"THE EXPERIENCES OF LEPROSY AFFECTED PERSONS AT SHASHEMENE REHABILITATION CENTER FOR DISABLED"

BY

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Thesis Approval

This is to certify that the thesis prepared by Henok Zewdu, which is entitled *"The Experiences Leprosy Affected Persons at Shashemene Rehabilitation Center for disabled"* and submitted in partial fulfillment of the requirements for the Degree of Master of Arts (Social Work). Hence, this thesis fulfills the regulation of the University, and meets the accepted standards with respect to originality and quality.

APPROVED BY THE EXAMINING BOARD

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Acronyms

WHO: World Health Organization

ALERT: All Africa Leprosy &Tuberculosis Rehabilitation

& Research Training Center

PALs: Persons Affected by Leprosy

MDT: Multi Drug Therapy

ENAELP: Ethiopian National Association of Ex-leprosy Patients

GLRA: German TB and Leprosy Relief Association

FMoH: Federal Ministry of Health

Abstract

This study described the experiences of leprosy affected persons at Shashemene Rehabilitation Center for Disabled. The study aimed to address the psychosocial effects of leprosy and institutional supports in improving the lives of leprosy affected persons under institutional support. Qualitative approach, particularly descriptive case study design was used. Purposive sampling technique was employed to select participants. The research participants were leprosy affected persons who are found under institutional support. Additionally, key informants from Shashemene rehabilitation center for disabled and the Association of Leprosy Affected Persons were participated in this study. The tool for primary data collection was in-depth interviews guide. Data were also sought from secondary sources such as document reviews. The data generated from different sources were analyzed using thematic data analysis methods. The study found, leprosy affected persons had encountered several psychosocial problems resulted by leprosy that led them (PALs) to seek institutional support. With this regard, most Persons affected by leprosy families', friends', and community's unwelcoming reactions towards Persons affected by leprosy's conditions resulted to restrict them from engaging in any social occasions/gatherings with non-leprosy people and they had less relationships with family, relatives, and friends. The study also found that the disease left immense destructions on the lives of leprosy affected persons in light of behavioral changes they brought with regard to feeling fear, shame, anger, and blame. Even though leprosy affected persons are institutionally supported, they haven't brought any considerable improvements in their livelihood in spite of the contribution of the supports rendered by the institution. The institutionally supported leprosy affected persons had negatively associated perceptions towards the supports rendered by the institution. The study concluded that the psychosocial effects of leprosy still unresolved problems and as a result, the support of the institution does not help institutionally supported leprosy affected persons to improve their life. Instead, institutionally supported leprosy affected persons have psychosocial problems yet that hinder them from social participations & social relationships and unchanged behaviors, which resulted due to the disease and the inability of the institution to overcome these issues in providing better psychosocial supports. Rather, institutionally supported leprosy affected persons have used the institution to hide themselves from the outside world. Thus, the rehabilitation center should exert its effort to the maximum point of providing holistic treatments for leprosy affected persons under institutional support.

Key words: Leprosy affected persons, Psychosocial, Institutional support, contribution

CHAPTER ONE

2. Introduction

2.1. Background of the Study

Leprosy is stated mainly as an old aged and chronic disease that is caused by Mycobacterium also known as Hansen's disease, after discovered by Gerhad Armaver Hansen in 1873, which affects (leprosy) peripheral nerves and cells damages of the person, leads to deformity and disability (Tigist Shumet et al, 2015).

It is stated as medico-social problem with a declining in its medical form due to the presence of effective treatment with Multi Drug Therapy (MDT). According to WHO (2013), World Health Organization received reports from 115 countries and territories for the first quarter of 2013; showed that the registered prevalence of leprosy worldwide amounted to 189,018 cases which is decreasing. The psychosocial aspect in terms of stigmatization, disability, loss of self respect, and loss of self esteem and ostracting of affected one, and misconception of the disease by the community have been well identified as a major threat, therefore making patients more vulnerable to destitution and social isolation (Ajibade et al, 2013).

WHO, (1996) revealed leprosy, with no regard to deformities occurrence it often mainly results a deepen stigma and social exclusion of patients and their families. Moreover, it is briefly asserted that it causes tremendous social problems (WHO, 1999 (a)). In line with, Mesele, (2005), stated that in many societies leprosy has commonly associated with the idea of guilt, rejection, and isolation.

An online document retrieved from ALERT stated that the disease was identified in the late 1950s in Ethiopia. It discusses that from that time on, efforts had been made to keep leprosy under control as a public issue through establishments of national leprosy office with accompany to German Leprosy Relief Association (GLRA). The document also stated about the regions where leprosy is endemic in the country mentioning, Oromiya, Amhara & SNNPR & South Eastern highlands (Ethiopia, Leprosy & ALERT, 2005).

Introducing MDT made the prevalence gone down from its peak towards infection in the country (Ethiopia) though, it is still a significant health problem as in other parts of the world (Ramos, et al, 2014). The Ethiopian Federal Ministry of Health (FMoH) report revealed the prevalence of the disease was increasing until 2014/2015 since recent previous years (annual performance report, 2014/15). Measurements, which were taken in the late years to control the disease was ineffective. It is stated only that strategies were done towards treating people affected by leprosy (PALs), particularly with the chemotherapy. The social and psychological aspects and other related issues of the disease were not given due attention (Ethiopia, Leprosy & ALERT, 2005).

Therefore, studies imply that, the psychosocial aspect of the disease, which affects in Ethiopia, does not given an intense consideration yet. Because the disease has the potential to expose patients and their families to social restriction from social participation and they could be obliged to leave their houses due to social rejection. In other words, they are prone to dehabilitation towards mentally and physically. Also, these (PALs) would go to live with leprosy colonies who had the same issues (Kaur & Brakel, 2002).

Mishra and Gupta, (2010), also discussed the consequences of the disease which, leprosy unless cared properly for injuries to intensive parts, it leads to stigma and discrimination. Particularly, lack of social and psychological support may occur against persons affected with leprosy. From the former statements, it is possible to have an insight even though the introduction of MDT has become fruitful in controlling the spread of the disease, even it cures.

Despite the prevalence also declining at good range, the disease's social, psychological, economic & physical effects kept the problem still flourished due to the stigma associated with leprosy. PALs are restricted from social participations (gatherings) and disregarded from their social roles in a way that affects the psychosocial well being of the leprosy affected persons. Therefore, these leprosy affected persons are obliged to be displaced from their residents and join to segregated PALs' colonies or admitted to helping organizations.

2.2.Statement of the Problem

Studies and reports of international organizations like WHO asserted that leprosy is a pandemic disease that has been a global issue, which could potentially devastate a person's life as a whole; not part of life (Bulletin of the World Health Organization, 1999).

Many leprosy-affected persons try to conceal the disease even from their dear and near ones because of fear of ill-treatment by the society; patients' initial response is to hide not only the disease, but also the treatment (Kumar, et al, 2014). This is to mean that leprosy, which is pandemic disease, is a global issue of public health affecting and harming not only the physical of a person but also the psychological and social wellbeing of a person infected. More precisely, it can be easily understood that persons affected by leprosy suffer greatly socially and psychologically from leprosy in the rest of their lives as they suffer from it physically.

The wrong public perception associates the disease with God's punishments for transgressions and negative attitude towards the disease, which in turn enforced the society to avoid all kinds of contact with the people having the disease. As a result, people with leprosy are obliged to leave their homes and live in segregation being socially and psychologically affected in their lives (NLEP, 2008*). Similarly, Melak Haileleul, (2008), stated that* fearing the contagion to the disease and long aged social taboo associated with the disease, people affected by leprosy are segregated, stigmatized and socially excluded. These imply that their relations with the community are broken. Rafferty.J, (2005), also stated the adverse situation for people with leprosy in the society make them lose attachment with their family members and it has the potential to bear a much grave psychosocial consequences than losing their fingers and toes.

Although extensive researches have been conducted on the medical aspects of leprosy, comparatively little researches have been done in the sphere of the psychosocial effects of the disease. Similarly, in case of Ethiopia, Kindu Fiseha, (2013), revealed that the psychosocial effect of the disease on the lives of the patients has not been studied. Much of the work that has been done so far in Ethiopia are concerned with medical detection and treatment.

Very recently the trend seems to change and there have been researches conducted in the area of psychosocial consequences of the disease in countries like India (Kumar, et al, 2014), and Brazil (Leite and Caldeira, 2014), where leprosy is endemic. The studies suggested, there was significant reduction in the symptoms of depression after intervention, positive impact was shown for psychological, physical, & environmental domains, but for social relations domain the results were adverse. This brings the issue of institutions providing supports for leprosy affected people and subsequent conditions of the people in to discussion. Such institutions are colonies or rehabilitation centers where PALs join when the psychosocial consequences of the disease (leprosy) enforces them to leave their residence or exposes them for dehabilitation and destitution. In such institutions, persons affected by leprosy receive medical, nursing, psychological, nutritional and dental care, physiotherapy and occupational therapy (Leite and Caldeira, 2014).

The psychosocial issue, in the Ethiopian case remains with inadequate studies in the area. Predominantly, for instance the study done by Kindu Fiseha, (2013), pointed out that Persons affected by leprosy were vulnerable to psychosocial complications, specifically, towards social issues they were found to have social participation restrictions and relationship problems and psychologically: lower self-esteem and depression were the majors with no gender differences.

An assumption taken in line with the reviewed literatures towards the psychosocial effects of leprosy on people who contracted in a way that demands holistic view with regard to social work interventions. Thus, institutionalized PALs are expected to obtain holistic treatment apart from the chemotherapy (medical treatment). Rather, social and psychological dimension of supports (services) have to be rendered to PALs under institutional support and it has to improve the lively of them.

As a result the present researcher, based on the above stated premises, is convinced that the psychosocial effects of leprosy on PALs and especially the case of those leprosy affected persons who are receiving institutional support in light of contributing to their (PALs') psychosocial issues is not well studied. So, the researcher believed in the need for more researches in the area. Moreover, it is timely and crucial to put effort in to the problem of such parts of the society, so that better understanding of the issue and insights towards solutions can be obtained. Thus, the present study attempted to assess the psychosocial effects of leprosy on institutionally supported persons affected by leprosy and the psychosocial contribution of institutional support in coming up psychosocial effects of the disease in particular.

2.3. Rationale of the study

The reason that the researcher initiated to conduct this study, in the locality of the researcher there are leprosy affected persons resided. The researcher witnessed that these people face difficulties in light of being reluctant in participating in any social gatherings like Iddir, Mahiber, weddings, and so forth and the social network they have with the society (non-affected) whom they belong to and their aggressive behaviors. Thus, the researcher interested to study institutionalized persons affected by leprosy if they have supported to improve their life with the aforementioned issues in light of the psychosocial effects that the disease resulted to these people (PALs) due to institutionally supported.

2.4. Objectives

2.4.1. General Objective

The general objective of the study is to assess the experiences of institutionally supported leprosy affected persons in terms of the psychosocial effects of leprosy and the psychosocial supports of the institution.

2.4.2. Specific Objectives

The present study is particularly attempted to:

- Identify the psychosocial factors that forced persons affected by leprosy to seek institutional support.
- Identify the social and psychological effects of the disease brought on people affected by leprosy.

- Discern the psychosocial reliefs that persons affected by leprosy gained because of institutionally supported.
- Describe the perception of persons affected by leprosy towards the supports rendered by the institution and their satisfaction, complains & expectations.

2.5. Research Questions

In order to achieve the set objectives, the researcher posed the following research questions:

- What psychosocial situations led leprosy affected persons to seek institutional support?
- What social and psychological effects of the disease brought on persons affected by leprosy?
- What are the psychosocial contributions of the institutional support on the lively of persons affected by leprosy?
- How do persons affected by leprosy consider the contribution of the supports from the institution? (And what are their satisfaction**,** complains, and expectations towards the institutions' support?)

2.6. Significance of the Study

The study intended to address the psychosocial effects of leprosy and the psychosocial contribution of supports that rendered by the institution to persons affected by leprosy. Thus, the result of the study provides an ample contribution for social workers at first hand in account of assessing the best fit for needs assessments and in providing holistic treatment for persons affected by leprosy in the rehabilitation center in order to improve their life.

Health professionals, governmental or non-governmental organizations, which work in relation to leprosy related issues, particularly for rehabilitation centers, which provide supports for persons affected by leprosy is a good input, and for policy makers to rely on valid and benefiting decisions. The study is anticipated to provide some insight and serve as a supplementary source of information for those people who deal with the psychosocial related concerns of leprosy.

2.7. Delimitation of the Study

This study is geographically delimited to Kuyera city, specifically, Shashemene Rehabilitation Center for Disabled and circumscribed to deal with the psychosocial (social and psychological) effects of leprosy on those persons affected by leprosy under institutional support and the supports rendered to them. The psychological issues consist like shame, fear, anger, and blame of persons affected by leprosy. On the other hand, the social effects include social participation restriction (social gatherings) and social relationship (family, relatives and friend relationship) of persons affected by leprosy under institutional support. Additionally, the contribution of psychosocial supports rendered for institutionalized persons affected by leprosy. Thus, the researcher wanted only to assess the aforementioned stated issues of leprosy that defy institutionally supported persons affected by leprosy due to they contracted the disease.

2.8. Challenges of the Study

The researcher while conducting this study had faced major problems in searching for reference materials/sources, which could be used as input for the study. Particularly, psychosocial issues of leprosy related sources were scare to do so. The researcher tried to overcame this problem by exerting his effort in searching for available materials in libraries, in leprosy associations' surveys, and using online search engines.

In addition, by the time of data collection, the researcher was supposed to find the history of institutionally supported persons affected by leprosy to come up with the designed purposive sampling of participants in the rehabilitation center. The researcher couldn't find recent, organized and up to date information (report) (Personal information) about persons affected by leprosy under institutional support. The fore planned schedule for data collection was dashed due to this, the researcher spent many hours. Moreover, it was demanding though very hard to get very close to participants to make express their feelings thoroughly, due to this the researcher was obliged to spend more time to smooth communication barriers.

Since most of persons affected by leprosy that were institutionally supported were illiterate, they (PALs) had limited understandings to the questions asked by the researcher and there were difficulties to explain the answer. Instead, the researcher was enforced to contextualize it with their (PALs') levels of knowledge.

2.9. Operational Definitions

Psychosocial: refers to the social with regard to social relationship & social participation and psychological in light of behavioral and emotional issues related to leprosy.

Psychosocial effect: refers to social and psychological outcomes (social participation restriction and relationship, fear, shame, blame,) occurred on leprosy affected people for the reason that the disease of leprosy.

Institutional support: refers, an institution, which admits and gives supports and care for people who have problems (sufferers) in relation to leprosy.

Fear: in this context is a major driving force of isolation because of deformity and social exclusion attached to leprosy. As a result, PALs may fear to participate or interact with other people (NLEP, 2008).

Shame: the state of humiliation due to having leprosy resulted deformities and related issues. (People are ashamed of having leprosy. Often, this is a reason for people to conceal the diagnosis as long as possible. It is a reason for people to abandon their own families, because they fear their presence will have serious negative effects on the family) (NLEP, 2008).

Blame: the state of guilt for contracting leprosy, due to the physical deformity or mutilation and socially segregated or loss of an owned status because of the disease.(people affected by leprosy may be blamed for having the condition as being their own fault or they must have done something very bad to be punished in this way) (NLEP, 2008).

Social relationship: refers to the relationship that institutionally supported persons affected people have with their family, relatives, and friends.

Social participation restriction: denoted that persons affected by leprosy under institutional support who have difficulties to participate in social occasions or gatherings due to their problems resulted from the disease.

Social exclusion: denotes the rupture of social bond, which is cultural and moral, between an individual and society because of leprosy (Duff, 2005).

Visible deformity: refers to those leprosy-affected people who have grade one and two level of deformities (easily identified body deformities resulted due to leprosy).

Destitution: a leprosy-affected person may be forced to leave his or her home and settle in a rehabilitation home or leprosy colony with other leprosy affected ones (Scott, 2006).

Dehabilitation: denotes, loss of former place in society or social role, causing loss of dignity, job, and position leading to physical displacement (Brakel, 2002).

