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# Lived Experience of Leprosy Patients in Alert Hospital, Addis Ababa, Ethiopia

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BAHIRDAR UNIVERSITY COLLEGE OF MEDICINE AND  
HEALTH SCIENCE

LIVED EXPERIENCE OF LEPROSY PATIENTS IN ALERT  
HOSPITAL, ADDIS ABABA, ETHIOPIA

BY SHEMSIA KEMAL (BSC)

A THESIS RESEARCH SUBMITTED TO THE DEPARTMENT OF HEALTH  
PROMOTION AND BEHAVIORAL SCIENCES, SCHOOL OF PUBLIC  
HEALTH, COLLEGE OF MEDICINE AND HEALTH SCIENCES, BAHIR  
DAR UNIVERSITY IN PARTIAL FULFILLMENT OF THE  
REQUIREMENTS FOR THE DEGREE OF MASTER OF PUBLIC HEALTH IN  
HEALTH PROMOTION

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BAHIR DAR

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## **ABSTRACT**

**Back ground:** Leprosy is a chronic infectious disease caused by mycobacterium leprae. That predominantly affects the skin and peripheral nerves, resulting in neuropathy and associated long-term consequences, including deformities and disabilities. Leprosy is one of the diseases that leave a strong social and psychological impact on the persons affected (including their families) and the societies in which they live.

**Objective:** To explore the lived experience of patients with leprosy at ALERT hospital, Addis Ababa, Ethiopia.

**Method:** a phenomenological study design is used to explore the lived experiences of leprosy patients from February 30/2020 to March 27/2020 at all Africa tuberculosis, leprosy treatment and rehabilitation center. 11 leprosy patients from the outpatient and leprosy ward are participated. The study participants were leprosy patients who meet pre identified inclusion criteria. They were purposively selected by using criterion sampling technique. The data is collected by the principal investigator through face to face in-depth interview with the participants. The average time taken to the in depth interview is 25-30 minutes. The collected data is transcribed, translated, coded, categorized and interpreted. Atlas ti 7 computer software is used to analyze the data.

**Result:** In-depth audio taped interviews were conducted with 11 study participants; data was analyzed and managed by using Atlas ti 7.5 software. The process of analysis identified four central themes: physical constraints, restricted Social life, economic constraints and psychological instability. Notably, physical disabilities push patients with leprosy to the extreme of poverty. Failure to meet the basic human needs increase the inability to meet the basic necessities of life was seen to decrease social acceptance and respect from community members who are not affected by leprosy.

### **Conclusion**

From the study, physical and economic dependency of the patients increases their susceptibility to stigmatization and discrimination. As result, people affected by leprosy experienced psychological instability and they are forced to leave their hometown thereafter they suffer from different kinds socioeconomic problems.

## **ACRONYMS AND ABBREVIATIONS**

AAU:	Addis Ababa University
ALERT:	All Africa Tuberculosis and Leprosy Rehabilitation and training Center
BCG:	Bacillus Calmette Guerin Vaccine
G2D:	Grade Two Disability
HIV:	Human Immune Virus
IDI:	In Depth Interview
IRB:	Institutional Review Board
MB:	Multi Bacillary
MDT:	Multi Drug Therapy
MOH:	Ministry Of Health
OPD:	Outpatient Department
P:	participant
PAL:	People Affected By Leprosy
PB:	Pauci Bacillary
TB:	Tuberculosis
WHO:	World Health Organization

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# 1. INTRODUCTION

## 1.1 Background

Leprosy is a chronic infectious disease caused by *Mycobacterium leprae*. The disease predominantly affects the skin and peripheral nerves, resulting in neuropathy and associated long-term consequences, including deformities and disabilities. The classification of leprosy is based on the number of skin lesions, presence of nerve involvement and identification of bacilli on slit-skin smear as paucibacillary (PB) or multibacillary (MB) (1).

Although the mode of the disease transmission is poorly understood, it is thought to be through inhalation of droplets containing the causative agent, *Mycobacterium leprae*. However, transmission via skin contact or other means cannot be entirely excluded (1,2). The incubation period is variable, ranging from 2 to 20 years, or longer (1). The peak age of onset is young adulthood, usually 20-30 years of age; the disease is rarely seen in children less than five years old. Whereas humans are considered to be the major host and reservoir of *M. leprae*, the armadillo and a few other animals have been incriminated as reservoirs of infection (1,2). BCG vaccination is known to have some protective effect against the disease (2). The disease can be treated by using multiple (two or three) drugs; the duration of treatment, dose and number of antibiotics depend on the type of leprosy (PB or MB) and age of the patient (1).

Disability among persons affected by leprosy is more common in old age compared to other age groups. Deformities were more among male patients, multi bacillary cases, doing unskilled occupations that have more chance of getting injuries and illiterates and poor socio economic group patients. Sensory impairment was more common in hands compared to feet (3). Leprosy is one of the diseases that leave a strong social and psychological impact on the persons affected including their families and the societies in which they live (2). Stigma is a complex and dynamic phenomenon, and has many common aspects across conditions and cultures (4). Leprosy-related stigma and discrimination are prevalent in almost all cultures around the world. In many societies, leprosy-related stigma has received a historical confirmation. Often, leprosy is seen as a punishment for sin, or misbehavior or as the result of breaking a taboo. Despite leprosy is known as a disease caused by germ since 1873, in many communities, these beliefs still persist. In some countries still they have discriminatory laws allowing like divorce or deportation of migrant laborers on account of leprosy.

These laws continue to stimulate stigma and discrimination. Due to that, people affected by leprosy are aware of the usual negative attitudes towards leprosy and stereotypes regarding them. This internalized stigma is manifested without any intention to blame the community they live. The impact of stigma may adversely affect a person's mental health. For instance increased levels of anxiety and depression reduced Self-esteem and attempted suicide. Stigma also affects many aspects of social participation. Most common are a negative impact on work performance, ability to find work, reduction in earnings, marital and other relationships, opportunities for education and access to medical care in general health services. Stigma has also impact to delay diagnosis, affect treatment compliance and implementation of prevention of disabilities activities, such as self-care (4)

### **1.2 Statement of the Problem**

According to WHO report a total of 217 968 new leprosy cases were detected, corresponding to a rate of 2.9 per 100 000 population in 2016. And the registered prevalence was 175 361 or 0.2 per 10 000 population. More than 60% of all cases are reported by India, Brazil and the WHO African Region (4). Ethiopia is the seventh among 18 high burden African countries. leprosy is a leading cause of permanent physical disability (2). The global G2D rate was 1.75 per million populations. G2Dis higher in African region 14% followed by the South-East Asia Region 4.6% (4). Since leprosy is a chronic disease, it affects the quality of life of patients, especially with regard to physical and psychological aspects (5).

