage
5 th	50	F	9	Trade	Marriage
6 th	65	F	0	Unemployed	Marriage
7 th	47	F	Rea and write	Daily work	Marriage
8 th	68	F	Red and write	Unemployed	Divorce
9 th	43	F	4	Daily work	Single
10 th	41	F	10	Daily work	Divorce
11 th	53	F	5	Daily work	Single
12 th	43	F	5	Daily work	Single
13 th	54	F	5	Trade	Marriage
14 th	38	F	6	Daily work	Single
15 th	30	F	10	Daily work	Marriage

(Source own data 2023)

4.3. Perceived causes of leprosy

Women respondents were inquired how they got to be mindful of their status. They were inquired their family's recognition around the infection and its cause. Out of the fifteen women respondents influenced by disease as it were seven of them felt that it is microscopic organisms or germ. Four of them don't know the case and four of them felt it is either revile or God related.

As per the thought gotten from one of my respondents, leprosy may be a infection caused by microbes. But she felt that she has procured the infection due to poverty or need of treatment. She clarified the detail as takes after. "We were living in kolfiekeraniyo sub city Woreda one. I was not flawless and our living standard was destitute and hopeless, a few kind of bizarre white stamp that at times gets to be ruddy like pepper showed up on my body. No one knows almost the infection. As the illness started its impact on my hand at early age of my childhood and I may not move my finger as I like, my guardians were irate at me and constrained me to move my fingers as some time recently appropriately. No one gets it me at the time. Since it is exceptional within the community, most individuals don't have an understanding approximately the malady. When it exasperates the circumstance on my body, my family brought me to the at that point 'Borchole" in Addis Ababa for checking my blood and get treatment. Borchale alluded me to the at that point Zenebework Healing center. For the perplexity of all almost the infection and need of treatment on time, my fingers my toes disabled and gotten to be debilitated. Disease isn't a commonplace type of infection in our community. Individuals in my locality don't know all almost the illness and they don't know that I have been uncovered to leprosy"

For the address how they obtained the data approximately sickness nearly all have at first confronted a few kind of check or harmed on the skin and afterward they had got the data around the case from companions and relatives but one out of them that gone to wellbeing offices know the case after one a long time of serious harm of her leg that uncovered her to inability.

One of the Women respondents influenced by disease told me that

"I was uncovered to disease when I was a child and I am the as it were one from the family that obtained the illness that I felt that it is my fate. I still don't know the cause of the malady why I am contaminated by it. Sickness was known in my town or the provincial zone and

named as ‘TilikuBeshita’ meaning the ‘The Incredible disease’ that made it something unnerving. My children are too free from leprosy”

One of the key respondents from partaking in exchange told that she comes to know around sickness after she has been taking part in exchange. She felt that disease isn't genetic but something that will come after birth .Still she does not have clear data almost the cause. The other respondent moreover clarified that Woreda one and the adjacent Woreda six have numerous casualties of sickness. She said that the conviction that disease is innate made profound established shame and segregation among the people groups of casualties.4.3. The Family vulnerability and resilience effects of leprosy on affected women

4.3.1 Leprosy its physiological effects

Disease in the event that it isn't treated on time incorporates a result of losing the hand; leg etc. or that can be uncovered to inability. Other than, it is effectively irresistible some time recently getting the medication.

One of the respondents say the psychological effect that came from locale at the age of 17 in 1986 E.C.34 a long time back says“I came to Addis Ababa for treatment after two a long time. At first I went to wellbeing station where I was living in Amhara. On my skin especially on confront and leg white interesting check showed up and checked. I went up to BahirDar and at long last I was alluded to RasDesta Clinic Addis Ababa. I came to Caution after three a long time but for I remained there I misplaced one of my legs. The other issue that I felt is that for I was resting with my most youthful sister some time recently I got the treatment; my sister had moreover been uncovered for it is irresistible.

Sickness as a infection confronted each of the respondents at diverse age, Six of the respondents told that they were uncovered amid child hood and don't know precisely their age, Two of them at 15, three at 18, three at 11, one at 9 and one at 5.

The respondents of FGD moreover rose how the impact of sickness extremely uncovered numerous to inabilities. As disease unequivocally harmed the sense of feeling numerous ladies voyage long remove and unconsciously harmed their leg.