CHAPTER TWO

3. Review of Related Literature

In the literature part, most major issues raised in relation to leprosy in general and specifically with its psychosocial related issues. Thus, the literature covers, the general over view of the disease (leprosy) in worldly trend and specifically in Ethiopia. Others, issues related to the effects of the disease on those sufferers, and institutional supports against the disease are covered in line with the study's concern**.**

2.1. Brief Overview of Leprosy Epidemiology and Control

Leprosy is the oldest slow killing, physically and consequently socially crippling, that man has known since immemorial. Given its ability to infect small and isolated human populations, it has been asserted that leprosy must have developed over a long period of human evolutionary history (Mesele, 2005).

Mishra and Gupta, (2010), in stating leprosy is an old aged and set hurdles, leprosy is the oldest scourge of mankind and still present in many parts of the world as public health. Additionally, described that it continues to remain an enigma in spite of progress in medicine and social sciences in recent years leprosy still situated in twilight zone between science and myth.

Nonetheless, many scholars couldn't find when and where leprosy has been exited on the earth yet apart from speculating the suspected areas of the world. Even though medical historians have relied on the place where leprosy first appeared, for instance in Egypt, Middle East India, china and Japan are included mainly (Pierre, 2012).

In 1873 Norwegian physician, Gerhard Henrick Armaver Hansen discovered leprosy in tissue samples and theorized that the causing agent was bacterium. He continued to research the disease and six years later, Hansen gave the tissue samples to German physician Albert Neisser who confirmed Hansen's findings that leprosy is indeed caused by bacteria (Powell 2006).

Indeed, leprosy (Hansen's) disease is a chronic infectious disease that can affect all age groups and both sexes. It can be transmitted through physical contact or the respiratory tract. Leprosy causes skin lesions, positive skin smears, sensory loss and enlargement of the peripheral nerves. It can also cause painless ulcers and weakness of the feet, hands and face.

In other words, Sileshi Baye, (2015), Leprosy, is a chronic inflammatory mycobacterial disease mainly involving skin and peripheral nerves and occasionally other organ systems, is not particularly age or gender specific disease. It can affect all ages and both sexes since infection can take place at any time depending upon the opportunities and levels of exposure. Poor living standards and inadequate nutrition make people more susceptible to leprosy and disability. The behavior of individuals also helps the transmission cycle to continue, as many people are reluctant to seek medical care even after being diagnosed because of misconceptions, stigma and superstitions.

Similarly, Scott, (2006), explained that leprosy is mycobacterium leprae, affects primarily the skin and peripheral nervous system and to a lesser extent the upper respiratory system, eyes, liver and testes (sensations) are infected, too.

Accordingly, Subraminiam, (2003), describing the clinical manifestation of leprosy disease expalined that Myco-Leprae as an acid-fast, rod-shaped, gram-positive bacillus that is an obligate intracellular parasite, which can be demonstrated in skin smears or biopsy sections in patients. Additionally, it is stated that human are considered the main host reservoir of the leprosy bacillus.

In fact, the way that leprosy is transmitted, considered, the droplet transmission from the multibacillary cases occurring as a consequence of prolonged close contact with an infected person (Subramaniam, 2003). In other words, the disease transmitted via the nose and mouth during close contact with infected people who are untreated (Bergman and Britton, 2014). Even though, Duff, (2005), claimed, many researchers are of the opinion it is spread from person to person in respiratory droplets by coughing and sneezing, but this is not scientifically proven .

Moreover, the diagnosis issue stated according to Pierre, (2012) in line with WHO, (2013), leprosy is often difficult to diagnose because in the early stages symptoms may be few or absent. The signs of the disease are skin lesions that may be lighter than the surrounding skin or reddish or copper colored. Additionally, the lesions often take the shape of macules (flat), papules (raised) or nodules; besides, it is stated that loss of sensation in the lesion is also common as is thickening of the nerve trunk.

In fact, according to the American Leprosy Mission, (2014), stated the early signs of leprosy that include spots on the skin that may have a different color compared to surrounding skin. Usually these appear on the arms, legs and back. However, spots do not always appear and in some cases, the only noticeable symptom is numbness in one or a few of the fingers and toes.

The major risk factors known for those afflicted by leprosy, Mycobacterium leprae induces immune reactions and invades nerves and ocular tissues. Nerve damage and residual inflammation lead to sensory or motor impairment. Erythema nodosum, skin ulceration, and scarring, facial disfiguration, blindness, claw fingers, foot drop, and missing limbs are the physical squeal of leprosy. In fact, the most common complication of leprosy is physical disability (Cheng et al, 2012).

Regardless of the early 1900s to the late 1940s, leprosy was treated by giving injections of oil from the chaulmoogra nut. While this appeared to work for some people, long-term benefits were questionable (Pierre, 2012). Particularly, in Ethiopia also, before 1950, an effort was made to implant and apply for remedial of PALs via the chaulmoogra oil injection (Mesele Terecha, 2005).

When time heals everything, three decades earlier, in 1981, Multi Drug Therapy (MDT) consisting Dapsone, Rifampicin, clofazimine was introduced for the treatment of the disease (leprosy) and its claimed that MDT since has proved to be highly effective in curing the disease and the cornerstone in leprosy elimination campaign. Currently, MDT generally treats leprosy. (Subramaniam, 2003 & Pierre, 2012).

According to Iyor, (2013), the consequences of the disease if untreated, may cause vast destruction, since leprosy as regarded a special health problem because permanent disabilities and deformities could develop if intervention is delayed or poorly implemented. Additionally, when leprosy left untreated, it will continue to destroy nerves causing anesthesia and once lost, feeling will never return, meaning prevention of disability becomes a lifelong battle (Duff, 2005).

3.9.1. Leprosy in Ethiopia

"The ground reason of leprosy endemic in Ethiopia, its believed that the get in touch with different leprosy ridden countries of the world due to the long standing trade and other cultural

relations" (Mesele Terecha, 2005:p 21). The author also claimed, consequently, leprosy, might have been one of the most ancient disease of the Ethiopian region and society.

Additionally, Sileshi Baye, (2015), Leprosy has a long history in Ethiopia. Literature indicated that leprosy had been recognized as major public health problem for more than half a century. The disease in Ethiopia was identified in the late 1950s. From that time on, efforts made to keep leprosy under control as a public issue through establishments of national leprosy office with accompany to German relief association. Furthermore, the document also stated the regions where leprosy is endemic in the country mentioning, Oromiya, Amhara & SNNPR & South Eastern highlands. (Ethiopia, Leprosy & ALERT, 2005).

Motbainor Abera and Girma Lemma, (2003), asserted, in Ethiopia the course of multi-drug therapy (MDT) implementation, between 1983-1999, 107,311 patients have been released from treatment as cured. These researchers also reported in taking the average disability grade I and II recorded among these people (that is 20%), other things being equal, about 21,462 released from treatment as cured, would require lifelong care for the management and prevention of their ulcers.

Chronically, study conducted on the Epidemiological trends of Ethiopia from 2000 to 2011 With more than (14%) disability rate, more than 700 Ethiopians are disabled every year, and around 5000 new cases of leprosy per year on average are reported despite the efforts of stakeholders (Sileshi Baye, 2015). Even though, Ministry of Health reported on its annual bulletin, Ethiopia has benefitted greatly from the implementation of MDT (FMoH, 2015).

Sileshi Baye, (2015), also claimed the number might be far higher than this figure if active case detection and proper diagnosis are incorporated in the national tuberculosis and leprosy control program. Huge number of undetected new cases of leprosy usually remains under-reported because of misdiagnosis. More specifically, in countries like Ethiopia where the state of leprosy research is clearly in decline, the need to assess the epidemiological trend of the disease leprosy in comprehensive manner seems imperative.

Later on, Tigist Shumet et al, (2015), attained that in Ethiopia, a total of 4374 new leprosy cases was reported in 2013, which is lower than the report in the previous year, among these, 4374, 466 (10.65%) were children and 361(8.25%) of new cases of leprosy had disability grade II. The proportion of patients with grade-2 disability (9.3 per 100) remained high, indicating a significant delay in the diagnosis and treatment (Sileshi Baye, 2015). The study indicated though claimed leprosy was under control in Ethiopia. It also remarked, reduction in endemicity of leprosy to an acceptable level should not deceive planners and decision makers while allocating resources and making other efforts. Rather, they have to further strengthen leprosy control activities and programs until the disease is eliminated from the pockets of each administrative regions of the country.

In general, the treatment result of Myco-Bacterium cases also helped Ethiopia to be categorized among the few African countries to have achieved the WHO targets. Nevertheless, the nation failed to achieve a 100% success rate despite a long history of treating cases freely. In fact, the socio-cultural beliefs and stigma, literacy level of patients and side effects of the treatment itself may be among the potential reasons for such failure (Sileshi baye, 2015.)

3.10. **The Psychosocial Consequences of Leprosy**

To begin with, for many centuries, leprosy has signified problems both medical, between the host and the parasite, and social, between the patient and the society (Mesele Terecha, 2005).

If leprosy goes untreated, small muscles become paralyzed and the entire hands become numb which causes the fingers to curl. When leprosy affects the legs, it affects the communication of sensation in the feet.

The ability to feel pain is lost and wounds may go unattended and cause infections leading to tissue loss. When the nerves in the face are affected, the ability to blink is lost which eventually leads to dryness, ulceration and blindness. When bacteria enter the mucous lining of the nose it can lead to scarring and internal damage, which in time causes the nose to collapse. Thus, if leprosy goes untreated it can lead to crippling, blindness and deformities (American Leprosy Mission, 2014).

Moreover describing, an equally important aspect of the disease it is attendant social consequences consisting stigma and discrimination attached it, particularly, the psychosocial impact also can be termed an immense (Iyor et al, 2013). Besides, Powell, (2006), also stated that the social consequences of being affected with leprosy could be devastating, causing victims to be humiliated or isolated from society.

Certainly, research has shown that leprosy has a negative effect on the sufferer's life, affecting their marriage, social life, employment and personal relationships. In many of the communities where leprosy is an issue family life is highly valued, compared to the individualism (Bergman & Britton, 2014).

However, reduction in prevalence alone is not sufficient, as the social consequences on the life of patient are often severe and persist even after successful medical therapy. Ideas of the contemporary society are in no way different from what they were nearly hundred years ago (Kumar et al, 2014). Leprosy as a disease brings misery to the patient and the family members overreact when they come to know that one of them is a leprosy patient. Hence, some of the patients did not reveal the disease even to their family members for fear of rejection. It can be no easier task to analyze the traumatic experience that a leprosy patient receives not only physically, but also mentally.

In fact, Scott, (2000), asserted that much research has been conducted on the medical aspects of leprosy, but there is a need in various parts of the world for specialized studies of the Psychosocial aspects of leprosy. Leite and Caldeira, (2014), stated the prevention of leprosy at the time consisted of assuming control of the body of the individual afflicted by the disease. As such, patients were isolated in leper colonies and subject to forced confinement to prevent the spread of illness in the "world of the healthy".

This exclusion policy generated both physical and psychological scars and sequel in isolated patients. In fact, Leprosy is a disease that has been known since biblical times. Apart from strongly affecting social, family and emotional ties, it is a highly incapacitating disease and is capable of affecting the functional dimensions of the body. Although leprosy is curable, it remains a major public health problem.

Eventually, Ajibade, et al (2013), conducted a study to determine the prevalence, management of leprosy disease and perceived psychological impact of the disease among residents of leprosy training centre, revealed: social isolation (94%), Anxiety (90%), shame (84.4%), depression (81.8%), emotional disturbances (71.4%). Besides, loss of self-respect, loss of self-esteem and emotional disturbances associated with disfigurement were some of psychosocial disorders resulted from the disease are reported. Accordingly, the high rate of suicidal thoughts among leprosy sufferers highlights the patients' concept of the psychosocial turmoil created by this disease. A variety of emotions is intensely experienced by leprosy sufferers. Grief appears to be the first and most general reaction that leprosy sufferers showed after a diagnosis of leprosy had been made (Scott, 2006).

Specifically, in Ethiopia , the society still continued to associate the cause, transmission, and treatment of the disease either with hereditary or superstition pushing and sending out new cases in to “leper colonies”, which as a result made the leprosaria important self-protection areas (Mesele Terecha, 2005:p181).

3.10.1. Beliefs about the Causation of Leprosy

Prior to this medical discovery people thought leprosy was hereditary or even caused by sin, especially since the Bible uses the terms “leprosy” and “lepers” in reference to a wide range of disfiguring skin conditions, including leprosy (Powel , 2006). Social taboos were created about leprosy patients being "unclean" or "cursed by God”. This stigma causes leprosy patients to face embarrassment and possibly become outcasts in their own communities. The stigma may force people to hide their condition and not seek treatment in order to prevent discrimination, which only contributes to the spread of leprosy.

From the very beginning, the belief of causes of leprosy differs across continents and communities. Some of the most common factors however are beliefs regarding the cause of leprosy, the fact that leprosy has traditionally been seen as a death sentence, fear that it may be transmitted, fear of the disabilities that it can cause odor as well as self-stigmatization (Bergman & Britton, 2014). Correspondingly, under the study of Melak Haileleul, (2008), it is found that the majority of PALs believed leprosy is the punishment of God due to their sin.

Therefore, the social image of leprosy is not greatly changed in many parts of the world; this is all too well reflected in the attitude of the community, particularly towards individuals disabled due to the disease (Kumar, et al, 2014). In addition, Mesele Terecha, (2005), asserted in the way that it might not be an exaggeration if he had concluded claiming an additional hundred year campaign of leprosy control initiative is needed, concentrating on the "social remedy" of the disease.

Further, a study conducted in Singapore on community knowledge, beliefs and attitudes on leprosy with 400 adult participants confirmed that an overall lack of knowledge regarding leprosy and prevalence of misconceptions regarding the cause, transmission and outcome of leprosy was identified among the respondents (Subramaniam, 2003). The stigmatizing attitudes towards leprosy patients were also present and found to be primarily associated with misconceptions regarding the spread of leprosy.

Accordingly, the writer recommended to facilitate the re-integration of persons cured of leprosy into the society, there is a need to educate the community in order to alleviate the stigma and misconceptions regarding leprosy and promote a positive change in attitude.

3.10.2. The Social Exclusion of Persons Affected by Leprosy

To come up with specific point of social exclusion, it's mentioned by Melak Haileleul, (2008:p.27), on the concept focuses on whole person who is:

> *cut off from different bundle of the social bond attached to the society its reflected in a combination of lack of normative integration and low degree of social participation, material deprivation, and insufficient access to social rights.*

Certainly, social exclusion and human rights abuses are major problems for leprosy affected people, and argued that these issues are not addressed by the medical ‘cure’ for leprosy (Duff, 2005). Consequently, in many countries, when governments forced people with leprosy into remote, isolated areas for the remainder of their lives. Families were split, children taken from their mothers, and those with the disease left alone with others in similar predicaments to gradually perish, forgotten by society.

Accordingly, a study which is conducted in Southern Region of Ghana, towards Health related quality of life amongst people affected by A needs assessment consisting physical functioning, role functioning, social functioning, cognitive functioning, health perception and pain people affected by leprosy in three selected leprosaria, confirmed that low overall quality of life. Among its shown to be influenced by many factors including inability to engage in social and physical activities, altered role functioning and poor mental health (Iyor et al, 2013). The leprosy suffers lose social status and become isolated from society, family and friends (Scott, 2006).

As (Duff cited in Yokota, 2005) the inhumane way some governments and societies have treated leprosy affected people, and their families, amounts to serious human rights violations. Enforced lifelong social exclusion in isolated areas with poor facilities, abandoned by those closest to them, poor or no health care and employment opportunities are just some of the violations experienced by people with leprosy. In some instances leprosy affected people have been targets of abuse and physical attack. Often marriage and giving birth to children has also been denied to them Besides, Leprosy once affected every continent and it has a terrifying image in history and human memory of mutilation, rejection and exclusion from the society (Kumar, et al, 2014).