Psychologically leprosy patients have a decreased quality of life because of physical impairment as result of the disease outcome. Besides to this, pain and difficulty of access to health service is often stated by leprosy patients. People with physical deformity of leprosy have faces a social stigma and difficulty of living in ordinary society. In relation to the environment, safety and patient attribute. Thus, while not feel safe and feel lack of an appropriate leisure (6). Leprosy is still perceived to be feared and concealed because of potential discrimination in various aspects such as marriage, job, sharing food from the same plate with people affected by leprosy and sitting with persons affected by leprosy in public transportation. In addition to this children with leprosy travel to distant villages to continue education fearing stigma in their own village. The stigma was strongly associated with visible deformities(4,7).

Deformities deny leprosy patient's the ability to perform annual activities hence pushing them to the extreme of poverty. Failure to meet the basic human needs for themselves increases their susceptibility to chronic ulcers and an enduring hospitalization. Conversely, some patients experience negative consequences of the disease some continued to enjoy self-worth and respect from their communities (8). But the psychosocial impact of the disease is still unresolved problem in Ethiopia (9). Although the disease leprosy has physical, social, economic and psychological impact on the affected population (4–11), to the best of our knowledge there is information gap on the lived experiences of leprosy patients in Ethiopia. Therefore, studies describing the lived experiences of those clients are needed and I am interested to fill this gap through exploring the lived phenomena of leprosy patients.

### **1.3 Significance of the Study**

The study will explore the impact of leprosy disease on people affected by leprosy and it will pin points the special needs of leprosy patients through exploring their lived experiences. Therefore, the result of the study will have a contribution for health care providers helping them to provide client centered services and it will helps for both governmental and none governmental policy makers to develop evidence based intervention strategies that are focused on enhancing employment opportunities and productivity of the leprosy affected people. Also it will help as a base line data for further studies.

## **2. LITERATURE REVIEW**

### **2.1 Overview of Leprosy Epidemiology and Control**

Leprosy is a disease of public health concern mainly because of its potential to cause disability in those affected and is a cause for social stigma and discrimination (12). In 2016, 3076 new cases were registered. Of them 12% were children suggesting continued transmission in the community; 14% of the new patients presented with G2D (4). A qualitative study conducted at Indonesia shows that, individuals with leprosy are face with various problems arising from leprosy both in the community and the health facilities. The life experiences of people with leprosy provide information that is so diverse and has some similarities around the world. The experiences of persons affected by leprosy, those under treatment and those that have completed treatment and have been declared cured, are diverse and go well beyond leprosy as an infectious disease or medical issue (13). A systematic review at Indonesia reveals that, diverse experiences of forming individuals with leprosy have diverse perspectives and attitudes in placing themselves in the environment. The uniqueness of each individual with leprosy make the problem different (14). A qualitative study on Caregivers' views on stigmatization and discrimination of people affected by leprosy in Ghana shows that, the care givers of people affected by leprosy also faces challenges. Unquestionably, the fear of contagion was the main reason why the caregivers experienced courtesy stigma and this was mainly due to the myths associated with the cause and treatment of the disease. This could lead to social isolation and in consequence, many of the caregivers are likely to be confined to the Leprosarium with little opportunity for social participation outside of the facility (15).

#### **2.1.1 Leprosy in Ethiopia**

Leprosy has been identified as a public health problem in Ethiopia for the past five decades ago. Ethiopia reached the goal of elimination of leprosy as a public health problem in 1999 and Sustained the prevalence at less than one case per 10 000 population (4). Review on the Burden of Leprosy in Ethiopia revealed the prevalence of leprosy in Ethiopia has declined across time but the emerging of new cases is still challenged the national health sector (10). A Cross-sectional study conducted at ALERT hospital shows, the prevalence of disability is very high (16). The most vulnerable age group of the diseases are children and adolescents. The disease has a socio-economic impact on the victims (10).

Persons with a family history of leprosy are not preferred for marriage and similar negative attitudes are observed in the workplace also. Fear of getting disease and deformities are known causes of stigma in Ethiopia (4). In media and other documents, derogatory expressions do occur in local languages, for instance: segadawe in Amharic, kurchi or juzam in Oromo. This implies that the society's misconception about the disease as it is incurable disease. This spreads stigma in the community. Fetha Nagast, a traditional code inherited from the king's times, gives a humanitarian view of the disabling disease. This code also allows the separation of a healthy husband from a wife with leprosy by giving her an outfit or dowry (4). qualitative study conducted at shashemene leprosy treatment and rehabilitation center shows that, the psychosocial impact of the disease is still unresolved problem in Ethiopia (9)

## **2.2 The Psychosocial Consequences of Leprosy**

### **2.2.1 Beliefs about the Causation of Leprosy**

A qualitative study conducted at west Nigeria identified, two broad ideas about causations of leprosy: super natural and natural causes. Persons affected by leprosy and most community members claimed leprosy as caused via supernatural affliction than by natural means. Besides to this, belief in natural causation of leprosy was gaining popularity. Perception about causation of leprosy is different in different age groups for instance: most people with age group of 18–39 years believed that leprosy was contracted through natural causes while those aged 40–80 years believed leprosy was a supernatural condition deliberately inflicted on a person by sorcery. There are also three themes about causation of leprosy were existed majority of community members believed leprosy was hereditary; the other popular view was that leprosy was caused by air droplet infection. Most of those who believe in air–droplet infection were aged 18–39 years. Less popular modes of natural causation included casual contact with skin lesions and ulcers; and the sharing of cups, plates and bedding with persons suffering from leprosy (17). Factors like fear of contracting the disease or becoming disabled get influenced by the stereotypes prevalent in the community against persons affected by leprosy. This could further restrict their participation in the community, which might affect their mental health and could lead to poor quality of life (4). A qualitative study at Ghana reveals that, the experience of stigma in people with leprosy who have disabilities affects negatively on their emotions, thoughts, behaviors, and relationships. Many individuals with leprosy get experiences related to stigma and discrimination while interacting with others (15).

A study conducted at Nigeria reveals that, Certain socio-demographic and clinical factors strongly associated with depression and anxiety in people with leprosy (18).Mental distress also higher in patients with leprosy (19).

