



**THE LIVED EXPERIENCES OF WOMEN AFFECTED BY
LEPROSY RESIDING IN WOREDA 01 ZENEBEWORK AREA,
ADDIS ABABA: A PHENOMENOLOGICAL STUDY**

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This is to certify that the thesis prepared by Biftu Jemal entitled: The Lived experiences of women affected by leprosy residing in woreda 01 Zenebework area, in Addis Ababa submitted in partial fulfillment of the requirements for the degree of Master of arts in Sociology complies with the regulations of the University and meets the accepted standards with respect to originality and quality.

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I, the undersigned, declare that this thesis entitled as “**The Lived Experiences of Women Affected by Leprosy Residing in Woreda 01 Zenebework Area, Addis Ababa: A Phenomenological Study**” is my Original work and has not been presented for the award of any degree or diploma in this or any other university. All sources of materials used in the thesis have been accordingly acknowledged.

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List of Acronyms

AALVRA	Addis Ababa Leprosy Victims Rehabilitation Association
AHRI	Armauer Hansen Research Institute
ALERT	All Africa Leprosy & Tuberculosis Rehabilitation & Research Training Center
EMOH	Ethiopian Ministry of Health
ENAPAL	Ethiopian National Association of Persons Affected by Leprosy
EPRDF	Ethiopian People's Revolutionary Democratic Front.
FDRE	Federal Democratic Republic of Ethiopia
LME	Leprosy Mission Ethiopia
MDT	Multidrug Treatment
NCDR	New Case Detection Rate
NGO	Non-Governmental Organization
NLCP	National Leprosy Control Program
NLTB	National Leprosy and Tuberculosis Program
SNNPR	Southern Nations and Nationalities and peoples region
UNICEF	United Nations International Children's Emergency Fund
WHO	World Health Organization

Abstract

This phenomenological qualitative study explores the lived experiences of women affected by leprosy residing in Woreda 01, Kolfe-Keranyo Sub-city, and Addis Ababa. The study delves into these women's knowledge and perceptions of leprosy, their interactions within social networks, accessibility and treatment within public and traditional institutions, and the coping mechanisms they employ to navigate daily challenges. Using purposive sampling, in-depth interviews were conducted with 15 women with leprosy and 7 key informants, including social workers, health professionals at Alert hospital, and officials from relevant NGOs and government sectors in Woreda 01. Additionally, Observation was used to collect data. The data was analyzed through phenomenological analysis to capture the subjective experiences of affected women. Findings reveal a knowledge gap between scientific understanding and participants' beliefs about leprosy's causes and transmission. The result of the study also demonstrates that women often experience strained relationships within their close social networks, such as family, neighbors due to a tendency for self-isolation prompted by fear of discrimination. Many participants also self-isolate to shield themselves from anticipated social stigma, which the community may reinforce by excluding them from events and gatherings. If leprosy symptoms are visible, society tends to discriminate against affected individuals in public institutions. Additionally, financial constraints prevent them from participating in Equb or Edir. However, some women gain strength through solidarity with peers in similar circumstances and engage in religious practices that provide emotional support and a sense of belonging. The study concludes that the intersection of social, economic, and psychological challenges imposes a complex burden on affected women. To address this issue, the finding highlights the need for a robust awareness campaign targeting both the affected and the wider community. Additionally, effective implementation of existing policies, programs and strengthening associations that support leprosy-affected women are suggested to enhance their access to services and capitalize on existing coping mechanisms.

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1. INTRODUCTION

1.1. Background of the Study

Leprosy is one of the world's oldest diseases, affecting millions of people worldwide, primarily in Asia, South America, and Africa (Ermias 2019). Hansen's disease, more commonly referred to as leprosy, was first discovered by Armauer Hansen, a Norwegian physician who identified the pathogen disease's bacterium in 1873 (Hyowon 2022). According to Ermias (2019), leprosy is a chronic infectious disease caused by *Mycobacterium leprae* that primarily spreads by droplets from the nose or mouth. *Mycobacterium leprae* is an acid-fast bacillus that causes leprosy illness, primarily harming the outer layer of skin and nerves around the body. Early diagnosis and treatment significantly reduce disability limitations in leprosy affected, with preventative rehab reducing the occurrence of disabilities through early diagnosis and treatment (Cheng 2016).