Duff, (2005), asserted that Leprosy is a highly stigmatized disease and the word leper has a near mythical status as a synonym for extreme social exclusion. The reasons for society hark back to the history of leprosy and an inherent fear of the disease misconceptions including beliefs that is incurable, hereditary, or a divine punishment contribute to stigma which in turn intensifies the social exclusion that inevitably follows.

In addition, a study conducted in Ghana found that all the informants described the exclusion that people affected by leprosy go through as a major problem. They described leprosy patients as being excluded from social interaction by being denied physical contact and closeness (Bergman & Britton, 2014).

3.10.3. Social Participation Restriction of Persons Affected by Leprosy

The social participation of persons affected by leprosy is much more distressing to them than their individual effects. It impairs their life in various ways. Persons with stigmatizing conditions experience problems in their marriages or difficulties in getting married and in their employment or being employed. Their community interaction is affected, such as social relationships and friendships. Their families may experience reduced educational opportunities, leading to further inequities between those affected and those who are not. All of these negative effects result from poor community knowledge of the disease, and the misconceptions held about them (Luka, 2010).

3.10.4. Social Relationship of Persons Affected by Leprosy

Analytical study conducted in Brazil on two leprosy colonies, found that there was identified a good score in social relations, also, they were more likely to get along with colleagues from the colony, since they have no contact with the world outside the colony. They pointed out that prejudice is a concern, and that is present in their lives (Leite, et al 2015).

The social relationships domain, the score appears high, since institutionalized patients interact well with each other. It is worth noting that there is a social stigma in patients with physical appearance of leprosy, and therefore these individuals have difficulty of living in ordinary society.

3.10.4.1. **Family and Marriage**

When coming to the family and marriage issues related to Leprosy, a study conducted in South Africa, demonstrated rejection by (extended) family members appeared quite frequently, as ten of thirty participants' families had rejected the leprosy sufferer after diagnosis. Many of the participants kept the name of their disease secret. When participants who did it known (disclosed), twenty were rejected by their friends. As a result, Fear of the transference of the disease, is accepted as the largest single cause for rejection by family members (Scott, 2006).

Meanwhile, Scott, (2006), asserted that Leprosy is unique in its psychosocial aspects and it is difficult to analyze the traumatic experiences to which not only the patient, but also the family members are subjected. The disease may exert tremendous pressure on the relationships of leprosy sufferers who are married. It is substantiated by the fact that the divorce rate among the leprosy-affected is relatively high.

3.11. **Pushing Factors of Leprosy for Dehabilitation/Destitution**

Before effective medical treatments were introduced, forced isolation was the only worldwide strategy used to treat leprosy. Several sanatoriums were built globally to isolate patients with leprosy (Cheng et al, 2012). The prevention of leprosy at the time consisted of assuming control of the body of the individual afflicted by the disease. As such, patients were isolated in leper colonies and subject to forced confinement to prevent the spread of illness in the "world of the healthy"; this exclusion policy generated both physical and psychological scars and sequel in isolated patients (Leite and Caldeira, 2014).

As a result, when diagnosed with leprosy, patients often try to conceal the disease, for example by seeking treatment from a health centre at some distance from their home. To avoid negative behavior from their community, leprosy patients and, on occasion, their spouses may withdraw from communication with other members of their community (Sermrittirong et al, 2014). People who have been defected with leprosy are stigmatized since their deformities are visible to the whole community (Melak Haileleul, 2008).

In addition, Sermrittirong et al, (2014), also found that self-isolation practiced by leprosy patients, community members also express their negative attitudes by avoiding them, forcing them to leave, gossiping about them, and refusing to share public transport with them. Such behaviors have a negative impact on the physical, psychological and socio-economic status of people affected by leprosy. Psychologically, they may suffer mental stress and anxiety leading to depression and even, in some cases, suicide. In many cases, their economic situation may decline, their marital partner may reject them, and opportunities for further education may be reduced.

Once diamino-diphenyl-sulfone therapy (chemotherapy) became standard after the 1940s, policies of forced isolation were abolished. Although the widespread use of multi-drug treatments has dramatically reduced leprosy's disease burden, complications continue to be an issue for some patients. Despite the passage of over a half-century of drug therapy, in Japan, Korea, Taiwan, the United States (Hawaii), and the Philippines, many of those leprosy patients that were isolated still live with their complications in sanatoriums. (Leite and Caldeira, 2014).

3.12. **Institution Based Rehabilitation**

Segregation that is more formal has been practiced since the 13th century when leprosy occurrence reached pandemic proportions during the Crusades. In addition, the treatment and care of leprosy patients usually occurred in separate institutions. After the discovery of Dapsone in the 1940s, there was a gradual shift to outpatient care. In 1982, the World Health Organization declared that leprosy was curable. Although compulsory institutional segregation is now outdated and leprosy is curable, stigma is still widespread across the world (Sermrittirong et al, 2014).

Besides, due to the need for proper treatments of leprosy and to get far away from their community, the settlers are moved to the area separated from their parents, relatives and original birthplaces (ENAELP, 2002). For the reason, arresting Mycobacterium Leprae, in the second half of the twentieth century was not equally complemented with education of the society as a remedial solution to the society's traditional attitudes on the cause, transmission and treatment of the disease (Mesele Terecha, 2005).

The society continued to ostracise the sufferers forcing them to isolate themselves searching for their "own kind" and settle permanently around the leprosaria which, served as a means and a place of self-protection. Thus, Devadas, (2006), stated that rehabilitation in the field of leprosy requires greater efforts than the rehabilitation in other types of persons because the question of social acceptance does not arise in non-leprosy persons.

3.12.1. Supports Offered by the Institutions

PALs under intuition-based care, receive medical, nursing, psychological, nutritional and dental care, physiotherapy and occupational therapy. It may be assumed that, despite receiving multi-professional care, these PALs have unaddressed psychosocial situations (Leite and Caldeira, 2014).

Leite and Caldeira, (2014), also claimed that Leprosy is still a major public health problem and psychosocial rehabilitation services for patients suffering from the disease remain insufficient. With this regard, Nicholls and Smith, (2002), proposed that rehabilitation programs must be responsive to the overall needs of the patient, including the physical, psychological, social, and economic needs. As the impact of psychosocial adjustment and adaptation are important in this population. Moreover, Leprosy rehabilitation program must have an individualized rehabilitation care plan to fulfill personal needs (Cheng et al, 2012).

3.12.2. Integrating Persons Affected by Leprosy with the Community

In an institutional rehabilitation program, the community is not linked with the process. Hence, when the PALs return home, it may become difficult for them to integrate into their community (Devadas, 2006). Besides, the study conducted in South Africa, revealed, the majority of leprosy sufferers in the study felt that lengthy institutionalization and hospitalization had more disadvantages (Scott, 2000).

As a result, Leite and Caldeira, (2014), asserted that many patients (PALs) continued to live in institutions since they had lost their family and social ties and either saw no prospect whatsoever of living in the outside world or encountered difficulties during the social reintegration process.

Finally, studies have shown that the use of therapeutic workshops in mental health care is a useful tool for promoting re-socialization and individual integration into groups, through activities that stimulate collective experiences and thinking based on a psychosocial approach and respect for individuality, alterity and subjectivity. Thus, for successful implementation of rehabilitation services, it is suggested that a close co-operation between these specialized services and Community Based Rehabilitation programs should be promoted (Leite and Caldeira, 2014).

CHAPTER THREE

4. Research Methods

4.1. **Study Paradigm**

The way an individual views the world depends on the persons' paradigm. Hence, the world is how we view it not like as it is. For that reason, it is vital to make clear about the philosophical assumption of the researcher. This study is influenced by social constructivist world view throughout its implementation in so many ways. In the process of data gathering, the study raised broader and general issues and asked open-ended questions to let participants construct the meaning of their situation. (as Baxter, 2008 cited in Searle, 1995, Crabtree & Miller, 1999), constructivism is built upon the premise of a social construction of reality One of the advantages of this approach is the close collaboration between the researcher and the participant, while enabling participants to tell their stories.

The researcher recognizes the importance of the subjective human creation of meaning it is a people's conceptions and interpretations of representations in particular contexts. Creswell, (2009), confirms, the goal of a research written under constructivist world view is to rely as much as possible on the participant's views of the situation being studied. So that the researcher believes researches on human experiences need to relay on participants' own meanings and explanation. Accordingly, the researcher chose to investigate the questions prepared to guide this study by using qualitative methods. Through these stories, the participants are able to describe their views of reality and this enables the researcher to better understand the participants' actions.

4.2. **Research Design**

The research method chosen for this study was qualitative research method. According to Mouton (2001), qualitative research enables the researcher to gain a live experiences, perceptions and beliefs of the participants. Thus, a qualitative research approach was therefore followed in this study to obtain a rich data on the life experience of persons affected by leprosy through listening to the voices of the participants. In addition, to obtain a better, more substantial picture of the phenomenon so as to gain an in-depth understanding of the issue based on the research questions and its objectives in a natural way (Denzin and Lincoln, 2000).

Furthermore, the qualitative case study research design was used for it allows the researcher to share the understandings and perceptions of others and to come up with how people structure and give meaning to their daily life (Berg, 2001). Accordingly, qualitative data gathering tools and methods of qualitative data analysis was used in the study design.

Particularly, the study used descriptive type of case of study approach, which used in this study in order to describe the natural phenomenon and the real-life context in which it occurred within the data in question that the goal set by the researcher (Yin, 2003). Thus, the psychosocial effect of institutionally supported persons affected by leprosy and the institutional support at Kuyera Rehabilitation Center was focused in the study because of the need for a detailed and robust description of the issue.

4.3. **Description of the Study area**

In case of qualitative research, for thorough understanding of the subject matter under study or research question, it is up to the researcher to make a decision on the research participants, sites and even the material to use (Creswell, 2007). Thus, the study area was in

Kuyera town on Shashemene Rehabilitation Center for Disabled, which is governmental organization and situated about 240kms far to south of Addis Ababa under Oromiya region. Additionally, according to the document retrieved from the institution stated that the rationale for establishing the rehabilitation center belonged to come up with the society's attitude towards persons affected by leprosy that was negatively attached to the disease and the blurry understanding of what was the disease all about. Besides, the initiation when the rehabilitation center established it aimed to provide the necessary health and other social related rehabilitation programs (supports) to persons affected by leprosy (destitute) even though the rehabilitation established mainly aimed to religion broadening terms in such a way faith based organization by the Sudanese Mission.

Moreover, the rehabilitation center before it began rendering supports to persons affected by leprosy; it was facilitating the necessary preconditions for not less than three years. Thus, when the rehabilitation center began its main work officially, it was in 1944 E.C. it has been providing different services including necessities (shelter, clothe, food), medical, social, psychological and economic supports to Persons affected by leprosy who are under the rehabilitation program (History of Shashemene Rehabilitation Center, 1988).

The ground reason was for selecting the institution for the study, it has been institutionally supporting persons affected by leprosy who were suffering due to the effect of the disease brought unto them. Additionally, the institution was the first to be established as a rehabilitation centre in the southern region of the country.

4.4. **Target Population**

The study population of the study was persons affected by leprosy who are segregated /excluded and dehablitated from the society (i.e. socially, psychologically, physically, economically, etc) due to the effects attached to the disease (leprosy) and then living in the institution to obtain supports from Shashemene Rehabilitation Center for Disabled.

4.4.1. Study Participants

The participants of this study were institutionally supported persons affected by leprosy, key informants from management personnel of the institution whose position has close exposure to institutionally supported persons affected by leprosy and the other from the Association of the Persons Affected by Leprosy in Kuyera town. The number of samples in this study was subjective with regard to data saturation in a way that the samples were included until the redundancy of information forth coming. Mack, (2005) confirms, qualitative study sample sizes are often determined on the basis of theoretical saturation where the point in data collection when new data no longer bring additional insights to the research questions. Since qualitative data are bulkier than quantitative data, qualitative researchers usually use small number of sampling. This is because during data analysis qualitative data become very extensive if the number of sample size is large Grinnell and Unrau, (2005).

Thus, the study consisted eleven persons affected by leprosy who fulfilled the inclusion criteria that were institutionally supported in the rehabilitation center who were aged from 40-75 years among them seven of them are female and the remaining four are male.

Additionally, a female Social Treatment Officer of persons affected by leprosy in Shashemene Rehabilitation Center for Disabled included that had close contact with institutionalized persons affected by leprosy. In addition, the other male one consisted, who was Programs Coordinating Officer in association of persons affected by leprosy.

4.5. **Sampling Method**

In order to come up with participants of the study, the researcher chose purposive sampling technique as the most important kind of non-probability sampling, to identify the primary participants Since the study looking for those who have had experiences relating to the phenomenon to be researched (Welman and Kruger, 1999). Hence, the sampling method was purposive sampling method since the study focused on the effect of the disease and institution based care psychosocial support of PALs. According to Merriam, (1988), sampling in qualitative study tends to be small number of people nested in their context and studies in-depth unlike quantitative studies, which aim for large number of context of stripped cases and seek statistical significance. Thus, the participants were selected purposively in order not to participate subjects merely in the study. If not doing so, it might have an effect on reliability and credibility of the collected study data. Therefore, units were selected deliberately. In doing so, the participants were selected by the aid of the institution’s documented history of institutionally supported persons affected by leprosy, additionally; the management wings supported in referring participants of the study.

4.5.1. Inclusion and Exclusion Criteria

In the inclusion and exclusion criteria, the researcher gave much attention to select samples in a way, which is relevant and consistent with the study’s focus to describe. Thus, the researcher posed much effort to come up with the study’s relevant samples as stated above with regard to filtering irrelevant samples as well. Therefore, the researcher included institutionally supported persons affected by leprosy samples relying on the bottom stated inclusion criteria.

4.5.1.1. **Inclusion Criteria for Institutionally Supported Persons Affected by Leprosy**

- Must be resident in the institution.
- long time of residence when obtaining the services from the institution.
- Age is between 30-75 years (in order to look at the experienced psychosocial effects of the disease and the gained institution based psychosocial support and also age above 75 years could not be considered effective to respond appropriately).
- Willingness to participate in the study.
- Availability of the participant during data collection.
- Visible deformity of the subject (to look at shame, fear, & related psychosocial issues towards social participations and relationships).

4.5.1.2. **Inclusion Criteria for Key Informants**

- Enthusiastic to participate in the study.
- Work experience of more than three years,

4.6. **Data Collection Procedure**

Initially, a permission letter was issued from the School of Social Work that helped the researcher to collect the needed data in the intended study site. Then, the issued letter was given to the institution's concerning management staff in where the study was intended.

Moreover, a first impression was given due attention to launch better rapport and to evade barriers in the study data collection because, participants might tend to be uncertain and overly critical. Hence, the purpose of the study was explained to all purposively selected participants of the study and that the participation was voluntary and that they were free to withhold answers to any questions that might arise during the course of the interview and anonymity was assured.

The date for data collection was arranged when after the potential participants completed the inclusion criteria and when the participants decided to go through the interviews (in-depth and key informant interviews). Then, an appointment with each participant and place (suitable, quiet, and favorable) to conversation were set with the participants. Besides, a digital tape recorder and notebook during the interviews were used.

When tended to conduct the interviews on the scheduled days (April 11-May 11, 2016), the researcher before each interviewing, granted honor for the participant with regard to the time and willingness for being part of the study, and reminded the participants about the agreement (informed consent), explained that it was in depth or key informant interview. Subsequently, the researcher asked a permission to record the audio of the interview and the participants had given verbal and written consent prior to conducting the interview.

Moreover, the questions were first prepared in English language and then translated to local language Amharic to eliminate communication barriers and unclear questions that hinder participants to respond. Moreover, due attention was given to crosscheck the clarity when translated in to Amharic language which was intended to do so.

Further, during conducting the interview, Amharic was the medium of communication of eleven participants. Foremost, to conduct such kind of in depth interview, building rapport had given a crucial attention to create a conducive and friendly circumstance with participants to gain detailed information. In addition, the interviews were conducted in making the interview awesome, energetic, and precise with separate quiet room that was allocated for this study sprinted an average of twenty-five to forty minutes. In addition, all the interviews conducted were audio recorded and notes were also taken during the interviews in accordance with the permission of the participants.