## **2.2 .2 Social Participation Restriction of People Affected By Leprosy**

A qualitative study at Uganda revealed as leprosy is a dreadful disease associated with stigma to the extent of even the closest relative shunning the sufferer (8). A systematic review and a study at Nepal show, the basis of stigma appears to be the visibility of the disfigurements and disability (7,20).A study conducted at Ghana shows that people affected by leprosy are stigmatized and discriminated against by the larger society thus making their movements and interactions restricted to the leprosarium. Another study studied at India reveals that, there is social participation restriction in women affected by leprosy. And this phenomenon is higher among old aged group of women. The stigma of leprosy continues to be one of its most persistent and damaging features (21). Findings from studies at India show that, social participation restrictions are highly influenced by education and type of occupation. In addition to that, the characteristics such as gender, age, locality and disability are moderately affecting the participation restrictions (22).Disease duration and the economic status of people affected were also have an effect on social participation restriction (21). People affected by leprosy with low socio economic status and grade II deformity had to face extreme participation restriction (23). Another study at Brazil shows that, people affected by leprosy showed limitations in daily activities, restrictions in social participation and reduced work capacity. Individuals with greater daily activity limitations had the lowest capacity for work (24). The social exclusion of people affected by leprosy impairment triggers a negative social judgment which increases the disability experienced by the person. This results in exclusion and contributes to the poverty of the person affected and this in turn increases the impairment (4). As a study conducted at India on leprosy affected beggars shows that, due to social and physical problems associated with the disease negative out comes make the people affected by leprosy de-habilitated from their locality (25). A study conducted at Brazil reveals that, psychosocial factors and health care access are associated with migration in this vulnerable population, in contrast to none leprosy affected population (26).In other study ,factors associated with poverty were found to be also associated with migration for people affected by leprosy in a highly endemic area (27).



### **2.2.3 Social Relationship of People Affected By Leprosy**

The social relationship of people affected by leprosy has stigma and discrimination problems. People affected by leprosy facing discrimination experience loss of wages and social exclusion in the community (4). As a study shows, the fear of prejudice resulted in sharing only the closest ones and keeping the diagnosis of leprosy as a family secret, as well as the attempt of cover up the spots in the body that to avoid stigmatization in the context of interpersonal and intergroup relationships, interfering greatly in their social participation. And also separation, discrimination, and changes in the behavior of relatives and friends after making the diagnosis and treatment are emerging as a complex range of negative connotations (28). The experiences of people affected by leprosy were generally expressed as social rejection whereby people see people affected by leprosy as outcasts and therefore, would not want to be close with them. As a result of this, there is limited or no interaction that take place between them and the society in general. People affected by leprosy also had physical deformities which they are not comfortable with especially when they come into contact with the public (15). They are stigmatized and therefore they find it difficult to interact freely with the public and this makes to them difficult for securing jobs and engaging in intimate relationships with implications for their finances and psychosocial wellbeing. The associated physical deformities with the disease also tend to impede their ability to relate to the general public (15). Thus, people affected by leprosy with disability had lower quality of life (29). Studies reveal that, there were factors associated with perceived stigma for instance: level of disability and education, cultural value, age and unemployment. Similarly, perceptions about leprosy such as difficult to treat, severe disease and punishment by God had higher perceived stigma (20,30,31).

#### **2.2.3.1 Family and Marriage**

A study conducted at India shows that, marriage has always been a problem in leprosy patient's family. Visible deformity in the leprosy patients is still the biggest cause for social stigma (32). Stigma and discrimination due to leprosy do not affect only persons with the disease but also their family members and relatives. In this way, it may become a family curse with negative social consequences for the entire family. For instance, siblings may have reduced opportunities to get married and children of affected parents may be denied access to school (33).

As study at Nepal shows, many women experienced marital problems and sexual abuse, as result of their leprosy or disability status (34). Caregivers of people affected by leprosy also find it difficult to interacting with people outside the Leprosarium due to society's misconceptions and beliefs about the disease. Many people perceive the disease as being caused by supernatural forces and this could serve as a barrier to finding suitable partners. Many none leprosy affected men perceive the care giver women as being infected with leprosy and therefore shun them. They do not want to get close to the care giver women. Despite they assurance that people living at the Leprosarium are cured (15). The family members are also affected by stigma causing difficulties in their activities of daily living and some suffered depression due to this. In some situations, services to women with leprosy were particularly affected (4). As a study shows, people including family, friends and the neighborhood have ignoring people affected by leprosy since they had the disease (15)

### **2.3 Economy of People Affected By Leprosy**

A study conducted in china shows that, leprosy places a heavy economic burden on leprosy patients (35). A comparative study conducted at India, shows people affected by leprosy are in a poor economic status compared to that of none leprosy affected groups (36). This is the result of the disease out comes and the attitude of the societies they live towards the disease leprosy make the leprosy affected people poor work opportunities. Poor living standards are a common phenomenon in those affected by leprosy-related disabilities (37). This is also due to the physical impairment resulting from the disease, this leads to physical activity limitation and unable to get income through manual works. Another study shows that, not only the leprosy affected people but also their care givers suffer from the negative attitudes of the community they live: The caregivers experienced courtesy stigma, which makes employment opportunities are unavailable to them thus making them exposed to financial challenges (15).

## **4. OBJECTIVE**

### **4.1 General Objective**

- To explore the lived experiences of patients with leprosy at ALERT Hospital, Addis Ababa, Ethiopia 2020.

### **4.2 Specific Objectives**

- To explore the psychological experiences of leprosy patients at ALERT Hospital, Addis Ababa, Ethiopia 2020.
- To explore the social experiences of leprosy patients at ALERT Hospital, Addis Ababa, Ethiopia 2020.
- To explore the economic experiences of leprosy patients at ALERT Hospital, Addis Ababa, Ethiopia 2020.
- To explore the experiences of leprosy patients with physical disability at ALERT hospital, Addis Ababa, Ethiopia 2020.

## **5. METHODS AND MATERIALS**

### **5.1 Study Design and Period**

A Phenomenological study design was used. The study was conducted from February 30/2020 to March 27/2020 G.C.

### **5.2 Description of the Study Setting**

This study is conducted at all Africa, Tuberculosis and Leprosy Rehabilitation and training center (ALERT) in Addis Ababa. This is located in the capital city of Ethiopia, Situated south west of Addis Ababa on the way to Jimma. ALERT was officially founded on 1965 in Addis Ababa Ethiopia. The ministry of health (MOH) and Addis Ababa university (AAU) together with the international society rehabilitation of the disabled, the leprosy mission, London and the American leprosy mission were the founding members. The main purpose of ALERT was specified as to train men and women in all aspects of leprosy with special emphasis on control, treatment and rehabilitation for working in African countries. It is the largest referral center for people with leprosy in Ethiopia, as well as being an international training center. It has different outpatient and in-patient services. The outpatient clinics are divided into leprosy follow-up clinics and general medical clinics for people with leprosy (38). The center currently serves 100,000 populations through 14 different departments including dermatology, ophthalmology, surgery, orthopedic and others. The leprosy treatment unit on the average sees around 480 patients annually. It provides service to patients coming from all regions of the country (ALERT hospital annual report 2011 E.C).

### **5.3 Study Participants**

The study participants were purposively selected leprosy patients who meet the inclusion criteria from leprosy treatment units at ALERT hospital.

### **5.4 Eligibility Criteria**

#### **5.4.1 Inclusion Criteria**

- Patients  $\geq 15$  years
- Patients admitted on the Leprosy ward or who have follow up at out patient
- Patients who consented to participate in the study
- Patients diagnosed as leprosy and on medication for at least 1 year

#### **5.4.2 Exclusion Criteria**

Leprosy patients who are diagnosed with mental health problems and leprosy patients with speech and hearing impairments are excluded from the study.