4.3.2 The psychological effect of leprosy

There was meet with respondents to degree the mental impacts of women in disease. All respondents react as they self-confident and self-respect. For the address of inclination to be

alone or isolated from the society as is of them react as they feel forlornness and needed to partitioned themselves from others. In any case, all respondents react as they don't have any contempt towards society, relatives and to non- women affected by Leprosy. With respect to feeling of second rate to others of them feel inferior to others. Because it can be observed from the portrayal but a couple of respondents numerous of them felt emphatically almost the internal feeling approximately themselves. Two respondents that she assessed her age to be around 70 a long time told us that her feeling due to disease. "I came from Tigray. I am uncovered to disease after I gave birth to two children. I had been treated at healing center level in Tigray and afterward on I am alluded to the RasDesta healing center. I got the data as I am casualty of disease after I have been eluded. I take after the treatment for two year and six months. I don't know the beginning and how I am exposed. Others part of the family don't have. I felt that it is fair a fate. There's a local saying that 'sometimes out of numerous beans one may not cooked well' and my case is similar to that. In a few families, you will watch all individuals were tainted and you will feel hereditary. Since I made my living here in this particular area, I don't go anyplace distant out of my encompassing. At the minute, I am a grandma my children and grandchildren came to me but I don't go to their domestic for I feel they don't be discouraged by their neighbors and companions. Indeed I don't go to wedding of quick relative. I would like to secure the feeling of my family individuals in spite of the fact that now and then they demand me to blend with other community.

4.3.3 The Economic vulnerability of leprosy affected

A few of the respondents were worker in their claim town organized in affiliation and working by their level and we reimbursed month to month compensation. But that's not the case of all ladies influenced by disease. The FGD with both the casualties of sickness and those who are not casualties of leprosy revealed that the most financial impact of disease is that when the individual influenced by disease gets to be crippling, it is troublesome to have one's possess salary. The normal salary of sickness casualties is beggary. They advance uncovered numerous driven their life by asking and taught their children. These days their children of course they were free from disease and have been utilized and are found in several position that made their family halt asking and lead a conventional life. One of my respondents told me that; "As a casualty of sickness we misplaced my hand, the major challenges we experienced is incapable to work and gotten to be the poor person that emphatically hurt we felling and made feeble for need of cash and financially ended up dependent".

Correspondingly, the FGD with women affected by Leprosy shows that a few of the individuals influenced by disease need to work in case there had been a condition set in their level. They too raised Ra'iy Women's affiliation as the only organized affiliation that makes work opportunity for the casualties by their level. There's not much exertion from government and NGO's to organize and make wage creating exercises to disease casualties. For the FGD respondents questions postured in relation to financial impact of sickness, they clearly expressed that in case the casualties of sickness have a few kind of incapacity that's clearly seen, the plausibility of being utilized is nearly nil. The FGD respondents transparently uncovered that

“There is no disease casualty especially that has unmistakable physical harm utilized in both government and private organization. As an illustration, a neighbor of them who was casualties of sickness utilized for a watch in private house, he was terminated when known he may be a sickness victim”.

4.3.4 The social effects of leprosy

The complete issue of social prohibition radiates from the misinterpretation of the community around the root causes of disease. Individuals influenced by sickness have their claim servitude for they were settled in particular region.

In this respect respondents were inquired questions for measuring social impacts of sickness casualties. Take part in social Issues within the community; compare with the society of non-women affected by Leprosy, and on the off chance that they were part of IDIR (either men or ladies) or any other shape of CBO. Nearly all react emphatically that they have great communication and conducive environment. On the contrary, one of the women casualties reacts appropriately approximately the complete circumstance.

“There may be altering of demeanor taking after the presentation of cutting edge pharmaceutical. We cannot deny alter in shame and discrimination in spite of the fact that there was still a crevice that needs to be worked on. In spite of the fact that we are free from the disease, we ourselves make the shame and segregation. We need to inquire ourselves to what degree we were attempting to approach the huge community. Were we not abstaining from them? Is truly the community that makes social avoidance or not? In spite of the fact that asking was appalling and it is the final choice for disease casualties, the community was liberal in supporting the hobo who were impaired that helped numerous to lead their life and made them taught their children”.