Leprosy is believed to have originated in eastern Africa or the Near Eastern region and spread with people via various travel routes, including trade in commodities and slaves (Nyamogoba and Mulambalah, 2019). Hyowen (2022) stated that the disease most likely spread throughout the world due to human migrations, such as displacement or invasion. Leprosy can be cured but not prevented; it remains a serious global health risk in developing nations with low incomes, including Ethiopia.

According to WHO (2007) report on the global burden of leprosy, between 500,000 and 750,000 newly identified cases of leprosy are reported worldwide each year. At the beginning of 2005, almost 500,000 additional cases were discovered, equating to more than 1400 daily or approximately 60 persons per hour. However, recent WHO data reveals a notable decline in new leprosy cases, with over 200,000 diagnoses reported globally in 2022. This marks substantial progress in disease control. Nevertheless, leprosy continues to disproportionately impact regions like Africa and Southeast Asia, where a significant share of global cases still occur, highlighting the ongoing need for focused intervention in these areas.

Leprosy remains a serious threat to public health across different parts of Africa, Asia, and Latin America (Hyowen 2022). Countries such as Brazil, India, Nepal, Myanmar, Madagascar, and Mozambique accounted for more than 90% of all reported cases of leprosy documented globally in 2002, with Brazil alone accounting for 80% of all leprosy diagnoses in South America (Nyamogoba and Mulambalah, 2019).

Between 2006 and 2009, a total of 1,500 new cases were reported in Uganda, with the number of new cases showing noticeable disability rising from 10% in 2005 to 19% in 2009. Uganda faces the challenge of ensuring the long-term viability of leprosy prevention initiatives to prevent an upsurge in this trend (Raphael, 2017). Kenya, an East African country, is also one of the African nations battling an outbreak of leprosy, with the disease being endemic in areas along the country's maritime strip and in the western regions. The nation's 2015 report showed a total of 124 new cases of leprosy, with 67% of the diagnoses being female (Nyamogoba and Mulambalah, 2019). According to Mishra and Gupta (2010), leprosy is an ancient disease that continues to be prevalent in various regions of the world as a threat to public health. Leprosy diagnosis rates differ significantly between men and women worldwide, with men outnumbering women in terms of detected cases, particularly in clinical manifestations (Grand, 1997).

Leprosy has been around for centuries in Ethiopia, with past evidences indicating that it probably existed during the middle of the 16th century (Mesele 2005). The Portuguese foreign missionary Chaplain Francisco Alvaes was the first to share knowledge about sickness in the nation in 1520. He speculated that the disease may have arrived in Ethiopia via international trade along with additional cultural connections, the treatments for the disease started in the nation in the year 1950, yet this doesn't suggest that the disease wasn't given any form of attention before this time. It gained a lot of attention back in the Menilk and Hailesilase periods when multiple towns and urban centers were constructed around the nation from 1900 to the early 1960s (Pankhurst, 1997)

Ethiopia is one of the most affected countries in the world (Hunegnaw, 2022). In 2010 the country was among the 17 countries registering up to 1000 new cases of leprosy on an annual basis, while between 2004 and 2010, an estimated 4000–4500 new cases were detected at medical centers per year (Ermias 2019). According to the author the overall number of people

suffering from leprosy recorded in the entire nation reached 5,303, with 4,430 being newly diagnosed, and it was discovered that there were 1,308 females along with 331 children among the newly reported cases.

Leprosy is higher in certain areas of Ethiopia, particularly in regions like Amhara, Oromia, Southern Nations Nationalities and Peoples' Region (SNNPR) and Afar. Addis Ababa's Zenebework area is particularly notable as a historical hub for leprosy care. However, these regions still see new cases, underscoring ongoing disparities in leprosy control across the country in spite of the nationwide multi-drug therapy (MDT) efforts made by the government and other stakeholders (Demissie & Mesfin, 2018; Sori, 2019).