Throughout the interview, efforts put forth to make the discussion open, free, non-overriding and unreserved. Since the researcher is the designer of the interview, he played an active role in making certain decision about the progress of the interview. Throughout this, the researcher admitted differences of participants and uniqueness of each participant. As a result, the researcher used his major efforts in light of empathetically understanding approach and strived to be a good listener, friendly and non-judgmental throughout the interviews process. Furthermore, after all done, document reviewing was resumed, in order to analyze and crosscheck the gathered data in searching the recorded data in the institution.

4.7. **Sources of Data**

To make the study certain, both primary and secondary data sources were used. To come up with primary data, in-depth interview was applied with the selected institutionalized participants to come up with detailed information of persons affected by leprosy under institutional support towards the psychosocial consequences experienced due to the disease and obtained psychosocial services from the institution. In addition, key-informant interview was held to participants who are considered to have ample experience and knowledge about the institution and related institutionalized persons affected by leprosy to verify the obtained persons affected by leprosy's responses in the in-depth interview. Additionally, documents reviews were intended and different sources, which are published and unpublished materials to access secondary data were implied to make the study to have scientific and multidimensional views.

4.7.1. Instruments for Primary Sources of Data

4.7.1.1. **In depth Interview**

Since the study's aim was to describe about the psychosocial effects of persons affected by leprosy who are found under institutional support, in depth interview was used to collect detail information from institutionally supported leprosy affected people in order to allow participants to discuss their opinions, views and experiences in detail. Therefore, the interview guide was developed in accordance with the research objectives. In other words, when tend to conduct an in-depth interview, the researcher prepared questions to utilize in depth and detailed information in line with the study's objective to address.

Particularly, the study used semi-structured interview guide with an open ended questions to get information on the psychosocial factors that led persons affected by leprosy to seek institutional support, the psychosocial effects of the disease, the psychosocial contribution of the support on the lively of institutionally supported persons affected by leprosy, and the perceptions of institutionally supported persons affected by leprosy towards the supports rendered by the institution. The interview guide allowed the researcher to maintain a certain level of control over the process while enabling the researcher to gather the most relevant data in relation to the phenomenon of interest (Burns & Grove, 2003). Thus, in depth interview was conducted with persons affected by leprosy who have been in the institution for long years. In order to get detailed information, efforts had been made to use probing questions depending on the significance of the statement given by participants.

4.7.1.2. **Key- Informant Interview**

The researcher used key informant interview that was mainly employed for these two individuals who have sufficient knowledge and experience in light of the institution based supports and towards the institutionalized social and psychological experiences of leprosy affected people. Additionally, the key informant interview was also conducted with one female officer who had ample experiences of services in the Shashemene Rehabilitation Centre for Disabled management and one male Program Coordinator professional from Shashemene association of Persons Affected Persons. Moreover, the questions were employed to crosscheck the in depth interview participants' response under institutional support and the overall psychosocial support of the institution. The questions used for key-informant participants were mainly emanated from the preliminarily used in-depth interview questions for the institutionally supported persons affected by leprosy participants.

4.7.2. Secondary Sources of Data

In the secondary data sources, published and unpublished materials were employed in all the process of the study when the materials found related to the topic of the study; including researches, journal articles, reports, books, and electronically browsed/ retrieved materials. These were used for advancing the scientific views of the research with regard to show the views of different authors towards the study related issues.

4.7.2.1. **Document Analysis**

The document analysis used to access data that kept by the rehabilitation center which dealt about the institutionally supported persons affected by leprosy and the supports of the institution rendered to institutionally supported persons affected by leprosy. According to

Merriam (1998), document analysis is a method that can spawn valid and replicable data from documents. Hence, the document analysis was used for data triangulation to crosscheck the obtained data trough one instrument over the other.

4.8. **Data Analysis**

In conducting this study, the researcher used audio recording to collect data from all participants using in-depth and key informant interviews with face-to-face interviews, which were conducted using a pre-prepared interview guides. After conducting all the interviews, the researcher translated and transcribed audio recorded sounds & notes directly from Amharic in to English in listening to their (participants') Amharic voices using laptop with more of meaning based translation of respondents.

Then, after the needed data collected through the in depth, key-informant interview tools, and document analysis, the data analysis was digested through appropriate scientific steps and inductive thematic technique of analysis. Besides, the notes were carried out in line with the research questions. Morse & Filed, 1995, (as cited by Abebaw, 2013), stated that thematic analysis involves the search for identification of common threads that extend throughout an entire interview or set of interviews. Therefore, the purpose of thematic analysis is to identify patterns or themes evident in several cases after pre-coding, coding, categorizing and theme development processes was formulated, the analysis was made on the findings and main themes described in line with the objective and research questions to be addressed. Lastly, the major findings of the study were presented and discussed.

4.9. **Trustworthiness**

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

In addition, participants selected by using pre-identified inclusion and exclusion criteria and consulted the documented data of the history of institutionally supported persons affected by leprosy and the management personnel to refer the selected participants who fulfilled the criteria. Moreover, to avoid inaccurate or insufficient data or misled , the researcher used his judgment based up on the best available evidence to choose subjects who know enough, can recall enough, and are able to responded precisely to questions asked.

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

4.10. **Ethical Considerations**

An official support letter was issued from Addis Ababa University, School of Social Work, which helped the researcher to conduct the study on the intended site, and then permission was obtained from the head staff of Shashemene Rehabilitation Center for Disabled.

Additionally, prior to the interviews were conducted, the proposed informants received information about the study and its purpose. Moreover, since an informed consent is the first and decisive ethical requirement of a study, in order to come up with ethical and viable scene, the informed consent agreement was translated from English in to Amharic. Moreover, in both verbally and written terms, informants were explained or briefed to participate voluntarily. Additionally, leprosy affected participants who were participating for the in depth interview, the informed consent agreement paper read for them orally since most of them couldn’t be able to read it by themselves and after they listened the dictated consent agreement they signed for their agreement to participate voluntarily. On the other hand, key informants had given the written consent and they approved their agreement signed after they read it to participate willingly.

In order to protect informants’ freedom and self-determination, they were set free at any time to terminate the participation, without having to give any reason and without fear of repercussion.

During the time of interview with informants, tape recorder and other relating aids were used after asking participants’ consent in word. Moreover, issues of confidentiality and anonymity were assured for participants and were given serious attention.

Furthermore, the researcher notified to participants that the results to be dispersed in the form of a research report. Besides, the results would not mention the participants’ names and the recorded files (audio recorded) and written documents to safely store or destroy after the study was done.

CHAPTER FOUR

Data Presentation

This chapter presents the collected data, which attained via data collection tools from participants under study. Thus, main issues presented in detail with their crucial subtopics to address the objectives of the study. To this end, the social and psychological factors that led persons affected by leprosy to seek the institutional support, the psychosocial effects of the disease, the contribution of the rehabilitation center which brought on the livelihood of persons affected by leprosy under institutional support, and the considerations of persons affected by leprosy under institutional support towards the supports rendered by the institution are presented briefly.

4.2. The Psychosocial Factors led Leprosy Affected People to Seek Institutional Support.

Under this section, major issues presentes towards the psychosocial factors that led leprosy affected persons to seek institutional support presented. In other words, the data mainly presented the social and psychosocial factors of leprosy which brought participants to the institution: particularly, the social (family & social reaction), and psychological (fear, shame, anger, & blame) factors are presented.

4.3.3. **Social Factors that Led Persons Affected by Leprosy to Seek Institutional Support**

Different social factors are reported that led persons affected by leprosy to seek the Institution. With this regard, participant (02) stated that family problems forced her to leave the area and joined the Institution due to her family had had daily quarrels because of her condition; as she explained it in the interview,

> *“Since childhood I faced many social challenges, starting from disturbing my family’s life. My dad and stepmother were fought and quarreled with each other because of me… at that time I reached at age of 15 and I disappeared from the area and came to Addis Ababa…They never even wanted to associate me in the family.”*

The above data indicated that family factor led the respondents to join the Institution. Similarly, respondent (03) who shared the community factor that made her flee from her former living place, Harare and joined the Rehabilitation Centre. She said,

> *“As a result of leprosy, the community out casted me when they knew I was infected. This happened when they observed some symptoms of the disease on my body. Because our community does not have the basic concept of leprosy, they stigmatize and never associate with the patient. Therefore, you have to look for your own association who look like you. Finally, I also came to live with people who are like me.”*

As can be seen from participant (03) statement above, lack of basic concept about leprosy and leprosy affected people by the society caused this patient to be discriminated; and which in forced her evacuate from the area where she was born and bred; she at last joined for Shashemene Rehabilitation Center for Disabled.

Participant (05) also shared similar experiences with regard the social factors that led him to sought institutional support. Further, stated that despite his sociable behavior he had with the community after they (society) knew that he disclosed with the status of leprosy, all the community neglected him; he further explained that, because of leprosy they ran away from him and he at last left his home. This shows how the social life issue hurts much due to being leprosy affected person.

Apart from neighbor and community reaction and pressure towards participants as have been seen above, other participants added that responses given by family and friends was harsh, mainly due to their disclosure to leprosy status.

In line with this, participant (09) who responded family reaction as a reason to leave his home place further stated about family treatment this way: *"My family stayed away from me (alienated in home). They used to remove the dishes and cups, which I used/ served. They all perceived me as a devil. So I went to other places where I could live with people like me."*

In addition, participant (07) who expressed the stigma from parents stated the situation as follows:

> "*Even though my family knew about my status and they were very concerned about my condition, my relatives like uncles, aunts, neighbors disregarded me…I was stigmatized; the dish which I was served to eat on food and the cup (nickel) which I drunk with were threw away in to trash after I used them once. Most often I stayed idle and was disregarded."*

The above data illustrated, some of participants stated the reaction from family members was unwelcoming for the leprosy they had. Participant (09) and (07) particularly confirmed how much family member's isolation of leprosy-affected people who are of their own family member really hurt them and caused them to leave their family. Particularly, siblings, neighbors, and community stigmatized and alienated them. Some were alienated due to leprosy by dumping their dishes and cups in to a trash after used as given by live respondents' interview above.

Similarly, the experiences of (KII 001 and KII 002) whose responses was also similar with in-depth interview participants confirmed that some reason for leaving their home place was deep rooted wrong social belief and awareness about leprosy affected people. With this regard, KII 001 who responded about the social reasons which caused leprosy affected people came to the Rehabilitation Center, said that: "*As a result of social pressure they face in their born places, they came to the Centre to live with society who are of their kinds.*"

(KII 002) who also reacted to this question said that, *"Because they are excluded by the society and seen as something unique by the society, they have been forced to live in this rehabilitation."*

On the other hand, a few participants (such as participant 01 and 06) reported that because they were infected by leprosy, they didn't recognize the reaction of their family and society towards them, mainly either because they were inflicted when they were children or because the community they used to lived in was well informed . They instead left their living environment and joined the Rehabilitation Centre due to the social pressures and personal reasons.

Participant (06) who was infected with leprosy during her childhood, remembered how the family and community was sympathetic towards her condition and explained the reason for coming to the Rehabilitation Centre as follows;

> *"My family and community were really concerned about my condition. When they look some white spots on the surface of my body, they were worried too much. Particularly my father worried and he even couldn't eat his food properly when he looked at me home; he was irritated... he was very frustrated about my condition. ... I was the third daughter of him; he loved me more than my elders... so I was taken to several churches and sprinkled in 'Holy Water'. Then, I was*

> *brought to Zenebwork Hospital and got the treatment before transferred to this rehabilitation center. When I grew up maturely, I began to realize that while my equal age friends at home have been employed and started to earn money, I thought I would still remain dependent on family if I got back home. So I quitted the idea of coming back to family home and have remained here."*

The above statement takes us back to the childhood memory of respondent and shows us how her parental care towards her wellbeing was full of tender and how the positive image of her family really kept her free from social stigma and separation. It was instead, her own image she created towards herself after maturity that caused her to remain in the Centre.

Furthermore, participant (01) who explained the financial reason that caused to leave the area, explained the social reaction this way: *"... The people (family, relatives…) felt empathy about my condition. There is no such stigmatizing leprosy affected person; rather they eat (share) foods together."*

4.3.4. Psychological Factors that Led Persons Affected by Leprosy to Seek the Institution

This section states that the psychological factors that leprosy posed on the behavior of participants to seek institutional support. Particularly, leprosy affected participants asked about the emotional reactions and behavioral changes they brought due to leprosy with regard to shame, fear, anger (sad), and blame and their needs to go back home and rejoin with their society.

Participant (07) stated that when he was told that he had leprosy, he wished to leave and die some other place than living with psychosocial repression coming from society whom he knew very well. He said*"…. I prayed to God to kill me in some other place."*

He also stated that his behavior was changed due to leprosy and he explained how it was hurtful his life this way; *"My behavior changed due to leprosy, I was feeling shameful and fearful about my appearance, and was angry and blamed God for what he gave me."*

Participant (10) who explained about the feelings of fear and shamefulness, he received from the society further stated that many people whom he met along his way out and back to home always said something that disgraced his mind after it was confirmed that he had leprosy in the community. He also stated that,

> *"I have had feared and ashamed of people's mouth whisper and speech I meet from my community. My father and my mother were blaming each other pointing their fingers one after the other about who should be the responsible for the transmission of leprosy disease to me. So, when these psychological factors mounted time after time, I decided to go some other place where I could live with treatment and likes."*

In line with this, participant (09) who responded family reaction as a reason to leave his home place above also stated about psychological factor forced to leave the area this way: *"My family all perceived me as a devil. They always image me like that. So, I went to other places where I could live with people like me."*

When leprosy affected persons recognized that the society they were living with was showed up negative attitudes and mal-treatment towards them (PALs), they (PALs) developed hatred and anger towards themselves and the society. In turn, it forced them to leave their long time living place and move to new places and like-community (similar to sufferers) who welcomed them with their deformity or ulcer body and to start a new life.

supporting the lately stated ideas KII (001) who responded about the psychological reasons which caused persons affected by leprosy to came to the Rehabilitation Center stated that:

> *"For the reason the disease inflicts all parts of the body and goes sever to cause even disability. The wrong attitude towards leprosy, the society had in mind that it is a wrath of God. For that reason they stigmatize and react negatively to a person who had leprosy."*

As a result, such conditions led them (PALs) to be angry and timid and even blaming God for everything happens around them. Thus, from this response it can be inferred that the social factors are still the basic factors that causes the psychological factors to emanate from.

According to KII (001) response, *"The social influence over the leprosy patients is still prevailed and the belief that the disease transmits not through bacteria, but due to wrath of God is still continues; that such social and psychological conditions led them to come to here (to the Centre)."*

Similarly, KII (002) confirmed that: *"Those who had leprosy and lived in the society perceived as something a monster."* The images that PALs were given in the society always irritated them and made them angry which mainly caused behavioral changes due to leprosy.

The majority of interview participants of deep interview stated that the reaction of the family, neighbor, and society, was unwelcoming when the status of leprosy came to disclose.

On the contrarily, a few (nearly two in number) participants shared the issue that their parents and the society were treating them with no any negative reactions.

4.4. The Psychosocial Effects of the Disease Brought on Persons Affected by Leprosy

The findings of this study also identified the psychosocial effects of the disease brought on institutionally supported persons affected by leprosy thoroughly presented below.

4.4.1. The Social Effects of Leprosy

In this section the social effects of leprosy on participants' lives such as social participations and restrictions in social gatherings (i.e. weddings, funerals, Iddir, Mahiber, & so forth.) and social relationships (i.e. family, friends, & society) they had and the social challenges they faced due to leprosy especially outside and inside the Rehabilitation Center are forwarded beneath.

To begin with, participant (08) who described her teenage time behavior as descent one, narrated her social experiences that she faced due to the community and her family. She said that:

> *"In my community, the people whom I lived with hate this kind of disease. They even thought, the disease would jump and catch them merely. Thus, they didn't like a person who was infected by leprosy."*(Field note, 2016).