The society made a favor for such hopeless casualties of sickness and nowadays there are numerous off springs of the casualty that worked in huge organization of the nation such as Ethiopian Carriers, Service of wellbeing etc. thus, the exertion must be from the victim's side as well to be free and absorb oneself to the community. Within the huge community of sickness patients, there was still a feeling of inferiority”

Additionally, the result I have gotten from FGDs indicates that;

‘Leprosy may be a skin and an open infection that has solid scorn among the community. It stigmatizes and separates the casualties of disease from the huge community. It made the casualties not to have a positive state of mind approximately oneself, made to lose self-confidence and regard. Disease made numerous of them to separate themselves from their adored, relatives, companions and neighbors. Casualties distance themselves whereas they cherish and do have fondness. Women casualties of sickness welcome individuals covering their hands beneath their dress for they stress for non-women affected by Leprosy .

The discussion with the FGD unequivocally contended that there's a social avoidance of ladies influenced by disease but numerous of them may conversation almost how they lead their life in concordance with the non-women affected by Leprosy. Women in disease started their life around this ponder zone and acclimated of it. In any case, they don't need to be seen out of this town for they were not comfortable. The same thought was raised by interview respondents that casualties of sickness live within the restricted put and don't need to acclimatize themselves with non- women affected by Leprosy. Indeed on the off chance that they come due to wellbeing issue or any other case, they fair keep up and remain. They avoid themselves from others.

4.4. Family Resilience (Coping) Mechanisms of women affected by Leprosy

Based on the result I have gotten from FGDs some potential resilience strategies for families **vulnerable to leprosy include:** From the finding of the study the respondent from coping mechanism was Knowledge and education Access to healthcare, Emotional support networks, Socioeconomic empowerment is, Advocacy and community engagement, Strengthening family bonds Families can empower themselves by seeking accurate and comprehensive information about leprosy, its treatment, and prevention. Understanding the disease can help reduce stigma and discrimination and enable families to actively participate in the treatment and support of affected members. Access to healthcare: Families can work towards ensuring that affected members have regular access to quality healthcare services. This can include

regular check-ups, medication adherence, and timely intervention in case of complications or disabilities associated with leprosy. Emotional support networks: Building a strong support network within the family and the wider community helps families deal with emotional and psychological challenges associated with leprosy. Sharing experiences, seeking guidance from organizations or support groups that work with leprosy-affected individuals, and providing a safe space for open discussions can help reduce feelings of isolation and stigma

Socioeconomic empowerment: Families vulnerable to leprosy can focus on enhancing their socioeconomic status to improve their overall resilience. This can be achieved through skills training, education, microfinance initiatives, or income-generating activities that help increase financial stability and independence. Advocacy and community engagement: Families can become advocates for leprosy-affected individuals' rights and needs by engaging with community leaders, local authorities, and organizations working in the field of leprosy. Raising awareness, dispelling myths and misconceptions, and promoting inclusive policies and practices can improve the overall well-being of families affected by leprosy. Strengthening family bonds: Maintaining strong family bonds can provide a sense of stability and support for leprosy-affected individuals. Engaging in regular family activities, fostering open communication, and promoting mutual respect and understanding can help families cope with the challenges posed by leprosy.

It is important to note that resilience strategies may vary depending on the specific cultural, social, and economic context of each family affected by leprosy. Additionally, support from healthcare professionals, social workers, and organizations specializing in leprosy can play a crucial role in assisting families in building resilience and overcoming the challenges associated with the disease.

CHAPTER FIVE

SUMMARY OF MAJOR FINDINGS, CONCLUSION AND RECOMMENDATIONS

5. Introduction

In this chapter, the summary, conclusions and recommendation of the research findings that had been analyzed and discussed in the previous chapter are briefly presented. Furthermore, based on the findings of the study possible recommendations were made.

5.1. Summary of Major Findings

The current think about demonstrated that the encounter of family helplessness and flexibility among ladies influenced by sickness, misfortune of sensation, skin dryness, wound, muscle shortcoming, physical distortion and inability. This finding shown that require for the change of wellbeing care and recovery administrations get to and quality and the got to raise the capacity and mindfulness of wellbeing experts almost sickness.

Among the mental challenges uneasiness and misery was the major mental disarranges detailed by the rustic Buddy in this ponder. A few of the signs of uneasiness and sadness detailed by the members were fear; stress, push, self-stigma, suicide endeavor; misery and forlornness. From the reports of the ponder members I can conclude that the mental challenges which are basically due to the disgrace and separation.