#### **5.5 Sample Size**

The sample size of this study was 11 leprosy patients 9 were males and 2 were females from OPD and in patient leprosy treatment units at ALERT hospital.

#### **5.6 Sampling Technique**

Leprosy patients who meet the inclusion criteria were purposively selected using criterion sampling technique. It was taken through making an initial interaction with the health workers who are working in leprosy treatment units in order to get better information to select the study participants who are eligible for the study based on pre-identified criteria. Since the health workers who are working at leprosy ward are more familiar with those clients, they help us to selecting the study participants. It is attempted to address leprosy patients who have experienced with the disease out come in physical, psychosocial and economic aspects of their life.

#### **5.7 Data Collection Technique**

Data collection was initiated after approval from the Institution Review Board (IRB) of Bahir Dar University obtained and permission taken from ALERT hospital. Data were collected through in-depth interview with the participants by using semi structured interview guide, the interview were audio recorded for in a while analysis and interview were continued until no new information raised from the study participants. Data was also collected by using observation. In this study 11 leprosy patients were participated. The interview process taken the time range of 25 to 30 minutes. The principal investigator used probing techniques by using how and why questions to get adequate data on the point of interest. It is attempted to address the experiences of leprosy affected people in physical, psychosocial and economic aspects of their life. The interview was transcribed and translated which means it have a written version of the interview. The principal investigator interviewed the study participants in ALERT hospital at convenient time and place for them. Informed written consent was taken prior to each interview. Audio recording during the interview time was done only after permission is gained.

## **5.8 Data Analysis and Interpretation**

Thematic analysis technique was used to analyze the data and discover the lived experiences of leprosy patients. After data collection, tape recorded data was transcribed in to written form word for word. Then the participants' verbatim was translated or the transcript was read carefully several times line by line to identify meaning full statements about the description of the phenomena. After that, the formulated meanings were aggregated in to categories under the pre identified themes. The data were interpreted based on the description under each theme and direct quote of the participants' explanation were used. Atlas ti version 7.5 software was used to manage and analyze the data.

## **5.9 Rigor of the Study**

### **5.9.1 Credibility**

To achieve credibility of the data, prolonged engagement with the participants were used. In addition, the researcher was used one- to –one face to face in-depth interview which were allowed participants to reveal their independent experiences of living with leprosy and peer review the result of the study by peers who have the same back ground. Participants were allowed to taking their time to narrating their experiences. In addition, use of tape recordings of the interviews and transcription of the verbatim were increase the accuracy of description of the participant's experiences, hence were increase credibility of the data. During prolonged engagement the researcher was passively active, more of a listener while taking note of the verbal and non-verbal signals. Probing questions were used so as to ensure that the data generated is true and consistent with participant's views (transcription verification with some participants).

### **5.9.2 Dependability**

The researcher was used probing during data collection and transcription verification with the participants. The generated information was correlated with the available literatures, so as to provide sufficient information and produce evidence that can be laid open to external evaluation.

### **5.9.3 Confirm ability**

Confirm ability was achieved through reflexivity. In the process of data analysis the researcher was suspend her own preconceived ideas and beliefs about patients with leprosy and concentrated on the information that was gave to the researcher by participants to avoid misinterpreting the phenomena (researcher bias).To capture rich and detailed information, researcher was allowed each participant to tell his or her independent experience deeply, until no new information will rise out and quotations from participants were used.

### **5.9.4 Transferability**

To achieve transferability, the researcher was described in detail about the setting by which research was conducted and participants. In order to give the readers enough information for them to judge the applicability of the findings to other settings.

### **5.10 Ethical Consideration**

Prior to data collection, ethical approval was obtained from (IRB) institution review board of Bahirdar University. Permission was asked from ALERT hospital chief clinical service officer. Verbal consent was taken from each participant after clarifying study objective and data collection procedure. The participants were told about their right to withdraw at any time and to refrain from responding to questions if they were not interested to respond.to keep the privacy of participants' history, name of the participants was not be stated in the study; rather a code was given for each participant. Audio recorded data was saved in to the researcher's lap top in locked folder and it will destroy after completion of the study. Participants were also informed as there is no harm from participating in the study and about the benefits of their participation in the study.

## **6. Result**

### **6.1 Socio demographic characteristics**

A total of 11 leprosy patients were participated in this study. From whom 9 were males and 2 were females. The age of respondents was ranging from 18-70 years old. Regarding their marital status, most leprosy patients 6 were married, while 4 were single and the remaining 1 was divorced. The majority of participants 4 were have no formal education, 2 participants were attended primary school, 3 participants were attended secondary school and the remaining 2 of the participants were can read and write. The employment status of the study participants reflects 4 of the participants were farmers, 2 of the participants were students, 1 of the participants was merchant and the rest 4 of the participants were jobless. The monthly income of the study participants reflects 5 of the participants have no monthly income, 3 of the participants have monthly income above 50 birr and the rest 3 of the participants have monthly income ranging from 800-1500birr. Year of disease diagnosis of the participants were ranging from 4 years to 50 years. The disability status of the participants reflects the majorities 5 of the participants have both hands and foot deformity, 3 of the participants have one side leg deformity, 2 of the participants have both hands deformity and the remaining 1 of the participant has one hand deformity. The participants were given codes from p1 to p11



Table 1: socio demographic characteristics of the study participants

Sex	Male	9
	Female	2
	Total	11
Age range		18-70
Marital status	Married	6
	Single	4
	Divorced	1
Educational status	Illiterate	4
	Read and wright	2
	Primary	2
	Secondary	3
	Certificate/Diploma/degree	0
Employment status	Farmer	4
	Student	2
	Merchant	1
	Jobless	4
Monthly income	No income	5
	>50 birr	3
	800-1500	3
Year of disease diagnosed		4-50 years
Disability status	All fingers of both hands and feet deformity	5
	left side feet deformity	3
	All fingers both hands deformity	2
	3 fingers of left hand deformity	1

## **6.2 Lived Experience of Patients with Leprosy**

Participants were asked to narrate what their lived experience was because of being infected by leprosy so as to generate the lived experience of patients with leprosy. In their narratives themes emerged as follows: physical constraints, restricted Social life, economic constraints and psychological instability.

### **6.2.1: physical constraints**

This theme emerged from 4 categories namely: limited daily life activity, injury due to loss of sensation, discomfort from wound and supportive materials conditions and the presence of body scars due to error in traditional healers.

#### **6.2.1.1: limited daily life activity**

Participants reported that they had experienced seeking supports from somebody while they are dressing, eating, drinking and taking care of their personal hygiene because of they are physically incapable of doing that things as narrated;

*A 20 years old girl leprosy patient: said, "... people wouldn't do anything to help you when you ask for help. For example when I ask my friends to help me unbraid my hair because I can't do that for myself they say we will help you tomorrow or something because they are uncomfortable to doing it. And that hurts me. I can't ask people for help to do something I should have been able to do by myself."*

The damage is not limited to the physical incapability to do any things but also creates a negative image leading to discrimination and social stigma against the affected individuals and their families from the societies they live in.