So, the lately stated respondent's community whom she lived once was not welcomed her because of her being a leprosy patient; and the deformities created on her body as a result of lack of treatment of the disease for long played its own role in increasing the social stigma, she added. In addition to this, the length of stigma and treatment her relatives had showed her was also deep that she explained the event as unforgettable one in her life; she further explained that as a result of their (society) response, she was enforced to beg in Addis streets. She stated the worst social effect in general, as "*It was unthinkable for me to beg and looking at people's eyes due to leprosy.*"

In the same way, participant (03) who shared the social effect of leprosy, particularly said that the community did not invite her to the coffee ceremony as a result of leprosy. She said she had always felt like an out casted person in society. This led her at last to get out of the area.

Participant (09), who stressed of gossip and finger pointing made by the people around over him, created big destructive social effect on his life. They spread rumors about leprosy as something he was caught because of "*heredity and evil spirits*" that because of having the disease, he added that*, "the people got afraid of me and restricted me to engage socially."*

Correspondingly, participant (10), who was also disclosed with his leprosy status to the society he used to live with and they (the society) isolated him from social participations as he explained it this way; *"I couldn't participate in social occasions and shares no meals together (in weeding, funerals, baptizing rituals) in my locality. As a result, the social well being of a person immensely gets down."*

Participant (06) also reported that*"… I didn't participate with people in my locality, because all of them point their fingers at me and I was on everybody's lip for what I had."*

Respondent (09) stated that leprosy affected his marriage. He explained the situation as follows;

> *"… I went back home after having a treatment for months in Zenebwork hospital. Due to the weather in my residence, the disease was relapsed and caused severe infection and finally I was mutilated my leg. At home because of my condition, my*

> *wife and other family members stigmatized me. Therefore, I went back and stayed at Zenebwork for a year. I finally decided not go back home, and applied there to get admitted….”*

Furthermore, concerning towards the social effects of leprosy, Key Informants also gave their own observations and experiences focusing on those factors which have had influences inside the Rehabilitation Centre. As a result, KII (001) said from his experience the following;

> *“… though still they are living in deep social stigma and stress, those who have a son and a daughter here would not be interested with their children to have marriages and live with the healthy society due to disgrace and discrimination they anticipate; they would meet from healthy society around.”*

The above data shows that how the society segregated persons affected by leprosy with prejudice and stigmas, which in turn caused the patient to isolate himself against marriage with normal/ non-infected people living around the Centre.

Nevertheless, KII (002) who stressed about the social effects of those leprosy affected people living inside the Centre, gave her reflection contrary to the above idea saying that leprosy affected people do not experience social hazards inside the Centre. She also said;

> “*They are happy because of their coming in this Centre and because of presence themselves among people who really look like them who could share and understands their ideas… They get a chance to observe and see other like-society encourage and braving them as they can do everything like normal people do in the society.*

This data observed that persons affected by leprosy who were living inside the Centre did not experience the social stigma. Because the discussant above reported that, there was strong social cohesion among the community, particularly among the institutionally supported leprosy affected people and the staff who work daily inside the Centre. She also indicated in her discussion that members of the administration workers and other people in the Centre encouraged patients to participate in different social gatherings.

Among institutionally supported persons affected by leprosy, a few participants such as (04) reported in support of the above (KII 002) idea stating that participant (04) had never experienced any social stigma in her family, too. She further reported:

> *"In my locality there is no such thing to get excluded from any social participation, rather they get closest. I even participated and invited my brother's wedding ceremony (celebration), I was there sat together and got treated very well (warm treat). They believed this disease was a matter of one's fate. The disease only hurts my body, no societal issues."*

From the above data**,** it was possible to infer that almost all participants with the exception of two participants (04) and (01), reached an agreement in their discussions that leprosy brought severe problems in their social life particularly in their social participations (weeding, Mahiber, Iddir, funerals… so forth) and family rejection or partners relationship problems due to the disease infection.

Almost all of participants reported that they were very sociable, friendly and interactive with the society they used to live. Among these participants, while one participant reported that she was enforced to beg due to the disease, which resulted alienation from her family and society, one more other participant reported that he faced problems in his early marriages since the time he was disclosed with leprosy status. In other words, participant explained that he couldn't stay at his marriage due to family pressure and social issues.

In general, the above data indicated that apart from social effects of leprosy reported by respondents, their cultural beliefs about the leprosy caused the society collectively to behave about leprosy victims, discriminate and stigmatize the sufferers. Particularly, the belief of society associating the disease with evil spirits, witchcraft, hereditary, and considering it as wrath of God, and not marrying leprosy victims stated above by the respondents were effects brought by cultural belief that such belief is similar throughout the country, as respondents represent different geographical part of the nation.

4.4.2. The Psychological Effects of Leprosy in Changing the Behavior of Leprosy Affected Persons

This section states that the psychological effect of leprosy, which brought on the behavior of participants. Institutionally supported persons affected by leprosy asked about the behavioral changes they brought due to leprosy with regard to shame, fear, anger (sad), and blame and their needs to go back and rejoin with their society.

In line with this the above stated issue, participant (04) stated that she was very confident about herself, but due to the leprosy, she reported that she had the feelings of being ashamed; fear others, blaming and anger (sad) easily. She further reported that, she once even tried to commit suicide by herself.

She added that she couldn’t accept the life after leprosy that it left her with obsession and sufferable mind because the disease disregarded her from the good life she used to enjoy with comfort at once.

Similar to participant (04) above, participants (03) and (07) who shared their experience about psychological effects of leprosy, also reflected some common idea on the issue. They stated that as they were prohibited from participating in different social, cultural and economic activities of their community, they become fearful, withdrawn, isolation and lose self-confidence and self-respect. Because of these psychological effects, both participants reported that they tried to commit suicide.

Respondent (10) still reported about the psychological effects of leprosy in a way; *“Due to the disease, my behavior was changed in terms of felling of shame, intense anger and blames my physical looks for everything messed. It even went severe to mental stress. I was irritated…. My mind always get hurts due leprosy, it’s heavy as a stone for me.”*

In similar story participant (06) who discussed her own experience of stigma, further stated the psychological effect of leprosy, when she became matured: *“…. When I got conscious about my condition, I began to stigmatize myself from the community. I was feeling fearful, ashamed and so forth even though the society didn’t neglect me.”* This response indicated how being leprosy-affected person influenced the belief and self-esteem of the infected person with despite of social welcoming. Correspondingly, this participant (06) also reported that because of the negative self-image, she always compared herself with her friends and gave herself a low value especially after she begun wearing an artificial leg; *“… For the reason fear and shame, I always feel that I am under my friends’ in status and displaced from my residence.”*

Similar to the above respondent, almost half participants (01), (08), (09) and (05) who explained the behavioral changes and the feeling of shamefulness of leprosy, also stated some psychosocial effects that have been came due to body deformity participant (09) stressed; *"... I feel bad, shame and fear, especially, when I take off and on my artificial leg in front of my relatives or others."* Moreover, "*Because of my body, it's impossible to get close with others and do as I like in a healthier people"* participant (08).

According to the grapevine, participant (09) who stated the feeling of angriness and shame for having leprosy, also stated the recent visit he had paid to his relatives who used to live in Addis Ababa, who had felt discomfort by his appearance (mutilated leg & clawed fingers) due to the disease, it was destructive during wearing of artificial legs.

Key Interview Informants who were asked to discuss about the psychological effects of the disease brought on leprosy affected people, they stated in detail referring the experiences of patients who live in the Rehabilitation Center other than the experience found outside the Centre. Therefore, according to (KII 001) conversation:

> *".... Even though there are works that have done by this Rehabilitation Centre to change the attitudes of the community towards leprosy patients, with regard to the attitude of patient himself, there is still problem in bringing the necessary behavioral changes. The attitude they have towards the disease is deep rooted that whatever work you do on these patients, they would not change their attitude towards themselves."*

From above quotation, (KII 001) confirmed that the people inside the Rehabilitation Centre would not stigmatize leprosy-affected people; instead, they were the patients themselves who did not feel comfortable about their selves (body appearances). They had the behavior concealing their deformity and feeling of fearful and shame. These feelings reported to be deep rooted that activities such as awareness development of the psychological makeup of these people should be done with the community based rehabilitation circumstances. Moreover, (KII 002) stated in general term that *"Due to the unimproved perception of their being patients, they still got hurt with regard to their psychological makeup."*(Field note, 2016).

From the above data, it was found out that, with the exception one (i.e., participant 02) whose experience towards the psychological effects the disease was not as such bold, almost all participants had suffered with psychological effects due to their being leprosy victim. Most institutionally supported persons affected by leprosy had psychological problems (emotional instability) mainly due to the association between their physical deformity caused by leprosy disease and accompanying disease associated stigma. As a result, particularly because of their physical appearances, negative consequences had been reported towards their self-perception and feeling such as shame, fear, angry/sad, and blame. Moreover, key informants claimed that persons affected by leprosy had encountered with the psychological effects of the disease that was brought mainly as a result of their own poor self concepts and values they (PALs) offered to themselves. In addition to this, one respondent (02) stated because she had bad self-perception, fear and shame, she stigmatized herself from the society though the society didn't out casted her. Moreover, some even reported that they had tried to commit suicide due to the stress they had in their mind and towards their conditions.

4.5. The Contribution of Institutional Support on Lively of Persons Affected by Leprosy

This section presents the contribution of the supports rendered by the institution in improving the life of institutionally supported persons affected by leprosy. Apart from presenting the contributions, the kind of supports that had been offered by the institution as a result of in coming up with the social and psychological effects of the disease persons affected by leprosy explained.

4.5.1. The Supports Rendered by the Rehabilitation Center

To begin with, the function of Shashemene Rehabilitation Center for Disabled had been restricted to the provision of some basic human needs such as food, shelter, health, education and shelter with inconsiderable psychosocial supports involvement as few participants' interview respondents such as (01) and (03) etc have indicated.

Participant (09) who was asked to elaborate the supports that were rendered by the Rehabilitation Centre to him and to other institutionally supported leprosy affected people; stated that; "*The institution offers basic necessities like food, shelter, clothes and medications; particularly with food provision, we get edible oil, wheat, Teff, sugar, chilli powder, maize and lentils (Misir)*."

Similarly, participants such as (01) and (03) who were asked the same question stated that the Rehabilitation Centre provided with "*... house, clothes, shelter, bed, blanket, food and medication*."

As it is clearly seen above, Shashemene Rehabilitation Center for Disabled rendered with some basic needs to all institutionally supported persons affected by leprosy consisting food, cloth, education, shelter and medical services. These supports stated above had been economic dimension of supports that the Centre provided.

Additionally, Key participants also acknowledged the existence of economy supports from the Centre. The basic assumption that help leprosy affected people benefit most from being included in mainstream programs to improve their life has been low. In this regard, (KII 001) who mentioned the basic supports such as food, clothes and shelters that have been provided by the Centre mainly using the budget allocated by the government, further stated "…*these supports are not enough in copping their social and psychological problems*."

(KII 001) who expressed his conviction about the limited supports that the Centre offered to persons affected by leprosy such as stated above, also shared his belief that "*The rehabilitation centre should not be restricted only within these little supports"*. He added that if the government allocates more budgets, they (the PAL's association & the center) had a plan that the service rendered by the Centre would be improved. *"By giving training, we are also striving to bring these leprosy affected people in to self reliance. Otherwise, currently we are only giving the basic needs of services mentioned above including health services.*"

4.5.2. **The Relieve of Institutionally Supported Persons Affected by Leprosy**

This section describes how institutionally supported persons affected by leprosy come up with the situation (psychosocial problems attached to leprosy) as well as the different implicit social (helping PALs to celebrate world leprosy and disability days) and psychological supports (rare counseling supports) that assist them in getting relief. The formal support system persons affected by leprosy got from the Rehabilitation Centre were in the form of food, clothe, shelter etc and from the Centre's hospital were medical supports.

Accordingly, apart from the center's service provision, all of participants reported because of they got a chance of living together under an umbrella, they remarked that they got big relieve. That means the existence of the institution by itself was identified as one major support that assisted institutionally supported persons affected by leprosy to come up with the psychosocial problems attached to leprosy.

In this regard, for instance, participants such as (03), (04), (05) and (09), expressed about their positive thought that was created due to their presence in the Centre. Additionally, the above participants forwarded their feelings as if they were reborn; participant (03) stated as follows "*…. I really feel I was reborn for finding people who are like me in here."*

Moreover, it was found out that all of persons affected by leprosy also explained that they have got relief in terms of belongingness because of their presence in the Centre with people the same problem. However, such relief and good feelings had been achieved with those limited basic supports. With this regard, participant (04) stated that further: *"Even though no changes brought in my life, I don't have anything to get distracted, because, we all are the same here, who have same problems."*

Participant (09) also mentioned additionally: *"… I have got relief, I don't feel anything wrong in here because we all are the same, but I wouldn't, if I was outside of this institution."*

From the above data, it was possible to attain, the supports rendered to persons affected by leprosy in the institution, presented that the supports that the institution provided commonly; necessities like shelter, food, cloth, and medical treatments. All (11) participants reported they felt relives for being existed in the institution as a result of all were living with leprosy affected people. With this regard, both key respondents also claimed that institutionally supported persons affected by leprosy felt nothing inside due to all of them were the same.

4.4.3.1. **The Social participation Restrictions of Persons Affected by Leprosy**

Participants reported that most of them had close interactions with colleagues and the staff, and the very near area to the rehabilitation center. They reported also that they attended social gatherings near around such as weeding, funeral, Iddir, Mahiber and so forth. In this regard, participant (05) and (08) who reported about their participation in social events in the Centre further said that; *"They (people around the rehabilitation center) invite us on weddings & other occasions, they treat us equally with others in this regard. No distortion and insults."*

Alike, participant (01), (04), (06), (09) and (10) stressed that they were limited in the Centre and visited if one of them got sick; they got help each other with the Iddir if someone died in the Centre, or they participated in social occasions like weddings, World Leprosy Day, World Disability Day and cheered together in the Centre. They even had the membership with local *Iddirs* inside the Centre and participant (10) for instance, particularly reported he had been serving as financial auditor in one of the *Iddirs*.

Nonetheless, the whole these social participations had been taking part, all these were done inside the compound only. In this regard, participant (03) widely stated about the issue as:

> *".... Because of the deep-rooted attitude of the community towards persons affected by leprosy, leprosy has affected our social image and our participating in social events with non-affected people. Unless you get someone who looks like you to participate with, it is very difficult to do so with normal people. So we are participating in Iddir or social gathering within ourselves mostly."*

Key respondent (KII 002) who also discussed in support to the above idea about the sharing of foods and other social participations leprosy affected people had in the Centre, confirmed that their participation was limited only inside the Centre; she further stated about one of the best social support the institution offers participate:

> *"...Especially during celebrating their annual holiday which is held at national level, Leprosy Day, they get happy because they get a chance to observe and see other society encourage and braving them as they can do everything like normal people do in the society. Such events contribute its own significance to develop their positive attitude. They attend and celebrate Leprosy Day with great enjoyment and amusements."*

In contrast with the above stated ideas, however, one participant (02) reported against to all other participants stating that she didn't participate in social occasions at all: *".... Others may do, but I have no that need to participate."*

The results of the study above thus indicated that majority of the respondents were participated in the social occasions, like, Iddir, weddings, funerals and other celebrations bounded with the rehabilitation center.

4.4.3.2. **The Social Relationship of Persons Affected by Leprosy**

In order to come up with the social relationship that institutionally supported persons affected by leprosy had, participants were asked to report whether they have close relationship (close contact) with family and relatives after they were infected by leprosy and since they started living in the rehabilitation center. In this regard, participant (04) stated that she had contact with her parents before she lost her leg due to leprosy but the relationship had been continued only with her daughter stressed; *"My relatives abandoned me but only my daughter* *calls currently. However, before times, I had good contact and relationship, even I visited them and they did too. After I lost my legs, no one dares to contact me.”*

Similarly participant (03), stated *“I have got a child who often comes and visits me here (in rehabilitation center) he got married and comes with his wife, children and friends.”*

Despite these truth reported by participant (04 & 03) above, the remaining respondents, however, explained that they had no any close contacts with any member of family, relatives, and friends.