A few of the social challenges said by the ponder members were an issue of social interaction, disgrace, segregation, conjugal relationship, instructive drop out and the community misguided judgment towards the Buddy. The effect of the physical environment such as the climate condition, geology and framework was gigantic within the reintegration of the rustic Buddy as the members expressed amid the think about. Be that as it may, the think about appeared that require for solid mindfulness creation for the friend, community and wellbeing experts by stake-holders to diminish the misinterpretation around the cause implies of transmission and treatment of sickness to decrease the shame and separation.

Another issue experienced by the friend specified in this considers was financial effects such as the diminishment of efficiency, an issue of property possession and misfortune of

resources. The finding shown that the impacts of the bio psychosocial and financial challenges on the kolfie keraniyo sub city Woreda one Buddy and the require for all encompassing mediation to improve the physical, mental, social and financial recovery of the kolfie keraniyo sub city Woreda one friend to extend their adapting instruments and to improve their Involvement of Family Defenselessness and Strength among ladies influenced by Disease.

The think about discoveries encourage appeared that a few of the adapting components of the kolfie keraniyo sub city Woreda one friend. Concurring to the discoveries of the think about the kolfie keraniyo sub city Woreda one Buddy attempted to manage up the bio psychosocial and economic challenges through distinctive survival techniques. They endeavored to manage up the natural challenge by taking after their treatment, Unit and rehabilitation administrations legitimately and through conventional implies of treatment.

Self-stigma, getting to otherworldly places and heavenly water destinations, health education, counseling and Psychiatry administrations, involvement sharing from the Buddy inpatient and out patients of Caution Clinic and by watching the foremost helpless parts of the Buddy in Caution Clinic and within the Community of Zenebework were a few of the adapting instruments of the consider members for the.

In common, the current study shown that the multifaceted challenges of the kolfiekeraniyo sub city Woreda one Buddy to Involvement of Family Defenselessness and Flexibility among women influenced by Sickness.

5.2. Conclusion

The finding was able to appear that the antagonistic impact of disease on both the casualty and the society is exceptionally tremendous. The general objective of the study was to explore experience of family vulnerability and resilience among women affected by leprosy in kolfie keraniyo sub city woreda one.

In spite of the fact that, disease may be a bio therapeutic issue it moreover go with other psycho social and financial issues which require an all-encompassing approach to address it. Other than, the think about was too able to uncover that the psychosocial and financial issues of sickness have got an obliterating impact on the prosperity of the patients in a much higher degree than its physical impacts. Thus, study was investigates endeavors to address the circumstance of family and women in leprosy and fill the gap on psychological, economic

and social effect Martial relationship women's in leprosy confront as a result of social stigma and marginalization the information, education and communication of women affected by leprosy.

In conclusion, the mental, financial and social needs of sickness sufferers especially women casualties in kolfie keraniyo sub city woreda one were comparable to those of sickness sufferers in other sub city. Desires for self-acceptance, social acknowledgment and Individuals with sickness see their life and the way in which they conceptualized the infection is unequivocal variables for their levels of mental wellbeing. The escalated of feelings experienced by disease sufferers instantly after determination underscores how critical it is to have back quickly accessible. The degree to which the psychosocial and financial needs of disease sufferers will be met depends in portion on the way in which they are treated by their back frameworks. These frameworks incorporate patients, families and relatives, employers, medical specialists and clinic staff. Community acknowledgments were the major arrangements to manage up with the psychosocial and financial challenges confronted by individuals influenced by disease. The methodology of the study was qualitative study and mixed approach, and method of data collection was interview focus group and questionnaires'

The infection needs due concern by Caution. Some of the time such perilous irresistible malady is being considered as unfavorably susceptible case and meanwhile individuals influenced and uncovered to incapacity. Consequently, comprehensive ponder has got to be carried out and such dismissed issue has got to be seen from distinctive angel's /FGD/. Respondents moreover included that at the minute Caution is for those who have cash and can pay for the wellbeing benefit and locked in for common treatment. In some cases casualties of sickness check their position at Caution but constrained to buy medication from exterior. Subsequently, women in sickness especially for they don't buy pharmaceutical on the time may be uncovered to another harm focused group discussion.