Despite leprosy being one of the world's oldest diseases and presenting a significant global health challenge, efforts to enhance the quality of life for those affected are unevenly distributed. On a global scale, initiatives like the World Health Organization's "Towards Zero Leprosy: Global Leprosy (Hansen's disease) Strategy 2021–2030" have made progress by emphasizing leprosy prevention through integrated active case detection, complication management, and disability prevention. These measures seek to reduce disease prevalence and stigma by integrating care into broader health systems and enhancing social support (WHO, 2021).

Although, Ethiopia does not have a specific policy exclusively focused on individuals affected by leprosy, they are typically encompassed within national health policies and disability legislation. The Ethiopian government combats leprosy through the National Leprosy Control Program with the aim of integrating leprosy services into the broader healthcare system, ensuring that those affected have access to essential treatment and care in a stigma-free environment, supported by partnerships with local and international organizations (MOH, 2019).

At the national level, Ethiopia has aligned with global goals by incorporating leprosy-related programs into its Third National Neglected Tropical Diseases Strategic Plan (2021–2025) and the National Leprosy and Tuberculosis Program (NLTB). These initiatives aim to address active case detection, treatment, rehabilitation, and stigma reduction. However, significant gaps remain, particularly for women, whose experiences with leprosy are shaped by overlapping factors like

gender, poverty, and disability. Evidence on how well these programs improve the lives of affected women is scarce, pointing to the need for research specifically addressing these issues (MOH, 2019:2021).

In Ethiopia, leprosy has been prevalent for centuries, with records of its occurrence tracing back to the 16th century (Mesele, 2005). Historically, those affected by leprosy have endured profound societal exclusion, poverty, and stigma. These challenges are particularly acute for women, who face additional marginalization due to deeply rooted gender inequalities. Research indicates that women bear a dual burden of discrimination first as individuals affected by leprosy and second as women navigating a patriarchal society (Hunegnaw, 2022). This compounded disadvantage often results in worse social, economic, and health outcomes for women compared to men.

Addressing these issues necessitates a sociological perspective. Leprosy intersects with dimensions of disability, vulnerability, and social exclusion, disproportionately affecting marginalized communities and hindering the social integration of those impacted. These intersections emphasize the importance of studying how such factors shape the lived experiences of specific groups, particularly women.

A phenomenological approach is well-suited for this research, as it aims to uncover the personal and subjective experiences of women living with leprosy. Focusing on Zenebework area of Addis Ababa a historic center for leprosy care, this study seeks to provide detailed insights into the lives of these women, examining their challenges, social realities and coping strategies. Through in-depth interviews, it captures participants' rich narratives, shedding light on the complex interplay between illness, gender, and societal stigma.

This focus fills a gap in existing research, which has largely explored general patterns in leprosy without fully addressing the specific experiences of women. Additionally, it contributes to broader discussions on health equity, gender disparities, and the sociology of illness, highlighting the urgent need for policies that prioritize the welfare of vulnerable groups.

1.2.Statement of the Problem

Leprosy remains a global health concern in countries where it is prevalent, such as India, Brazil, and Indonesia, which account for 80% of all new leprosy cases (Rahman and Rajaratnam 2022). Leprosy is one of the most serious medical issues in countries that are developing, with the disease having a negative impact on the affected socioeconomic status. Leprosy affects many parts of life due to its social stigma, including employment possibilities, mobility, finding partners, and compromising marriage relationships and family life (Hunegnaw 2022). According to Ermias (2019), Ethiopia was ranked seventh out of eighteen nations in 2009, accounting for 93% of all new cases registered worldwide, making Ethiopia one of Africa's most leprosy-affected countries. Recent statistics from the World Health Organization revealed that Ethiopia remains one of the country's most heavily impacted by leprosy, ranking third in the world for new cases in 2022, following India and Brazil. The nation accounted for about 6% of the global leprosy burden with 1,658 new cases recorded. These figures highlight the persistent challenges Ethiopia faces in effectively managing and treating leprosy, solidifying its status as one of Africa's most affected nations.