Eventually, the majority of participants including (01), (02), (07) (10) and (11) generally stated that they had no any kind of close contact with family or relatives since they began to live in the Center because of their family and relatives had blurry thoughts about leprosy and the problems attached the disease. The careful overviews of their interviews' data revealed that apart from traumatic experience that institutionally supported persons affected by leprosy had physical harms due to the disease, the loss of any contact or relationship with parents & relatives also made them being affected mentally in light of stress.

Participant (06) who shared the above-mentioned participants' idea also denoted that the contact was quitted with family due to physical appearance she said:

> *“…. I have a young sister in Addis Ababa. Whatever I yearn for her; I could not meet or visit her in whatever reasons… Whatsoever a hunger I feel her like a food, and thirst feel her like water, I could not, because she has been living with healthy people in wealth…. I have no contacts with her up to now.”*

Key respondent (KII 002) from the Shashemene Rehabilitation Center for Disabled, who had been working in the Administrative also illustrated that most of them had not any current relationship of contacts with their relatives.

From the above data, it was possible to infer that currently the majority of participants had no any contact with their familial or relatives mainly due to disease's factors they (PALs) had. In addition, Very few participants only had close relationship or contacts with their children instead.

Consequently**,** since participants came from different places of the country, they reported that they don't need to live with the society again where they were living with. With this issue, participant (11) stressed her idea: *"I don't even think! Because it's uncomfortable. I would be touched inside if I go there. My life got built here."*

Moreover, some participants affirmed that they would rather prefer committing suicide in the center rather than going back to former places for the main reasons they had in relation to the disease to do so. Besides, participant (04) stressed for instance,: *"Oh, to my place, I would die here, I will not go back there because, I am under the status of my friends now (I am the least). .... In the name of Father, Son & Holy Spirit, I really feel bad inside even though no one underestimates me."*

With this idea, participant (02) also stressed her reason as follows:

> *"I don't even think to rejoin with the community. Because there are many hardships: the attitude of the community towards me, like gossiping ... I would get hurt as a result. I may broke rather than this (feeling inside), because people knew me there when I was healthy but now, I am another person."*

Both key respondents (KII 001 & KII 002) claimed in light of the above stated issues reported that persons affected by leprosy who were under institutional support don't need to join the previous society for the primary reason of lack of better psychological supports they had. As a result, they (PALs) are not educated that much and they do not live with the society again.

From the above data, it was possible to get that all participants found, they didn't want to rejoin the prior society they were living with due to psychological factors (fear, shame, anger, & blame) towards their appearance and the status they gave for themselves as a result of leprosy. As a result, all (11of 11) participants, didn't found to have the need to join back to the community where they came from. With this regard, key respondents also asserted that PALs didn't want to join to their prior community.

4.5. The Perception of Persons Affected by Leprosy towards the Supports of the Institution

This segment mainly sticks with on what institutionally supported persons affected by leprosy's consideration looks like towards the supports given to them. Besides, the satisfaction, complaints, & expectations that institutionally supported persons affected by leprosy had with the Centre's supports, are presented.

4.4.1. The consideration of persons affected by leprosy towards the institutional supports

Participants reported what their perceptions were with the supports they get from the Rehabilitation Center. In this regard, participants reported what they perceived about the supports that they were rendered by the Centre associating it with their inability to do something by themselves.

Participants (04) and (09) explained they felt guilty about their being dependent on the Center's support for everything they need. Participant (09) stated that; *"I feel broke every time for being supported; waiting for government's hand to provide me something. Because if I were healthier, I won't be here, I would backup myself at least."*

Respondent (07) who also shared the above idea precisely mentioned his perception towards the services as follows: *"I really feel sad inside for receiving a charity."*

From the above data, it was possible to attain that almost all participants found having negative perceptions towards the supports rendered in the centre with regard to their being dependent on government's charity mainly due to their inabilities to support themselves, which happened as a result of leprosy.

4.4.6. **Satisfactions of persons Affected by Leprosy with the Supports of the Institution**

In this cluster, the satisfaction of participants presented towards the supports of the institution rendered to participants. Participants reported what satisfactions they had towards the supports rendered by the institution.

Relating to this, all participants (11) explained their allover common dissatisfaction towards the supports provided by the center, particularly mentioning the shelter and hygiene related issues participant, (04) stated this way; *"I am not satisfied with the supports at all I am provided with."*

In addition, participant (06) stated also she had no any satisfaction with the supports provided by the institution at all.

From the above data, it was possible to attain that institutionally supported persons affected by leprosy had no any satisfaction with the supports provided by the institution with regard to the unmet needs of the participants and the inability of the institution to support as well.

4.4.7. **Complaints of Persons Affected by Leprosy on the Supports of the Institution**

As a result of institutionally supported persons affected by leprosy are not satisfied with the supports provided by the institution, they (PALs) expressed their complaints for not being satisfied.

With this regard, Participant (10) who stressed the existing situation of the Centre in detail commented over the less attention given by the government in short this way: *"We have to know first that the situation is very weak to support us adequately, even the government does very weak support currently."*

Participant (03) who expressed about the decrement of supports from time to time also stated her complain in this way: *"The support is getting deceasing from time to time so does the satisfaction. So, it is better if the government supports us to do our own business."* Participant (04) also explained her complaint that her roof soaked up with water in the time of rain and her door was very old.

(KII 001) who confirmed about the limited supports offered by the Centre claimed, "*The supports are not enough at all to come up with their social and psychological issues in general."*

From the above data, it was found that the majority of participants were found that they had complained on the supports provided by the Centre. They (PALs) mainly complained towards the supports (such food, better shelter, & clothe) the reduction of qualities rendered by the Centre as it had been deducted from time to time apart from the previous medical treatment and better shelter, food, and clothe provisions.

4.4.8. **Institutionalized Leprosy Affected persons' Expectations from the Centre**

In this section, the issue presented about the expectations of institutionally supported persons affected by leprosy from the Centre that they need to be provided with. Participants presented different expectations which is stated as follows referring participant (08) *"I expect the institution to help me more than this (basic need supports), moreover, towards changing my behavior and to be happy"*

Furthermore, respondent (03) also stated; *"I need to participate more with the society around, I also expect encouragement and self supports means from the institution."* participant (09) added that, *"I expect the institution would cooperate us for private works and to have self-supporting means."*

Similarly, respondent (06) wished that would be better if the government hires new educated and experienced trainer who could help them (PALs) in encouraging to participate with the society with restrictions. Participant (06) also stressed her expectation: *"I expect a transportation fee to be provided by institution. I just only need to visit my home once."*

Besides, (KII 001) also suggested that: *"It's better to cooperate them and create self-supporting means. It helps their family too."*

Contrarily, participant (05) reported that; *"I don't expect anything from the institution to provide me since it doesn't support me properly."* Furthermore, participant (07) reported generally, it was unthinkable to expect anything from the center.

From the above data, it was possible to attain that half of the participants expected from the institution to provide them with adequate necessities (sufficient food, better shelter, and enough clothe). Almost half participants even though they shared to expect adequate services from the institution, they explained particularly, further expectations they had from the institution to provide them.

A few of them had the expectations from the Centre to be reported with skilled employers or they would expect from the Centre to cooperate them to be self-reliant. One participant stated she would expect to be supported with transportation fee to visit her home once.

Besides, one respondent suggested if the government would hire new educated person to give adequate trainings and counseling to come up with better behavioral changes towards themselves, which was resulted due to leprosy and to them (PALs) participate with the outside society. However, a few participants stated that they would not expect anything from the institution to provide them since all things (necessity services) went down with poor quality and quantity.

Summary

The major findings of the study, leprosy affected persons had encountered psychosocial (social stigma and social ostracization/exclusion and family problems due to the disease and the recognition of these PALs that the society perceived them as something different, they had brought behavioral changes to defend themselves) these were the factors to leave their residences and to seek institutional support.

As a result of their psychosocial problems insisted to seek institutional support, the psychosocial (feeling shame, fear, anger and blame and the social participation restrictions and social relations with their family) effects of the disease still remained with them.

The contribution of the support that provided to leprosy affected persons are not found to be vital in coming up the psychosocial problems that these people have. Rather these people are getting relief from concealing themselves in the institution to get far from the outer world. Leprosy affected people are not found dissatisfied towards the support of the institution that are provided to them. They also considerd the supports are provided for the inabilities they have due to leprosy and some PALs expected to get changes in providing the supports adequautely.

CHAPTER FIVE

DISCUSSION

From the report, the researcher's intention was to deal with psychosocial factors that led persons affected with leprosy to institutional support, psychosocial effects that leprosy brought on affected persons, and the psychosocial contributions of institutional supports to persons affected with leprosy are discussed beneath.

5.5. Leprosy and its Psychosocial Factors to Seek Institutional Support

To come up with the findings of the present study towards social factors that led persons affected by leprosy to seek institutional support, the majority of leprosy affected people received negative reactions from their family members, friends, neighbors in a way that stigmatized and alienated leprosy affected people. Because of having leprosy, PALs are neglected and excluded from their family & the society due to fear of the disease that caused them (PALs) to leave their family.

The finding of the study also indicated that, other than the social stigma problem and particularly, reasons such as social ostracization, social participation restrictions to join social occasions (Iddir, wedding, Mahiber, & so forth) and social relation (close interactions) problems with family, friends, and community were the causes to leave their living environments and joined the Rehabilitation Centre. Opposite to the findings of this study, Kumar et al, (2014), whose finding indicated that, the majority of his leprosy affected participants did not perceive negative reactions from people who know about the disease.

The studies of Kumar & Anbalagan, (1983) and Scott, (2006), they found that lesser persons affected by leprosy experienced negative attitude from their family members and more than half of from friends, neighbors, and the community because of fear of the transference of the disease, and accepted as the largest single cause for rejection. Despite the fact, lesser persons affected by leprosy experienced negative attitude in relation to the fear of transference of the disease.

Even though the current study found out the majority of persons affected by leprosy had received negative reactions from their family members, friends and community. Even, few PALs' members of the family thrown leprosy affected persons' dishes and cups in to a trash after being used due to fear of transference of the disease.

Additionally, (Mishra and Gupta, (2010), (Sermrittirong et al, (2014), & Powel, (2006), also reported that the stigma and discrimination caused leprosy affected persons to face clumsiness and possibly become exile members of their own communities and community members expressed their negative attitudes by avoiding them & forcing them to leave. Thus, self-isolation practiced by leprosy patients.

The current study found out that few participants received positive reactions from their families, relatives, neighbors and the society. Although they (PALs) received empathy, they isolated themselves from the society. It was their own attitude that they have towards their conditions caused them to isolate and left their living places.

With regard to the psychological factors, which caused persons affected by leprosy to seek institutional support in fact, emotional disturbances associated with leprosy which a disease that destroys not only the body but also the soul (Scott, 2006). The results of the studies showed that participants experienced with fear, worry, stress, sadness, hopelessness, disbelief and difficulty of accepting leprosy disease.

Likewise, the finding of the present study revealed that because of societal pressure towards persons affected by leprosy such as stigma and discrimination, and accompanying the above-mentioned issues, persons affected by leprosy experienced hatred and shame towards themselves. And also, blame God and fear of their relatives and the community due to what they had, and feeling anger, which in turn forced them to leave their long time living place and move to new places due to the wrong perception of society had including visualizing them like a monster.

5.6. Leprosy and its Psychosocial Effects

With regard to psychosocial effects of the disease brought on persons affected by leprosy, the finding of the study revealed their (PALs') social gatherings (such as wedding, funeral, Iddir, 'Mahiber', & so forth.) and social relationships (i.e. family, friends, & society) they had and the social challenges they faced due to the effects of leprosy. Therefore, the finding of the current study indicated that participants had suffered with unwanted emotional reactions due to the disease they had.

In other words, persons affected by leprosy's behavior was totally changed with regard to feeling of shame, anger, fear, and blame due to the disease which resulted in account of their physical appearance (deformities, finger claws, wounds, & mutilation of legs).

This finding mainly contended with the study, which conducted on the psychological impact of the disease, found the general emotional disturbances. Specifically, Anxiety, shame, depression loss of self-respect, and loss of self-esteem associated with disfigurement were some of psychological disorders resulted from leprosy (Ajibade, et al, 2013). Kumar, (2014), asserted also that over almost half of persons affected by leprosy thought of committing suicide and stated it could be happened everywhere since committing suicide is not contextual to one place. This shows, the issues of suicidal thoughts among leprosy sufferers highlights the persons affected by leprosy's concept of the psychological disorder created by this disease (Scott, 2006).

Similarly, in the existing study, it was found that there were suicidal thoughts in the minds of persons affected by leprosy. Not only suicidal thoughts were, but also trials were there for committing suicide due being alienated from the past warming life they (PALs) had with their family & society and the disfigurements due to leprosy.

Even though these leprosy affected persons supported in the rehabilitation center, their feelings or emotional changes/reactions remained with them. They feel shameful and fearful mainly towards their appearances and felt angry and blaming due to their disabilities and the leprosy they had.

As a result, the current study found out that almost all participants currently had no any close relationship with their families, relatives or friends. As a result, the wrong public perception and negative attitude towards the disease that in turn enforced the society to avoid all kinds of contact with the people who had the disease. In addition, they (PALs) referred their major reasons in light of disabilities, deformities, the fear of ostracism, gossips, and other cases attached to the disease and the feeling of uncomfortable with the society to get back homes.

Likewise with the aforementioned findings of the study, Leite, et al (2015) and Mesele, (2005), also reported, since there is a social stigma in persons affected by leprosy with physical appearance resulted by leprosy, the society continued to ban the sufferers which in turn forcing them to cut off themselves searching for their likely people. In addition, settling enduringly around the rehabilitation centers served as a solution and a place of self-protection. Consequently, these individuals have difficulty of living in ordinary society, many patients continued to live in institutions since they had lost their family and social ties and either saw no prospect whatsoever of living in the outside world or encountered difficulties during the social reintegration process.

5.7. The Contribution of Institutional supports

The present study found out that the Shashemene Rehabilitation Center for Disabled had been providing supports for persons affected by leprosy with basic needs of human; specifically, food, clothe, education (i.e. for children of supported PALs), shelter and medical services. This finding supports the claim that the Centre only provided only the very limited needs of the persons affected by leprosy.

However, the finding of the present study contradicts with Leite and Caldeira, (2014), findings, which asserted that persons affected by leprosy under institutional support received medical, nursing, psychological, nutritional and dental care, physiotherapy and occupational therapy. It even claimed that despite receiving multi-professional care, these persons affected by leprosy have unaddressed psychosocial issues.

The present study shows that how long the Shashemene Rehabilitation Center stuck far away from the needs of leprosy affected persons to be addressed and to alleviate their psychosocial problems in light of providing adequate supports. For instance, psychological supports consist psychotherapy, counseling, and the likes and the social supports goes to creating exposures for PALs to interact well. Therefore, the rehabilitation center should exert an effort to come up with the needed supports to provide.

In the present study, it was found that persons affected by leprosy under institutional support only participated well in Iddirs, weddings, and funerals among themselves (with own likes) while with non-infected ones very rarely. Persons affected by leprosy mostly visit each other who are their own like people (PALs) in the rehabilitation center only since they (PALs) interact well with each other since they have nothing to feel due to the appearance they have. Because, all of them have same problems even though it was found also leprosy affected people participated on leprosy and world disability days, they (PALs) put their main reasons that they don’t feel better inside and it was inevitable to feel something like fear and shame.

With the same fashion, Leite, et al (2015), reported that social relations that institutionally supported persons affected by leprosy were more likely to get along with colleagues from the colony, since they have no any get in touch with the outside world of the rehabilitation center. Besides, theses scholars pointed out that prejudice is a concern, and that is present in their lives.

Thus, the researcher claimed that institutionally supported persons affected by leprosy are only bounded within the rehabilitation center to hide themselves from the outside world due to the psychosocial effects of the disease still remain unchanged. That shows the psychosocial dimension of supports like counseling, psychotherapy, and social interaction exposures means from the institution are not given due attention to do so. The social relationships that institutionally supported leprosy affected people had appear worse for the reason institutionalized persons affected by leprosy had no any contact with any of their family, relatives, and friends currently and institutionally supported persons affected by leprosy didn’t need to join with the society they were living with before they came to the rehabilitation center.