*A 18 years old male leprosy patient narrated as: "...I don't go to social gatherings. How would I even eat the food? How would I even take off my shoe as I enter the house during social gatherings? For these reasons I don't go there, they don't like people like me."*

This shows that, patients with leprosy lose social participation in different events or programs as result of physical dependency.

#### **6.2.1.2: Injury due to Loss of sensation**

Participants pointed out that they had faced different types of injury like burn, sharp and penetrating injuries. Thus, they are at high risk of getting infection, further amputation and disability, as a result of the infected wound formed due to the loss of sensation as narrated;

*A 70 years old male leprosy patient said: "... I have no sensation or pain on my limbs. If it gets burnt, it swells up, discharges watery fluid and slowly heals. But now it's no longer healing"*

A 40 years old male leprosy patient described as: *“...When living in the country side the hills and the slopes cause my legs to get hurt which causes me a lot of anguish. I was punctured with a nail and I didn't feel it because I had no sensation. I had history of skin graft operation therapy for that but no one talks about the fact I have leprosy. They just know I had an operation for the nail injury.”*

#### **6.2.1.3: Discomfort due to wound and supportive materials**

Participants described that they had experienced discomforts from wound condition and the supportive aids they have used as narrated;

A 27 years old male leprosy patient said: *“... I use a crutch when I walk and I am extremely anxious when I walk. If I stop using the crutch my leg would get hurt which limits me from many things.*

From this leprosy patients face many problems from the disease condition as well as the supporting materials they used like shoes and crutch. From those unable to move freely, getting tired while using these supportive aids and feeling ashamed when involving in public areas.

#### **6.2.1.4: The presence of body scars due to error in traditional healers**

Participants experienced using different kinds of traditional medications for their disease and it brings to body injuries as described;

A 65 years old male leprosy patient cited: *“ in the morning when I woke up from my sleep, a traditional healer came and said it (the rash on his skin) has to be burnt with fire. They heated Niger seeds on a pan and tied me up and burnt me while I cried and shouted. I was sick for 6 months and it got worse. It was in my arms and it go to my feet.”*

By showing scars on his body parts. From this some of the participants and their parents have low awareness about the disease leprosy as it is treatable medically.

### **6.2. 2: Restricted Social Life**

This theme emerged from 3 categories namely: stigma and discrimination, debilitation, lack of social support and acceptance.

#### **6.2.2.1: Stigma and discrimination**

Physical impairment triggers a negative social judgment which increases social impairment experienced by the person or a group of persons. And the stigma and discrimination related to this disease result in restriction in social participation. Thereafter it contributes the poverty of the person affected.

Having a stigmatizing disease like leprosy severely affects different aspects of life of leprosy patients such as social life status, employment or work opportunities, marriage and family life relationships narrated as;

A 22 years old female leprosy patient said that: *“...the illness makes you to be stigmatized. At first, I used to cry a lot. There is no such thing in our town. I feel a little better when I come here for treatment. I am still here. It has been a year since I started treatment. No one from my house wanted me to be seen outside. I stopped going out when it started. I also quit school. I left my home town and came here. When it ends, I want to live here. Work here as much as I can and live here.”*

Self-stigma is also mentioned by the participants as people affected by leprosy became ashamed and isolated themselves. It is because of fear of social stigma described as;

A 20 years old female leprosy patient explained that: *“...I couldn't go to weddings and other events. I hide myself from society. I wasn't happy. When my friends went to school and come back from learning I used to cry. I was unhappy. When I was at my home town I had contemplated suicide. It's a good thing that I left even when my home town wasn't working out for me.”*

#### **6.2.2.2: Dehabilitation**

participants experienced dehabilitation from their home town as result of the disease leprosy they described it as since they have a number of problems related to their illness, they cannot fulfill their community norms and the community members starts to isolate leprosy patients in different ways and they enforced to leave their home town stated as;

A 27 years old male leprosy patient narrated that: *“... I am staying here because I have many problems. I come from Oromia region people there don't like to see this kind of disease. It is a rare condition there. I am the only one with this kind of disease. I discontinued school because I didn't want to get hurt and felt sad. I isolated myself from my families and friends and it is the main reason why I am here.”*

#### **6.2.2.3: lack of social support and acceptance**

Participants faced the problems related to the disease outcome like lack of social support and acceptance described as;

An 18 years old male leprosy patient said that: *“...They don't even see me like I am a human being. I am very scared about that. Even when it comes to bathing, I have to go to a water source no one knows about. I don't want people to see me, if they see me it will be difficult and I won't be able to do anything about it. I bathe where no one can harm me.”*

From this, participants faced disrespects from their families and the community members as result of the visible disfigurements and deformities from the untreated leprosy outcome.

The disease may exert great pressure on the relationships of leprosy sufferers who are married described as;

A 70 years old male leprosy patient: *“my wife is with me. Her behavior is not as it used to be. She despises me. She wants to make all the decisions and she does not want me to get involved. She is acting like the husband and I am the wife. She does not know how to make the decisions. It is better if it is done with discussion but she does not discuss with me.”*

Therefore; individuals need family and social supports and acceptance.

### **6.2.3: Economic constraints**

This theme emerged from 3 categories namely: lack of work opportunities, loss of assets and property ownership and decreased quality of life. Deformity disturbs the quality of life of leprosy patients which could become so severe and it will lower their productivity and later caused difficulties in finding a job. And then they were forced for begging to manage their financial problems.

#### **6.2.3.1: Lack of work opportunities**

Participants experienced having lack of work opportunities stated as;

A 65 years old male leprosy patient: *“...When the Derg regime came we were allowed to work but no one wanted us to work. There were people who were not allowed to work in the bus selling tickets. Somewhere forced out of offices. Back then we used to beg to support our kids. But now it is better thanks God. If you have the education you can work anywhere. It is not like before.”*

A 22 years old female leprosy patient: *“... I have absolutely nothing to do. I cannot rent a place and live because I have no job. I worry and think how am I going to finish this feeling and change it to another level “*

From this leprosy patients faced physical impairments this make them incapable of doing manual works there after people affected by leprosy suffer from low work opportunities.

#### **6.2.3.2: Loss of assets and property ownership**

Participants described as; when the disease left untreated it is mostly led to physical deformity and crippling the body and people living with leprosy might end up with being economically dependent.

A 40 years old male leprosy patient: *“... if you can't work as much as others can and if you can't be as productive as others you are bound to reach poverty. And that worries me a lot. I used to be a great farmer; I used to work as hard as I could to be successful. But this disease has prevented me from achieving that.”*

People affected by leprosy have a number of problems to be productive and successful in their life as result of the disease outcome.