Several researchers have studied in the past the real-life experiences of leprosy affected people in Ethiopia. Henok (2016), for example, employed a qualitative research approach to investigate the experience of leprosy affected at Shashemene Rehabilitation Center. He argued that the psychosocial concerns associated with leprosy have an irreversible impact on the well-being of people affected with leprosy. The author also claimed that those suffering from leprosy continue to feel ashamed, anxious, and frustrated as a result of the disease's impact on their lives.

Yonas (2020), on the other hand, explored the living conditions of people with leprosy in Zenebework area using a qualitative study approach. Yonas's finding showed that people with leprosy earn low income and encounter prejudice in the workplace due to their physical condition.

On the other hand Hunegnaw (2022) conducted his study on leprosy stigma and its impact on leprosy affected marital experiences in Addis-Tesfa Hiwot settlements. He claimed that leprosy

severely hampers the social, psychological, and economic productivity and wellness of those affected, subjecting them to cruel treatment and discrimination.

Rahel (2016) on her study has adopted a qualitative research approach to assess the psychological, economic, and social effects of leprosy on affected women in Addis Ababa. According to her findings, the incidence of leprosy is concerning especially for women who are affected by the disease, in part due to a lack of sufficient understanding and awareness about the disease. Furthermore, Rahel observed that women affected by leprosy often face intensified stigma, which leads to their marginalization from both their families and communities. This compounded discrimination deepens their feelings of isolation and makes it challenging for them to seek support and forge connections with others.

Van't Noordende et al. (2020) utilized a qualitative methodology to examine how leprosy, podocniosis, and lymphatic filariasis affect family quality of life in Northwest Ethiopia. Through in-depth interviews and focus group discussions with affected individuals and their families, the research aimed to identify the social, psychological, and economic difficulties they experience. The findings emphasized that stigma and poverty are critical factors that worsen these challenges. Social exclusion, driven by stigma, often limited families' engagement in community activities and reduced their access to support networks and opportunities for marriage. Additionally, economic challenges were aggravated by healthcare costs, reduced productivity, and restricted job prospects for those showing visible symptoms.

Shemsia (2020) on the other hand conducted a qualitative study at ALERT Hospital in Addis Ababa to explore the lived experiences of individuals affected by leprosy. The study involved interviews with both patients and healthcare providers to gain insights into the social, psychological, and economic hardships faced by those living with the condition. Using a phenomenological approach, the research sought to understand participants' personal experiences and the daily challenges associated with leprosy. The findings highlighted severe social exclusion and emotional distress among patients. Many participants reported feelings of shame and diminished self-worth, largely due to visible physical deformities and the ongoing stigma linked to leprosy.

Furthermore, Ramos (2012) wrote an academic publication on gender differences in the characteristics and outcomes of leprosy affected individuals treated in a long-term care rural hospital in south-eastern Ethiopia, employing quantitative research approach to carry out his study. His findings highlighted that women encountered more significant obstacles than men in receiving timely diagnoses and treatment, largely due to social stigma and a lack of awareness. This delay often resulted in women presenting with more advanced stages of the disease, which increased the likelihood of severe physical deformities. These factors further deepened their marginalization within their communities, reinforcing the cycle of isolation and limited access to care.

Several researchers and scholars studied the lived experiences of leprosy affected people in Ethiopia. However, the vast majority of existing leprosy research in Ethiopia has been centered on all categories of people affected with leprosy, with little emphasis paid to gender difference among women affected by leprosy in Ethiopia. Additionally, little is known about the lived realities of women affected by leprosy, particularly how intersecting vulnerabilities such as gender, poverty, and disability shape their experiences. This gap is particularly significant for women affected by leprosy, who often experience a unique and more profound form of discrimination due to entrenched gender norms in Ethiopian society. Nevertheless, this research targets at women being one specific study group.

Moreover, most of the researches conducted in Ethiopia are from the medical and epidemiological perspective such as diagnosis, and treatment rather than studying their social aspect which include lived experience of the affected women. This perspective is essential as it sheds light on the social and psychological hurdles, such as stigma and isolation that women affected by leprosy endure. This lack of attention to the lived experiences of women with leprosy represents a significant gap in understanding the broader implications of the disease.