Thus, the psychosocial contribution of the supports rendered by the institution in improving the lively of persons affected by leprosy under institutional support, didn’t brought any noteworthy role apart from helping them (PALs) to hide themselves from the outside world.

5.8. The Perception of Persons Affected By Leprosy Towards the supports of the Institution

Institutionally supported persons affected by leprosy had negatively associated attitude towards the supports provided by the rehabilitation center. The current study found out that institutionally supported persons affected by leprosy perceived that the supports offered to them for the reason the inabilities or incapability they had due to leprosy. Particularly, institutionally supported persons affected by leprosy were found they felt broke inside for waiting for government’s hands to provide the supports. Cheng et al, (2012), asserted that leprosy rehabilitation program must have an individualized rehabilitation care plan to fulfill personal needs.

Eventually, this issue shows that there is still a gap in providing the available limited basic supports to persons affected by leprosy and the institution had been providing the supports in a way that make them (PALs) feel they are donated and dependent for the disease they have. The institution did not give intense care for the way of providing or addressing the supports. As result, institutionally supported persons affected by leprosy perceived the supports offered by the institution as a charity for their incapability they have due to leprosy. Thus, the institution need to offer due attention on how to deliver the available services for leprosy affected people under the support of the institution.

The present study also revealed that leprosy affected people had no any satisfaction with the supports they had been provided by the institution with regard to even the basic provisions (food, shelter, and clothes). They (PALs) complained that on the supports that has provided currently had been deducted from time to time particularly, adequate food, sufficient clothe, and better shelter.

Contrary to the current study of Nicholls and Smith, (2002), reported that the rehabilitation support providing programs must be approachable to the overall needs of the persons affected by leprosy who are under institutional support, consisting the physical, psychological, social, and economic needs. These researchers asserted also that the impact of psychosocial adjustment and adaptation are important in persons affected by leprosy.

Accordingly, the researcher found from document reviewing in the rehabilitation center that the budget allocated for five fiscal years was not more than one million birr (five-year budget report of Shashemene Rehabilitation Center for disabled, 2015/16). From this small amount of money, there was deduction of a budget allocation had been transferred to rescue victims for the current drought.

Therefore, persons affected by leprosy under institutional support in the current study found, they didn’t expect anything from the institution to support them instead they need to get adequate supports of necessities that are rendered by the institution. The researcher could understand that persons affected by leprosy already gave on expecting for something from the institution to provide. While few expected from the institution to get support in light of cooperating them to create self supporting means. Few others found that they expect social participation & behavioral changing supports from the institution to render for them. This shows that those who expect could be taken as they are still struggling to get what they need. Whatever it is, they took the advantage of expectations with regard to changing their behaviors, participating with the society as well, and cooperating to support themselves.

The researcher under stood from the discussion the institution for the reason doesn't provide adequate supports, persons affected by leprosy have nothing to expect anything from the rehabilitation center. For the reason the budget allocation was deducted from time to time diminishes the services' adequacy. Thus, the government should budget more at least to offer the basic need supports for institutionally supported persons affected by leprosy. Moreover, to hire well qualified, related area professionals who are competent, and could understand & treat the needs of persons affected by leprosy under institutional support

CHAPTER SIX

Conclusion and Implications for Social Work

6.3. **Conclusion**

The study described that the experiences of leprosy affected persons at Shashemene Rehabilitation center for disabled that demonstrated leprosy affected persons were dehablitated and destituted from their former residences and sought institutional support due the psychosocial factors posed by their families, friends, and the community. The situation is worsened by social problems with extreme dimensions such as ignorance, fear, and social ostracization restricted PALs from social participation and social relationships.

The study was also able to reveal that the psychosocial problems of leprosy have got a devastating effect on the wellbeing of the PALs that they were emotionally unstable. Specifically, they still suffer from feeling shame, fear, anger and blame due to the effect of disease brought in their life. Leprosy affected persons are still face problems with regard to social relation (family and friendship) and social participation restrictions (Iddir, weddings, Mahiber, funerals) which demand due attention and changes for the reason institutionally supported persons affected by leprosy's lives are bounded only/ limited in the rehabilitation center.

In conclusion, although leprosy is a bio medical problem, it also accompanies other psychosocial issues, which require a holistic approach to address it. The support of the institution does not help institutionally supported leprosy affected persons to improve their life vitally. Instead, institutionally supported leprosy affected persons have psychosocial problems yet that hinder them from social participations & social relationships and unchanged behaviors. This resulted due to the disease and the inability of the institution to overcome these issues in providing better psychosocial supports since leprosy affected persons view their life and the way in which they conceptualized the disease is decisive factors for their levels of quality of life.

6.4. **Social Work Implications**

The habitual medical settings of health care principally concentrated and look for solutions only on the biological aspects of the disease that the patient has. As a result, the psychosocial aspects of the disease were not given much attention for long time even though contemporarily it has been started crawling. Therefore, with the existing problem in the psychosocial support provision to institutionally supported persons affected by leprosy's needs, it should be approached from different angles with regard to coming up with holistic approach to the person (PALs) since it bears various implications towards multidisciplinary approach for various concerned bodies. With regard to the perception of institutionally supported persons affected by leprosy towards the supports provided by the by the institution, it is recommended that the rehabilitation center should give due attention on how to address and treat their (PALs') needs with the supports.

6.4.1. **Implication for Social Work Education**

Overall, Social workers should advocate full holistic approach on behalf of persons affected by leprosy with respect to adequate and qualified services from the rehabilitation center with demanding social participations, enhancing psychological makeup with intensive care, and equity opportunity with non-infected people, blending leprosy affected persons with the society/re-socialization.

In terms of the psychosocial issues, the rehabilitation center should take decisive measurements in light of substituting non-professionals with qualified and competent professionals who can understand well the situation, work hard and achieve to the needed changes towards supporting persons affected by leprosy under institutional support. Particularly, the rehabilitation center should consist professionals who are qualified with counseling, and providing psychotherapy services to persons affected by leprosy (social/works psychologist and related fields) in order to come up with the psychosocial supports to provide.

To overcome social participation restrictions that institutionally supported persons affected by leprosy with unbounded fence order, rehabilitation centers should campaign with regard to enhancing the attitude of the community in generating awareness creating means among the society.

Furthermore, social workers should be engaged more in institutionally supported leprosy affected persons by abolishing their cultural, social, and psychological shackles to overcome their (PALs') attitude, which pulls them back from considering themselves as a purposeful person and productive part of the society. Besides, encouraging and supporting people affected by leprosy to participate in any social occasions, and other recreational activities could create better exposures to develop positive self. It demands great efforts to produce social workers who are qualified, skillful, and competent. With this respect, the authorization is to be left for higher educational institutions, particularly for the school of social work.

Moreover, the social work interventions can be seen at diverse levels stating from micro to macro level intervention. These can be taken at an individual, community, institutional and policy level. Besides, interventions must be engagement promoting, aimed at the individual, community and policy levels.

6.4.2. **Research implication**

It is too crucial to delve into on how to overcome the psychosocial state of institutionally supported leprosy affected persons, psychosocial supports to provide, and on how to create ways to resocialize persons affected by leprosy with the community since they are segregated from the community and developed emotional instabilities as a result.

The existing knowledge, attitudes, beliefs and practices of the target population applicable to the disease should see the sights and studies have to be conducted before launching programs' plans and put into operation. This would be the paramount, if done through a combination of qualitative methods and quantitative methods such as surveys most comparatively with other research target population to reach to plenty of targets and in one study and to fill one each other's research design weaknesses and to come up with ample & relevant results.

Therefore, studies mainly contextual to Ethiopia, intercultural studies should also be conducted among persons affected by leprosy, officers in rehabilitation center, and the concerning people to the effects of the disease and to contrast factors that have led persons affected by leprosy to evacuate from their homes due to the differing attitudes towards leprosy patients. We can learn from communities with more constructive attitude, apply, and adapt what we have learnt from them to less privileged communities.

6.4.3. **Social work implication at a Policy level**

In view of the fact that the major problem for the psychosocial problem of leprosy is stigma and ostracism attached to the disease, due attention has to be given to reduce and alleviate stigma from its grass roots for once and for all of. The rehabilitation center should insist the government need to pay more attention and allocate adequate budget for holistic treatment of persons affected by leprosy under institutional support by creating joint forces with non-governmental, humanitarian, and relief organizations to work collaboratively with the government.

Efforts at policy level should consist supplementary supports particularly, psychosocial rehabilitation supports need to be provided to institutionally supported leprosy affected people and their (PALs') current families with adequate terms. Moreover, in order to create stigma and delusion free circumstances, several leprosy programs need to focus first on offering adequate trainings to health care providers, care givers, and individuals who are working in close relation to leprosy rehabilitation programs in order to capacitate them on how to be more sensitive and empathetic to persons affected by leprosy's issues.

In addition, to melt away the fears, which are taken for granted (constructed) about the disease that genetically transmitted, non-curability and infectiousness to community related health educations have to be set. Since the problems that resulted from the disease not only remains in disabling or deforming the person, but also the psychosocial adverse effect of the disease on the person is unimaginable. Thus, the government should combat social stigma and ostracization to dry from its roots by designing projects, implementing, monitoring, and evaluating how it achieved.

6.4.4. **Advocacy**

At policy level, advocacy efforts must centre on a supportive, enabling environment that demands contextual legislative and policy changes in organizational circumstances and there should be due attention needed to be paid to the human rights evasions that are faced by persons affected by leprosy. Persons affected by leprosy under institutional support are bounded/restricted from the outside world to interact, thus it should strived to implemented new community-based rehabilitation directions by attaining supports should be committed with re-socializations activities At this point, social workers should play the foremost role of advocacy through promoting appropriate policy options and intervention programs.

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Appendix I

Informed consent

Hello, my name is Henok Zewdu. I am a Social Work postgraduate student at Addis Ababa University working my final thesis for masters of social work. I am conducting a qualitative case study entitled, “the experiences of institutionally supported persons affected by leprosy; specific to the psychosocial effects of the disease and institutional support: the case of Kuyera Rehabilitation Center.” The study would be subjected for partial fulfillment of the degree master of arts in social work.

Moreover, the purpose of this study is to assess the psychosocial effects of the disease and the psychosocial supports provided by the institution to and to come up with psychosocial issues of leprosy. Thus, you are invited to participate voluntarily in the study since the research requires your involvement voluntarily and the responses you provide for the interviews will serve as an essential input for this research.

As a result, if you are willing to participate, you will be asked questions about your past and present experiences about the issue for not more than forty-five minutes to an hour. This interview will be audio recorded for in a while analysis.

Besides, I will do my best to ensure that confidentiality is maintained by not citing your actual name within neither the study report nor the information you revealed be linked with you in the future. In other words, data will be kept in a locked cabinet during the study, but will be destroyed once when the study is completed. You are free to terminate your participation at any time or not to take part at all.

Accordingly, the information gained from this study may assist leprosy related social service providers, and other health professionals to better understand the psychosocial effect of leprosy on the affected people's life. Mean while, it may concern how the situation of leprosy affected people would be treated in the future, particularly institutionally supported ones. Therefore, there is no cost to you for participation .

I would like to thank you in advance for the priceless time you would spend in this interview and genuine responses to provide. If you have any question or concern, you may contact the researcher by the following telephone number 0920384918.

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_______________

Appendix II

ADDIS ABABA UNIVERSITY

GRADUATES PROGRAM

SCHOOL OF SOCIAL WORK

Semi-Structured Interview Guide for Institutionally Supported Persons Affected by Leprosy

Part I: Personal Information

Age___________

Sex___________

Marital status_________

Educational status__________

Duration of residency _________

Visible deformities _____________

Part II: Psychosocial Factors led Persons Affected By Leprosy to Receive Institutional Support.

- How did you come know you were infected by leprosy?
- When did you know you were infected by leprosy?
- Did your family know about your status? Probe, your family members, friends, neighbors, and society response to your condition?
- What kinds of social and psychological problems you faced because of leprosy?

- What were your reasons to leave your residence (destitution) and to come here?

PART III: Social and Psychological Effects of Leprosy

- How does your condition affect your personal relations/contacts with people and the environment?
- Do you have any relationships or contacts with your family or friends after you institutionalized?
- Did the disease (leprosy) result any unwanted behavioral changes in terms of feeling shame, fear, anger, and blame?
- Do you participate in social participations or social gatherings like Iddir, Mahiber, weeding, and other social occasions? If so, how it looks like for a person receiving institutional support?

PART IV: The Contribution of the Supports on the Life of Institutionally Supported Persons Affected By Leprosy

- Are you supported to participate in social activities like social gatherings?
- What does your relationship look like with your friends or family after you have been receiving supports from the institution towards your dehablitation?
- Did you bring any behavioral change for the reason you are supported here?
- Do you have better interaction with your colleagues & caregivers?
- Do you have the need to re-integrate with the society you left again? Probe your reasons?

PART V: Perceptions towards the supports offered by the institution (PALs' satisfaction, complains, expectations with the services rendered

- What kind of services you are receiving from the institution?
- What do you feel about receiving institutional support because of leprosy?
- How do you perceive the supports that are providing to you?
- Are you satisfied with the services provided to you currently? Probe whether these services are filling your social and psychological needs?
- Do you have any suggestions or complaints if there are improvements have to be made by the institution?
- What do you expect from the institution to provide you? Probe, with regard to helping you to participate with the society or family, or friends and improving your behavior affected because of your condition like shame, fear, anger, and blame?

Appendix III

ADDIS ABABA UNIVERSITY

GRADUATES PROGRAM

SCHOOL OF SOCIAL WORK

Interview guide for key informants

Part one: Personal Information

Age ___________

Sex ___________

Educational status__________

Occupation ______________

Part two: institutional (leprosy) services and its psychosocial effects of leprosy

- What do you think about the social issues forced persons affected by leprosy to leave their residence and receive institutional support?
- What do you believe the psychological issues forced persons affected by leprosy to leave their residence and receive institutional support?
- What do you consider the social effects of leprosy have on the lives of persons affected by leprosy?
- Do you think persons affected by leprosy are socially excluded and restricted? Probe, in terms of participating in social gatherings and activities or family, relative or friend relationships?

- What do think the psychological effects of leprosy have on the lives of persons affected by leprosy? probe their condition have things to do with their behavioral change like shame, fear, anger and, blame?
- What is the interaction they have with colleagues and with you?
- What supports particularly, supports does the institution is providing currently to institutionally supported persons affected by leprosy? Probe, how do they perceive the provision of the supports?
- Do you think the institution is fulfilling the needs institutionally supported persons affected by leprosy of while providing the supports? Probe, in coming up with creating better ways to improve their interactions with their family, friends or society?
- Do have any complaints or suggestions to improve the psychosocial needs of institutionally supported persons affected by leprosy?
- Does the institution working in terms helping institutionally supported persons affected by leprosy to re-join with the community? probe what you know about their (PALs) needs to do so?