### **6.2.3.3: Decreased quality of life**

Participants experienced decreased quality of life in terms of their living status, educational issues and living with their families and local communities is become difficult stated as;

A 70 years old male leprosy patient: "... (With sad disposition) what life is there to lead, I don't have a life. I can't rear farm animals, I can't grow crops, the country side doesn't even like people like me who go to church and beg for money. I don't leave my house not even to the back yard. People don't like me; they taunt me saying "yhe komata kager aytefam? you leper get out of here, leave, people like you need to be kept in a compound in Addis Ababa with your kind of people why don't you go there?" . Therefore I don't even go to other people's house to visit, I don't get close to people, I sit by myself and live by myself like this."

Some of the participants lost their hope due to their illness and the negative out comes of the disease narrated as;

A 27 male leprosy patient said: "... The disease still is impacting me. My best friends from primary and secondary school have become doctors and high school teachers and such. But If I had finished school I would have had a job but there is nothing I can do about that. It is with God's will that I'm still here. (With hopeless disposition) "

### **6.2.4: Psychological instability**

This theme emerged from 3 categories namely: anxiety and depression, unusual behavioral changes, low self-esteem.

#### **6.2.4.1: Anxiety and depression**

Participants experienced anxiety and depression as result of thinking about their disease condition narrated as;

A 27 years old male leprosy patient said: "... I have had high blood pressure from the stress. It has been there years since I have had high blood pressure because I used to be extremely stressed."

A 70 years old male leprosy patient said: "...there is no one like me where I was live in, I am the only one. Because of that I do not visit other people's houses; I do not spend time with people. I sit in isolation, drink coffee if I can get it and stay on my bed. I go outside and sit until sunset and I go back in my house. That is my life."

#### **6.2.4.2: Behavioral changes**

participants experienced bad behavioral changes like suspiciousness, self-hate, Sadness, frustration, loss of confidence, devaluation of their own capacity, stress, and hopelessness were some of the emotions described as result of the disease leprosy and its outcome narrated as;

A 30 years old male leprosy patient said: "... at first I was okay but after my illness, I stated to question my relatives. Are they the ones who let this thing happen to me? I was disgusted in eating food with them."

A 22 years old female leprosy patient: *''... I sometimes feel like I am really angry when I see my body again and again. God just gave me my first situation and I get very angry when he takes that from me again.''*

From this leprosy patients have a number of behavioral changes because of the illness and the society's response to their illness.

#### **6.2.4.3: Having low self-esteem;**

Participants faced to have low self-esteem because of leprosy, as it is a disease strongly affects the life of the victims. It make them to lost their self-confidence and self-respect due to their disease conditions narrated as;

A 40 years old male leprosy patient said: *''being handicapped makes me feel lesser than people because I cannot stand on my own two feet and I cannot walk as much as I want to. I try my best to treat the wounds on my legs to heal but they haven't. And it's not easy to have wound on your leg.''*

An 18 years old male leprosy patient said: *''... because the disease has deformed me early and it made my hands useless I have given up hope. I know that I am lesser than other people and that I don't deserve anything. There is nothing more.''*

Some of the participants described as the disease leprosy makes them hopeless that is because of having stigmatization property of the disease.

## 7. Discussion

From the report four themes are emerged: physical constraints, restricted social life, economic constraints and psychological instability. Participants in this study spoke of the problems endured being responsible for their disabilities. Although the degree of disability varied for each of the participants, it was very much correlated with the severity of the problems. The physical constraints of leprosy patients were reported in four categories; those are, limited daily life activity, injury due to loss of sensation, discomfort from wound and supporting aids conditions and the presence of body scars as result of errors in traditional healers. Participants spoke of problems associated to their physical disability as result of the disease outcome which is due to lack of awareness about the disease at the time of disease occurrence and it makes them to unable to seek medical cars earlier and they forced to seeking traditional healers by their parents. Some of the participants reported as they have faced traditional healers' treatment negative outcomes like burning out of the diseased body lesions and nipping the swollen body lesions with blade and making it to bleed. After all the disease become worsened and makes them physically injured or disabled. Finally, they become physically dependent on others like seeking supports from somebody while they are dressing, eating, drinking and taking care of their personal hygiene. In addition they described as they have a lot of challenges to involve in different social gatherings due to their physical dependency; some of the participants stated as they have faced troublesome social programs in their life time; like take off their shoes, serving foods and drinks for themselves in the social gatherings. This is true as mentioned a studies conducted at Ghana, Brazil and India (4) (15) (24). Participants reported about their discomforts from the wound condition and the materials they used for supporting themselves like protective shoes and crunch. Participants stated a kind of discomforts among them; dryness of their hands and feet, weakness of their muscles are unable to do fine tasks and being extremely anxious when they walk with crutch by regretting about what it would be like if it was like the time before. The other thing related to their discomfort is lack of financial support to change aperture shoes and this leads to penetrating and sharp injuries. This is as result of leprosy patients unable to sense pain at the time of injury as the participants described. This is cited in the same way as studies conducted at Ghana, Brazil and India (4) (15) (24) For some participants the course of leprosy infection changed their social life to being victims of social rejection and isolation, divorce, denied sex and dropping out of school.



Rejection and isolation meant that even their blood relatives disowned them or denied them any assistance or could not pay them any visit even while in the hospital. Which concurs with a study conducted at Gahanna, Nepal and India (15) (32) (34). Participants reported dropping out school due to inhumane treatment by both teachers and fellow learners. This is true as study conducted at Nepal and India (32) (34). People affected by leprosy faced restricted social life participation because of the disease burden and the societies attitude towards the disease this is described the same way as a study conducted at Gahanna (15) (28). Participants spoke of lack of economic rehabilitation after they had diseased with leprosy and they had forced to beg to taking care of their children and to survive themselves. This is similar with as a study conducted at India and china (25) (35) (36). Leprosy affects extremely poor people and even the cured keep at the margin of society. Some participants described that they depend on none sustainable small scale income generating activities. This is concur with a study conducted at India (36). Participants elaborated that they experienced dehabilitation from their home town because of the disease leprosy negative out comes and the societies attitude towards the disease. Which is similar with study conducted at Brazil and India (25) (26) (27). Participants in this study spoke of as they experienced poor quality of life in a number of ways such as in terms of physical incapability to do manual works to earn money, educational issues, living together with the societies and being productive as what they had before. This is similar with a study conducted at West Bengal (29).Participants stated about their behavioral changes like having anxiety and depression, after their disease condition. which is similar with a study conducted at Nigeria (18). Some of the participants experienced feeling of low self-esteem. This is similar with a study conducted at Nigeria (18)

### **8. Limitation of study**

The results of this study were specifically on leprosy patients at ALERT hospital Addis Ababa Ethiopia, thus the results may not be generalized to people affected by leprosy in the other areas. Besides, the small numbers of leprosy patients who participated in the study puts limitation on generalization of findings to all leprosy patients in Ethiopia. It is therefore recommended that future studies will consider people affected by leprosy in the other areas in Ethiopia. Shortage of related literatures was also one of the limitations to discuss the result of the study briefly.