5.3. Recommendation

- The government should be plan extraordinary bolster for women in leprosy. for illustration shoes has got to be provided to ensure them from fire and any other damage/FGD/- As there's program for incapacity by government, there ought to be extraordinary bolster and care for leprosy patients. /certifiable activity Esp. the community based organization who work on children, ladies etc. has got to center as well on women's sickness.

- At Woreda level due consideration should be given for sickness could be an open wellbeing and irresistible. Consequently, the government /official bodies should grant due consideration. As the focused group discussion .uncovered that ‘some wellbeing specialists at Woreda level themselves don't have the clear data on the cause of sickness instep they felt as hereditary. In addition, there's disgrace and pulverization of ladies in sickness among wellbeing expansion laborers.
- As the dialog with there’s change in shame and segregation for the limited put for them earlier has presently been possessed by other tenants of the city. Other than, there's alter of state of mind among the taught society than uneducated community. Be that as it may, still there's require of mindfulness creation.
- Victims themselves lose the strength to be with non-people affected by leprosy on the community side as well there's a profound established negative state of mind. The physical harm or the damage itself made them separate themselves. Subsequently, there’s require of social mobilization.
- Consultancy benefit for Buddies to fortify mentally as they can live, work and be changed.

5.4. Future Research Direction

There are some limitations that the researcher encountered that could be improved for further research. The first is the possibility of omitted variables. Perhaps considering some other variables which have not been included in this study may lead to more accurate prediction and understanding of the experience of family vulnerability and resilience among women affected by leprosy. Although experience of family vulnerability and resilience among women affected by leprosy have been operated throughout the country, this study has been geographically limited only to kolfie keraniyo sub city woreda one which might be limiting the generalization to the country level. Therefore, further studies are recommended to consider another part of the country including rural areas because of their possible effects of the factors. Since this study is conducted by using only qualitative source and open-ended questions, further studies are suggested to include quantitative source and methods like a closed ended questions.

References

- Adhicari, B. (2013). Risk Factors of Stigma Related to Leprosy: A Systematic Review. College of Public Health Sciences, Chulalongrorn University. Thailand. Vol.1. Issue2.
- Alston, M& Bowles, W. (2003). Research for Social Workers: An Introduction to Methods. (2nd ED). South Wind Productions, Singapore.
- Arulanantham, S. (2014, Augus). Addressing inequality and exclusion: the opinion of people.
- B., A. A. (2002). Attitudes Towards Females With Disabilities: The Case of Wolayitta Ethnic.
- Berg, B. L. (2001). Qualitative research methods for the social sciences. (4th Ed.). Boston: Allyn.
- Bryce son. A. and Pfaltzgraff E. . (1990). Medicine in the Tropics: Leprosy. (3rdEd.). Edinburgh,.
- Burako, Y. G. (2014). A Study on the Psycho-Social and Economic Situation of Leprosy Patients in Ethiopia: The Case of Admitted Patients at Alert center Addis Ababa, a university A Thesis Submitted to School of Social Work Presented in Partial Fu.
- Burns, S.N., & Grove, S.K. . (2003). Understanding nursing research.(3rd Ed.). Philadelphia:.
- Creswell, J. (2007). Qualitative inquiry and research design among the five approaches. (2nd. (n.d.). Creswell, Research Design: Qualitative, Quantitative and Mixed Methods Approaches, 4th ed. Thousand Oaks, California: SAGE Publications, Inc, 2014.
- CSSP. (2014). INSPIRE, CSSP Curriculum Program Design and Development unpublished.
- Denzin, N.K., & Lincoln, Y.S. . (2005). Introduction: The discipline and practice of qualitative.
- DesalegnTerecha. (2014). The pleasing Unspoken Voices Ethiopian National Associations of.
- Ethiopia, G. (2012). German leprosy and TB Relief Association Ethiopia 1957-2012/bulletin/.
- FMOH. (2015, March). Ethiopian Leprosy Mapping Report. Directorate for Disease Prevention.