Appendix IV

የተሳታፊዎች ፍቃደኝነት ማረጋገጫ

ሰላም! ስሜ ሄኖክ ዘውዱ ይባላል በአዲስ አበባ ዩኒቨርሲቲ የሶሻል ወርክ ትምህርት ቤት የድህረ ምረቃ ፕሮግራም ተማሪ ነኝ ፡፡ አይነታዊ የነጠላ-ጉዳይ ይዘት ያለው ጥናት እየሰራው ነው፤ይህም በሻሸመኔ ተሃድሶ ጣቢያ ውሰጥ የሚገኙ የስጋ ደዌ ታማሚዎች ከስጋ ደዌ በሽታ ጋር ተያይዘው በሚመጡ የስነ-ልቦናዊና ማህበራዊ ችግሮች ላይ ትኩረት ማድረግ እና የሚሰጣቸውን የማህበራዊ እና ስነ-ልቦናዊ ድጋፍ መዳሰስ ነው፡፡ በዋናነት ለትምህርቴ ማሟያነት የሚቀርብ ጥናታዊ ፅሁፍ ነው፡፡

ይህ ቃለ ምልልስ ለጥናቱ የጀርባ አጥንት እንደመሆኑ መጠን የእርሶን ከፍተኛ ፍቃደኝነት እና ለቃለ-ምልልስ የሚሰጡትን ተአማኒ መልስ ይፈልጋል፡፡ ስለዚህ በዚህ ጥናት ውስጥ በፍቃደኝነት እንዲሳተፉ እጠይቃለሁ፡፡ በዚህም ረገድ በዚህ ጥናት ለመሳተፍ ፈቃደኛ ከሆኑ ስለ ቀደመው እና ሰለ አሁኑ የህይወት ልምድዎ ይጠየቃሉ (ከስጋ ደዌ በሽታ ጋር በተያያዘ ማህበራዊ እና ስነ-ልቦናዊ ችግሮች እና የመሳሰሉትን)፤ ይህም ከ45 ደቂቃ እስከ 1 ሰዓት ይወስዳል ፡፡ ከዚህም ጋር ተያይዞ ለድህረ-ትንተና ይጠቅም ዘንድ ቃለ መጠይቁ በመቅረፀ-ድምፅ የሚቀዳ ይሆናል፡፡

ከዚህ ጎንለጎን በቃለ መጠይቁ ሲሳተፉ ሙሉ በሙሉ አቅም የፈቀደውን ያህል የቃለ ምልልሱን ምስጠራዊነት ለመጠበቅ ከፍተኛ ጥረት አደርጋለሁ፡፡ ይህም የሚሆነው የተሳታፊውን ሰም ባለመጥቀስ ወይም ተሳታፊው የሰጠው ምላሽ በምንም አይነት መልኩ የሚገለጥ አይሆንም በዚህ ረገድ በተሳታፊው የወደፊት ህይወት ላይ ምንም አይነት አሉታዊ ተፅዕኖ አይኖረውም ፡፡

በአዎንታዊነት ከዚህ ቃል ምልልስ የሚገኘው መረጃ ከስጋ ደዌ በሽታ ጋር በተያያዘ ማህበራዊ አገልግሎት ሰጪዎችን እና ሌላ የጤና ባለሙያዎችን በተሻለ መልኩ ስለ ማህበራዊ እና ስነ- ልቦናዊ የስጋ ደዌ በሽታ በተማሚዎች ላይ ያለውን አሉታዊ ተፅዕኖ እንዲረዱት ያስችላቸዋል፡፡ ለወደፊቱም

ይህን አይነቱ ችግሮች ያሉባቸው ሰዎች እንዴት ድጋፍ ሊደረግላቸው እንደሚገባ የተሻለ በጎ ተፅዕኖ ሊፈጥር ይችላል፡፡ በተለይም በተሃድሶ ጣቢያ ውስጥ (**እንክብካቤ**) **ለሚደረግላቸው ታማሚዎች፡፡ ስለዚህም በቃለ ምልልሱ ለሚደረገው ተሳትፎ ምንም አይነት ክፍያ አይኖርም ፡፡**

ለቃለ ምልልሱ ለሚያደርጉት ተሳትፎ እና ወደር በሌለው ጊዜዎት በቃለ ምልልሱ ለሚያደርጉት ተሳትፎ እና ተአማኒ የሆነውን መልስ ሰለሰጡ አስቀድሜ ማመስገን እፈልጋለው፡፡ ማንኛውም አይነት ጥያቄ ወይም የሚያሳስብ ነገር ሲኖሮት የጥናት አድራጊውን ስልክ ቁጥርበ09-20-38-49-18 **መገናኘትይችላሉ፡፡**

ከዚህ በታች በተቀመጠው የመፈረሚያ ስፍራ ላይ ከላይ የተዘረዘሩትን አንብበው ወይም ሰምተው (**ተነብቦሎት**) **እንደተረዱ እና ለመሳተፍ ፍላጎት እንዳሎት እባክዎን በፊርማዎ ያረጋግጡ፡፡**

- **የተሳታፊው ስም** -------------------------------
- **ፊርማ** --------------------------
- **ቀን**------------------------------

Appendix V

አዲስ አባባ ዩኒቨርሲቲ

በድህረ-ምረቃ መርሃ ግብር

የሶሻል ወርክ ት/ቤት

ለስጋ ደዌ ተማሚዎች የተዘጋጀ የቃለ-መጠይቅ መምሪያ

ክፍል 1፦ የማንነት መረጃ

- ዕድሜ----------
- ፆታ ------
- የትዳር ሁኔታ----------------------
- የት/ት ሁኔታ ---------------------
- በጣቢያው የኖሩበት ጊዜ----------------------
- የመጡበት አካባቢ------------------------------------
- በስጋ ደዌ ምክንያት የተከሰተ የአካል ጉዳት -------------------

ክፍል 2 ፦ የተሃድሶ ጣቢያ ድጋፍ ለማግኘት የሚያስገድዱ የሥጋ ደዌ ማህበራዊና ስነ-ልቦናዊ መነሾች

- በስጋ ደዌ መጠቃቶትን መቼ አወቁ?
- ስለ እርሶ የስጋ ደዌ በሽታ ሁኔታ ቤተሰቦችዎ ያውቁ ነበር?
- ምንድን ነበር መልሳቸው (አፀፋቸው) ስለ እርሶ ሁኔታ?
- ወዳጅስ ጎረቤቶችስ እና ማህበረሰቡስ?

- በስጋ ደዌ በሽታ ምክንያት ምን አይነት ችግሮችን ተጋፈጡ?
- የመኖሪያ አካባቢዎንስ ለቀው እዚህ ለመምጣት ምክንያትዎ ምን ነበር?

ክፍል 3፡-የስጋ ደዌ ያለው የስነ -ልቦና እና ማህበራዊ የተፅዕኖ ውጤት፡፡

- የእርሶ ሁኔታ እንዴት ከሰዎች እና ከአካባቢው ጋር ያለዎትን ግንኙነት ያውካል (ተፅዕኖ ፈጥሯል)?
- እዚህ ተሃድሶ ጣቢያ ውስጥ ድጋፍ ማግኘት ከጀመሩ በኋላ ከቤተሰብዎ ወይም ከጓደኞችዎ ጋር ግንኙነት አሎት ወይም በቅርብ ይገናኛሉ?
- በስጋ ደዌ ምክንያት ከአለማፈር፣ከመፍራት፣ከመናደድ እና ከወቀሳ አኳያ አሁን ያመጡት የባህሪ ለውጥ ምን ይመስላል?
- እንደ ማህበራዊ መሰባሰብ ያሉ ለምሳሌ እንደ (ዕድር፣ማህበር) አይነት ማህበራዊ ተሳትፎትስ? በተሃድሶ ጣቢያ ውስጥ ላለ ሰው ምን ይመስላል?

ክፍል 4፡- የስጋ ደዌ ታማሚዎች ድርጅቱ ለሚደርግላቸው የድጋፍ አገልግሎት ያመጡት መሻሻል

- እንደ ማህበራዊ መሰባሰብ ያሉ ለምሳሌ እንደ (ዕድር፣ማህበር ሰርግ) አይነት ማህበራዊ ተሳትፎ ውስጥ እንዲሳተፉ ያመጡት ለውጥ ምን ይመስላል?
- የመኖሪያ አካባቢዎን ለቀው ከመምጣትዎ እና እዚህ ከጣቢያው ድጋፍ ከማግኘቶ አኳያ ከጓደኞችዎ ወይም ከቤተሰብዎ ጋር ያለዎት ግንኙነት ምን ይመስላል?
- ከተሃድሶው ጣቢያዉ ባገኙት እገዛ የባህሪ ለውጥ አምጥተዋል?
- በስጋ ደዌ በሽታ ከመጠቃት እና በተሃድሶ ጣቢያው ውስጥ ከመኖር ጋር ተያይዞ ሃፍረት የመሰማት፣የመፍራት፣የመናደድ(የመበሳጨት)፣ እና የመውቀስ ባህሪዎችን?

- እዚህ ጣቢያ ውስጥ ካሉት ማህበረሰብ ጋር ከመቀራረብ ረገድበአሁን ሰአት የተሻለ ለውጥ አምጥተዋል?
- ትተውት ከመጡት ማህበረሰብ ጋር መልሰው መቀላቀል ይፈልጋሉ? ምክንያትዎን ይግለፁ?

ክፍል 5፡- የስጋ ደዌ ተማሚዎች ድርጅቱ ለሚያደርግላቸው የድጋፍ አገልግሎት ያላቸው አመለካከት የአገልግሎት እርካታ ፣ቅሬታዎች እና የሚጠብቋቸው ነገሮች፡፡

- ከድርጅቱ ምን አይነት የድጋፍ አገልግሎቶችን ያገኛሉ?
- በስጋ ደዌ በሽታ ምክንያት ስለሚቀበሉት ድጋፍ ምን ይሰማዎታል?
- የሚደረግሎትን የድጋፍ አገልግሎት እንዴት ይመለከቱታል?
- በአሁን ሰዓት ከድርጅቱ በሚያገኙት የድጋፍ አገልግሎት እርካታዎ ምን ይመስላል?
- የተሃድሶ ጣቢያው ከሚሰጠው አገልግሎቶች አኳያ ምን አይነት ቅሬታ ወይም የማሻሻያ ምክር አሎት?
- ከማህበረሰብ ወይም ከቤተሰብ ወይም ከጓደኞች ጋር ለመሳተፍ ተሃድሶ ጣቢያው ምን እንዲረዳዎት ወይም እንዲያግዞት ይፈልጋሉ?
- ከሁኔታዎ ጋር ተያይዞ የማፈር፣የፍራቻ፣የመናደድ እና የመውቀስ ባህሪዎችን ከማሻሻል አኳያስ?

Appendix VI

አዲስ አባባ ዩኒቨርሲቲ

በድህረ ምረቃ መርሃ ግብር

የሶሻል ወርክ ት/ቤት

የቃለ-መጠይቅ መምሪያ ጉዳዩ ለሚመለከታቸው ተቋማቶች ውስጥ ለሚሰሩ ባለሙያዎች የተዘጋጀ

<u>ክፍል 1፡-</u> *የማንነት መረጃ*

- *ፆታ*
- *ዕድሜ*
- *የት/ት ሁኔታ*
- *የስራ ኃላፊነት*
- *የስራ ልምድ*

<u>ክፍል 2፡-</u> *የተሃድሶ ጣቢያ አገልግሎቶች እና የስጋ ደዌ በሽታ የማህበራዊ እና ስነ-ልቦናዊ ተፅዕኖዎች*

- በስጋ ደዌ የተጠቁ ሰዎች ምን አይነት ማህበራዊና አሰድገድደዋቸው የመኖሪያ አካባቢያቸውን ለቀው የተሃድሶ ጣቢያ እርዳታ እንዲቀበሉ የሚያደርጋቸው ምን ይመስሎታል?
- በስጋ ደዌ የተጠቁ ሰዎች ምን አይነት ስነ-ልቦናዊ ጉዳዮች አሰድገድደዋቸው የመኖሪያ አካባቢያቸውን ለቀው የተሃድሶ ጣቢያ እርዳታ እንዲቀበሉ የሚያደርጋቸው ምን

ይመስሎታል? ለምሳሌ ከማህበረሰባዊ መሰባሰቦች እና እንቅስቃሴዎች (ተሳትፎዎች) ወይም ከቤተሰብ ወይም ጓደኞች ግንኙነት አኳያ ከማህበረሰብ መገለል እና መገደብ?

- የስጋ ደዌ በሽታ በስጋ ደዌ ታማሚዎች ላይ ያመጣቸው ማህበራዊ ተፅኖዎች ምን ይመስሎታል?
- የስጋ ደዌ በሽታ በስጋ ደዌ ታማሚዎች ህይወት ላይ ያመጣቸው ስነ-ልቦናዊ ተፅዕኖዎች ምን ይመስሎታል? ሁኔታቸው ከባህሪያቸው መለወጥ ጋር የሚያገናኘው ነገርስ አለ? ለምሳሌ ሃፍረትከመሰማት፣ ከመፍራት፣ ከመናደድ(መበሳጨት) እና ከመውቀስ
- በተሃድሶ ጣቢያ ውስጥ አብረዋቸው ከሚኖሩት ጋር እና ከእርሶ ጋር ምን አይነት ግብብነት (ቅርርብ)አላቸው?
- በአሁን ሰዓት ተሃድሶ ጣቢያው ምን አይነት አገልግሎቶች ላይ አተኩሮ ድጋፍ ይሠጣል?
- በተሃድሶ ጣቢያው ውስጥ ያሉ ተጠቂዎች እንዴትስ አገልግሎቱን (ድጋፉን) ይመለከቱታል?
- ተሃድሶ ጣቢያው አገልግሎቱን በሚሰጥበት ጊዜ በትክክል የስጋ ደዌ ተማሚዎች (ተጠቂዎች) የሚፈልጉትን ነገር ያሟላል ብለው ያስባሉ? የህክምና ድጋፍ ከመስጠት ባሻገር በአትኩሮትማህበራዊና ስነ-ልቦናዊ አገልግሎቶችንስ?
- ተሃድሶ ጣቢያው ለስጋ ደዌ ተማሚዎች የሚሰጣቸው አገልግሎቶች ህይወታቸውን ከስጋ ደዌ በሽታ አኳያ በእውነት (በትክክል) እያሻሻለ መሆኑን እና ከቤተሰቦታቸው ፣ከጓደኞቻቸውወይምከማህበረሰቡ ጋር ከማቀራረብ (ግንኙነት ከመፍጠር አኳያ) መንገዶችን እየፈጠረ ሰለመሆኑ እንዴት ይገልፁታል?
- የስጋ ደዌ ታማሚዎችን ማህበራዊና ስነ-ልቦናዊ ፍላጎታቸውን ከማሟላት አኳያ ቅሬታ ወይም ምክር አሎት?

- **ተሃድሶ ጣቢያው የስጋ ደዌ ተማሚዎችን ከማህበረሰቡ ጋር እንዲቀላቀሉ ለማድረግ ምን እየሰራ ነው? ከስጋ ደዌ ተማሚዎቹስ ጋር ይህ ፍላጎት እንዳለ ምን ያስረዱ?**

Appendix VII

Table 1. Socio-Demographic Characteristics of Institutionally Supported Participants.

Participants' Code	Sex	Age	Marital Status	Educational Level	Duration (year) of Entrance	Previous Place of Residence	Visible deformities due to leprosy
01	F	65	Married	Illiterate	1962	Gojjam	Artificial legs
02	F	50	Divorced	6th grade	1975	Awash	One artificial leg
03	F	45	Married	Illiterate	1966	Harar	Two legs mutilated
04	F	50	Divorced	Illiterate	1981	Gojjam	Artificial legs
05	M	60	Single	Illiterate	1976	Sidama	One leg artificial
06	F	55	Single	Illiterate	1985	D/Libanos	Artificial legs
07	M	75	Married	6th	1971	Wollega	Clawed fingers
08	F	41	Married	Illiterate	1990	Cheffe	One leg artificial and deformed hands
09	M	40	Married	9th	1987	West Shoa	One leg artificial & clawed fingers
10	M	74	Married	5th grade	1985	North Shoa	Deformed hands & and legs
11	F	65	Widowed	3rd	1953	Guraghe	Clawed fingers and deformed legs

Appendix VIII

Table 2. Socio-Demographic characteristics of key informants

Participants' code	Sex	Age	Educational level	Occupation	Year of experience
KII 001	Male	34	Diploma in Management	Self Employee & Programs Coordinating Officer in Association of Leprosy Affected People	6 years
KII 002	Female	29	Diploma in accounting	Social Treatment Officer of People Affected by Leprosy, in Shashemene Rehabilitation Center for Disabled	7 years

Letter of Declaration

I, the undersigned graduate student of social work declare that, this is my original work and has not been presented fully or partially for degree requirements in other university and all the source of materials used for the research project are acknowledged.

Researcher's Name: Henok Zewdu

Signature: ______________________

Date: __________________________

Place: _________________________

Date of Submission: _____________

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

Advisor's Name: Tenagne Alemu (PhD)

Signature: ______________________

Date: __________________________