## **9. Conclusion**

In this study the lived experiences of patients with leprosy at ALERT Hospital, Addis Ababa, Ethiopia emerged as four main themes; physical constraints, restricted social life, economic constraints and psychological instability. From the study, physical and economic dependency of the patients increases their susceptibility to stigmatization and discrimination. As result, people affected by leprosy experienced psychological instability and they are forced to leave their hometown and they suffer from different kinds of socio economic problems.

## **10. Recommendation**

For policy makers, there should have to sustainable health education programs concerning the disease leprosy especially for rural areas it will helps to change the image of the diseases in the society and to minimize social stigma and discrimination.

For health care providers, should be alerted for the early detection and management of the disease leprosy.

A multidisciplinary team of professionals ranging from social workers to health workers should be involved in the care of patients with leprosy in order to address the physical, social, psychological and economic needs of the patient.

It is evident, that patients with leprosy live in abject poverty due disabilities thus government, aid and charitable organization should support the economic rehabilitation of patients with leprosy and should facilitate work opportunity to those groups.

For the researchers, I would like to recommend conducting further studies to dig out problems other than my study findings.

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## 12. APPENDIXCES

### **Appendix 1: Informed Consent**

#### **Part I: Information Sheet (English Version)**

Good Morning/ Good evening, my name is shemsia kemal. I am a postgraduate student at Bahir Dar University, College of Medicine and Health Sciences, School of Public Health, Health Promotion and Behavioral Sciences department. I am here to collect data for my study which entitled with “lived experience of leprosy patients in ALERT Hospital”. I have got permission to do this research from Bahir Dar University, school of public health research ethics Committee and Amhara National Regional State Health Bureau as well as management bodies of the hospital. You are selected to participate in the study from leprosy patients atALERT Hospital. The study will be carried out in the form of interview and it will be audio recorded. It may require about 45 to 60 minutes to complete. Your participation/ non-participation will have no effect now or in the future on services that you or any member of your family may receive from any service providers. In between, you have the right to terminate from the study by any reason, related to the study or personal reason. To achieve the study, your honest and genuine participation by responding to the question prepared is very important and highly appreciated. You have also a right to continue or to discontinue as a participant and there is no any influence that insists you to participate unless you are volunteer. We will proceed to the interview after you understand the following points

**Objective of the study:** To explore lived experiences of leprosy patients at ALERT hospital Addis Ababa Ethiopia.

**Benefit:** There will no financial benefits for you in participating in this research project. However, the information you provide will be very helpful to improve quality service delivery system.

**Harm:** There is no harm to the participants because of participating in the study

**Confidentiality:** I would like to assure you that the privacy will strictly be maintained throughout. Your responses to any of the questions will not be given to anyone else and no reports of the study will ever identify you. If a report of the results will be published, only information about the total group will appear.

**Persons to contact:** If you want to ask the principal investigator about the research at any time, you can contact me through: E-mail: [kshemsia@gmail.com](mailto:kshemsia@gmail.com) or Tel: 0923985561

**Part II: Consent Form (English Version)**

I would like to thank you in advance for the priceless time you would spend in this interview and genuine responses to provide. By signing below you agree that you have read or heard and understood the above information, and you are interested to take in this study.

Name of the respondent\_\_\_\_\_

Signature\_\_\_\_\_

Date\_\_\_\_\_

**ባህርዳር ዩኒቨርሲቲ**

**ጤና ሳይንስ ኮሌጅ**

**የሕብረተሰብ ጤና ትምህርት ቤት**

**በአለርት ሆስፒታል የስጋ ደዌ ህመምተኞች ከስጋ ደዌ በሽታ ጋር መኖር ምን ይመስላል የሚለውን ለማጥናት የተዘጋጀ መጠይቅ**

**Appendix 2: Informed consent (Amharic Version)**

**ክፍል 1 የመረጃ ቅጽ**

እንደ ምን አደሩ/ዋሉ፤ ስሜ ሸምሲያ ከማል እባላለሁ፤ በባህርዳር ዩኒቨርሲቲ የህክምና እና ጤና ሳይንስ ኮሌጅ፤ የህብረተሰብ ጤና ትምህርት ቤት፤ የጤና ማበልጸግ የድህረ ምረቃ ተማሪ ስሆን፤ በዚህ ሰዓት የስጋ ደዌ ህመምተኞች ከበሽታው ጋር መኖር ምን ይመስላል የሚለውን ጥናት እያደረኩ ሲሆን የመጣሁት ለሁለተኛ ድግሪ መመሪያ በምሰራው ጥናታዊ ፅሁፍ መረጃ ለመስጠት ነው። ይህን መረጃ ለመስጠት ከባህርዳር ዩኒቨርሲቲ የህብረተሰብ ጤና ትምህርት ቤት፤ የጥናትና ምርምር ስነ ምግባር ኮሚቴ እና ከአማራ ክልል ጤና ቢሮ እንዲሁም ከሆስፒታሉ ሃላፊዎች ፈቃድ አግኝቻለው ይህንንም ጥናት ለማሳካት የእርስዎ ቅንነት የተሞላበት ተሳትፎ ወሳኝነት አለው። በዚህ ጥናት ላይ መሳተፍ፤ በፍቃደኝነት ላይ የተመሰረተ ስለሆነ፤ ስጠይቅዎት በመሃል ጥያቄ መጠየቅ፤ ጥያቄ መዝለል፤ ብሎም ማስቆም ይችላሉ። በቃለ መጠይቁ ወቅት መቅረፅ ድምፅ መረጃ ለመያዝ የምጠቀም ስሆን የሚወስደው ጊዜ ከ 30 እስከ 45 ደቂቃ ነው። በጥናቱ ላለመሳተፍ ከፈለጉ በዚህ ጥናት ያለመሳተፍ ይችላሉ። በዚህ ጥናት ባለመሳተፍዎ ማንኛውንም አገልግሎት ከማግኘት አይከለከሉም። ግን የዚህ ጥናት ዓላማ የተፈለገው ግብ እንዲመታና በጥናቱ መሠረት የሚለዩ የተለያዩ ችግሮችን በመንግሥትና በሌሎች ድጋፍ ሰጪ ድርጅቶች አካላት ትብብር አማካኝነት በጥናቱ የተደረሰባቸውን ችግሮች ለመፍታት እርስዎ እንዲሳተፉ ተጋብዘዋል።

በዚህ የምርምር ፕሮጀክት ለመሳተፍ ከመወሰንዎ በፊት ይህንን የማብራሪያ ቅጽ በጥንቃቄ በመረዳት ጥያቄዎች ካሉዎት ይጠይቁ። በተጨማሪም በጥናቱ መሳተፍ ከጀመሩ በኋላ በማንኛውም ጊዜ ጥያቄዎች ካሉዎት መጠየቅ ይችላሉ።