- Gijisberg, J,& Vrooman, C. (2007). Explaining Social Exclusion: A Theoretical Model Tested in.
- H, R. (2016). the psychological, economic and social effects of leprosy on affected women in addis Ababa city administration.
- Haileleul, M. (2008). The Social Exclusion of people affected by leprosy: the case of Bahirdar.
- Menberu A, Addisalem T, Hana N and Ayele. . (2001). Baseline Study on Persons Affected by.
- Nasrudin, C. Hadi, A. Yusuf, R. Hargono, and T.Suwandi,. (2018). “The effect of individual, family and environmental factors on family stigma with leprosy,” Adv. Soc. Sci. Educ. Humanit. Res., vol. 98, no. October,pp. 153–57, .
- Scott, J. (2006). Sense of coherence in leprosy patients. Retrieved March 9, 2014, From.
- TerechaKebede, M. (2005). Leprosy, Leprosaria and Society in Ethiopia: - A Historical.

Annexes

Introduction

Dear sir/madam, I am Meselch Desta a post graduate student of masters of social work St.mary University. Currently, I am undertaking a research for the title Experience of Family Vulnerability and Resilience among women affected by Leprosy mentioned as a partial fulfillment of social work. Since you are one of the respondents selected to participate on this study, I am sure you will give attention to forward your correct and complete information to have a representative finding on the current status of the Experience of Family Vulnerability and Resilience among women affected by Leprosy. In doing so, I confirm you that the information that you share will be kept confidential and used for the academic purpose only. This questionnaire has two parts involving the respondent's profile, qualitative type of questions that has been translated into Amharic language for simplicity. I kindly request you to forward your genuine response for these questions in each parts of the questionnaire since your response determines this paper's result.

Thank you in advance for your time and cooperation

Participant information sheet for the women affected by Leprosy

Background`

1. Age _____

2. Sex M _____ F _____

3. Educational status

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

E) Others Specify, _____

4. Occupation

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

Unemployed

f) Other specify, _____

5. Marital status

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

f) Others Specify, _____

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

Part two

Experience of Family Vulnerability and Resilience among women affected by Leprosy

1./What is the health related challenges (reaction, loss of sensation, deformity, disability, Lack of early diagnosis, shortage of proper treatment, prevention of disability and rehabilitation Service-----

2./What type of psychological problems (self-stigma, depression (suicide attempt, Hopelessness, isolation, anxiety etc...) you are encountered-----

3./How do you see your family members, relatives, friends and other community members' Attitude towards people affected by leprosy in your community.-----
--

4./What is the effect of leprosy in your daily life, marriage, work, academic performance and Social participation-----?

5. /How leprosy affects you economically (How it affects your productivity, income Generation, property ownership)-----

6./How do you cope up the bio psychosocial and economic challenges due to leprosy-----
-----?

7./ How did you come to know about the case/leprosy? a/ told by family/relatives b/ told by health professionals/ c/ told by other person d/ getting information on the symptoms from media e/ told by local healers f/ other/ specify _____

8. / what do you think the cause of the disease/leprosy? a/ curse b/ calamity/God related or spiritual c/ hereditary d/ Germ/ bacteria e/ other/Specify-----

9. /do you have any employment problem after the disease? A /yes b/ No If yes, why?
1/ Because I am disabled by leprosy and I am not fit for work 2/no one has wanted to
employ me c/ I prefer to be self-employed. d/ I cannot find work that fit my disability e/ due
to employment problem like any other citizen f/ other specify-----

10./How the problem on employment opportunity can be solved? a/ lobbying with policy
makers for employment. b/ Awareness creation in the society about the PAL c/ creation of
Income generating activities in our own settlement d/ advocating employment of PAL e/
/Assisting self-employment activity f/ other specify_____

11./ Do you participate in social affairs in the community? 1/yes 2/ No If no, why? ----

12./What are the major challenges? Specify-----

13./ what do you recommend improving the socio-economic problems of PALs in general
and women in particular?-----

----- 14./How do the family members respond to the people affected by leprosy? How
about friends, neighbors, & community-----?

15./How does people around you and the community understands the causes, aggravating
factors and the social effects of leprosy-----?

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

17./How does people affected by leprosy's personal relation with other people? Does it have
similar effect on the family members-----?

18. /did people affected by leprosy face any kind of discrimination and stigmatization for
being affected by leprosy? Probe, how do you cope up with it? If there is any-----
---?

19./What are the Coping strategies to overcome challenges related the psycho social and
economic effect of leprosy? -----

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