**የምርምር ፕሮጀክቱ ዓላማ:-** በአዲስ አበባ አለርት ሆስፒታል ውስጥ የስጋ ደዌ ህመምተኞች ከስጋ ደዌ ህመም ጋር የመኖር ተሞክሮአቸው ምን ይመስላል የሚለውን ለማጥናት የተዘጋጀ ነው።

**ጥቅሞች:-** የእርስዎ ጥናቱ ላይ መሳተፍ አሁን ለግልዎ የገንዘብ ጥቅም ባይኖረውም፤ የሚሰጡት መረጃ ግን ለጥናቱ መሳካት በጥናቱ በተለያዩ ችግሮች መፍትሄ ሲሰጥ እርስዎ እና ሌሎች ታማሚዎች ተጠቃሚ ይሆናሉ።

**ጉዳት:-** እርስዎ በጥናቱ ላይ ስለተሳተፉ ከጊዜዎት በስተቀር የሚደርስብዎት ምንም ችግር የለም።

**ምስጢር ስለመጠበቅ:-** ከዚህ ጥናት የሚገኝ መረጃ በሙሉ በምስጢራዊነት ይጠበቃል። ለዚህ ጥናት የሚሠበሰበው እርሰዎን የሚመለከት መረጃ በማህደር የሚቀመጥ ሲሆን ማህደሩም በስምዎ ሳይሆን በተለየ ኮድ ሲቀመጥ ኮዱ ከዋናው ተመራማሪ ውጭ ለማንም አይገለጽም።

ጥናቱን በተመለከተ ሊብራራልዎት የሚፈልጉት ነገር ካለ መጠየቅ ይችላሉ። ለበለጠ መረጃ የጥናቱን ዋና መሪ በሚከተለው አድራሻ ማግኘት ይችላሉ። ኢሜል : kshemsia@gmail.com ወይም ሞባይል ስልክ

ቁጥር : 0923985561

**ክፍል 2 የስምምነትቅጽ**

ከላይ በዝርዝር የተሰጡትን መረጃዎች እና ቅፁን አንብቤዋለሁ ወይም ልረዳ በምችለው መልኩ በ መረጃ ሰብሳቢው/ዋ ተነቦልኛል፡፡

የተሳታፊውስም \_\_\_\_\_ ፊርማ \_\_\_\_\_ ቀን \_\_\_\_\_

መረጃ ሰብሳቢስም \_\_\_\_\_ ፊርማ \_\_\_\_\_ ቀን \_\_\_\_\_

**Appendix 3 :Semi-Structured Interview Guide for Leprosy Patients (Amharic Version)**

**ክፍል1:- የማንነት መረጃ**

1. የታ \_\_\_\_\_
2. ዕድሜ \_\_\_\_\_
3. የትዳር ሁኔታ \_\_\_\_\_
4. የት/ት ሁኔታ \_\_\_\_\_
5. የስራ አይነት \_\_\_\_\_
6. የወር ገቢ \_\_\_\_\_ (ብር)
7. በስጋ ደዌ ምክንያት የሚታይየአካለልጉዳት \_\_\_\_\_
8. በሽታዎ ከታወቀ ስንት ጊዜ ሆነ? \_\_\_\_\_

**ክፍል 2:- የስጋ ደዌ ህመምተኞች አካል ጉዳተኛ ሆኖ የመኖር ተሞክሮአቸው**

1. በስጋ ደዌ በሽታ ምክንያት አካል ጉዳተኛ ሆኖ መኖርን እንዴት ይገልጹታል?
2. የእርሶ በሽታ ሁኔታ እና ከሌሎች ሰዎች ጋር ያለዎት ግንኙነት እንዴት ይገልጹታል?
3. በስጋ ደዌ በሽታ ምክንያት አካል ጉዳተኛ ከሆኑ በኋላ ከቤተሰብዎ፣ ከዘመድ፣ ጎረቤት ወይም ከጓደኞችዎ ጋር ያለዎት ግንኙነት እንደ በፊቱ ነው ወይስ ተቀይሯል እንዴት ይገልጹታል?
4. ማህበራዊ ሂደቶችን ይሳተፋሉ? ለምሳሌ እንደ (ዕድር፣ እቁብ፣ ማህበር፣ ስርግ፣ ለቅሶ እና የመሳሰሉት ) አይነት ማህበራዊ ኑሮዎችን ከአካል ጉዳተኝነት ጋር እንዴት ይገልጹታል?

**ክፍል 3 :- ከ ስጋ ደዌ በሽታ ጋር ተያይዞ ያለው የስነልቦናዊ እና ማህበራዊ የህይወት ተሞክሮ**

1. ለመጀመሪያ ጊዜ ስለ በሽታዎ ሲነገረዎት ምንድን ነበረ የተሰማዎት ስሜት? እንዴት ይገልጹታል?
2. ቤተሰብ፣ ወዳጅ፣ ጎረ ቤት እና የአካባቢው ማህበረሰብ ስለ እርሶ በሽታ ያውቃሉ? ምንድን ነበረ ምላሻቸው (አፀፋቸው) ስለ እርሶ በሽታ ሁኔታ?
3. በሽታው ከታወቀ በኋላ ከማህበረሰቡ ጋር አብሮ የመኖር ተሞክሮዎት እንዴት ነበረ?
4. በስጋ ደዌ በሽታ ምክንያት እንዴት አይነት ስነ ልቦናዊ እና ማህበራዊ ችግሮችን ተጋፈጡ?
5. በስጋ ደዌ በሽታ ምክንያት በህይወትዎ ላይ የደረሰዎት አላስፈላጊ የሆኑ የባህሪ ለውጦች ለምሳሌ፡ እንደማፈር፣ መፍራት፣ መናደድ እና እራስን መውቀስ አሉ? \_\_\_ ለምን?

**ክፍል 4 :- በስጋ ደዌ በሽታ ከተያዙ በኋላ ያላቸው ኢኮኖሚያዊ ተሞክሮ**

1. በስጋ ደዌ ከመያዝዎ በፊት እራስዎን እንዴት ነበረ የሚያስተዳድሩት? አሁንስ?
2. ከበሽታው ጋር ተያይዞ የደረሰዎትን ኢኮኖሚያዊ ተጽኖ እንዴት ይገልጹታል?
3. እርሶ በኢኮኖሚ ጥገኛ ነኝ ብለው ያስባሉ? ለምን?

**Letter of Declaration**

I the under signed declared that this is my original work has never been presented in this or any other Universities and that all the resources and materials used for the research, have been fully acknowledged.

Name of the principal investigator: shemsia kemal

Signature: \_\_\_\_\_

Date \_\_\_\_\_

Advisors Name:

1. Dr. Fentie Ambaw (PhD, associate professor)

Signature \_\_\_\_\_

Date \_\_\_\_\_

2. Hordofa Gutema :( BSC, Mph, assistant professor)

Signature: \_\_\_\_\_

Date \_\_\_\_\_