This study aims to fill existing gaps by focusing on the lived experiences of women affected by leprosy in Woreda 01, Zenebework area, Addis Ababa. Through a phenomenological qualitative approach, it seeks to gain a deeper understanding of the intersecting challenges these women

face, such as social exclusion, economic hardship, and gender-based discrimination. By shedding light on these experiences, the research will contribute to the creation of more inclusive and effective policies and programs that address not only the medical but also the social and psychological needs of women with leprosy. Ultimately, this study aspires to bridge a crucial knowledge gap, providing insights that can guide efforts to enhance the quality of life and social integration of women affected by leprosy in Ethiopia.

1.3.Objective of the study

1.3.1. General Objective

To reveal the lived experiences of women affected by leprosy residing in Woreda 01 Zenebework area, Addis Ababa, Ethiopia through a phenomenological lens.

1.3.2. Specific objectives

- To explore the knowledge and perception of women affected with leprosy towards the disease.
- To examine the personal experiences of women affected by leprosy within their close social networks, including family, neighborhoods, and workplace.
- To assess the access and the treatment women affected with leprosy have in basic public and traditional institutions such as health services, transport services, Edir, and Equb.
- To understand the coping mechanisms used by women affected by leprosy to navigate their daily lives.

1.4.Significance of the Study

This research is critical in determining the lived experiences of women leprosy sufferers residing in Zenebework area. The study holds considerable significance for multiple stakeholders, including policymakers, healthcare providers, social institutions, and the wider community. Eventually, the findings of this study will contribute to the development of more inclusive policies and programs that aim to improve the quality of life for women affected by leprosy. It will also inform community-based efforts to reduce stigma and discrimination, enhance access to basic services and create a more supportive environment for affected women.

1.5.Scope of the Study

This study sought to identify the lived experiences of women affected by leprosy residing in the Zenebework area. The study is distinguished by its scope and geographical coverage. As a result, the study's scope is specifically focused on a particular aspect, namely the social and psychological conditions of women affected by leprosy. Furthermore, this research is limited to a single location: Kolfe Keranyo Sub-city, Woreda 01, Addis Ababa, Ethiopia, specifically within the Zenebework neighborhood.

1.6.Definitions of important terms

Leprosy: is a chronic communicable disease brought about *Mycobacterium leprae* which mainly attacks the skin, peripheral nerves and mucus membranes of the upper respiratory tract.

Lived experience: is the internal, personal perception of everyday experiences, emotions, and interactions, shaped by one's background, social context and personal history.

Stigma: is a negative social marker that detaches an individual apart from others often leading to sidelining, discrimination and segregation.

Discrimination: is imbalanced treatment founded on leprosy status.

Social exclusion: is process by which individuals or groups are steadily prohibited from taking part in social, economic and cultural activities.

Social support: is the rank and quality of support delivered by family, neighbor and community.

Social isolation: is the process of being physically or emotionally disconnected from social interactions and relationships.

Coping mechanisms: are approaches employed by individuals to handle their situations.

1.7.Limitations of the study

One of the first limitations of this study was some of officials in Addis Ababa City Administration Bureau of Women, Children and Social Affairs Rehabilitation Center for Victims of Social Problems around Zenebework area was reluctant to give information about the subject matter. Additionally, the remote setting of the research site created logistical obstacles that may have impacted both participant recruitment and data collection efforts. In addition, financial limitations constrained the study's scope reducing the number of participants. The other limitation was that it was not easy to access health professionals.

1.8.Organization of the Study

This research is divided into seven chapters. The first chapter is an introduction that includes the study's background, objectives, a statement of the problem and its significance, the scope of the study. The second chapter provides an overview of the literature review and discusses the fundamental concepts, theories, empirical literature and conceptual framework as well. The third chapter describes the research area, methodological details such as data collection and sampling methods, and ethical considerations. The fourth chapter discusses attributes of the respondents; the knowledge and perception of these women have towards the disease. Chapter five presents the social experiences they have with their close networks and access and treatment these women have in public and traditional institutions. Chapter six presents the coping mechanism the women utilize to cope up with the challenges they face. The final chapter contains the conclusion and recommendations.

2. REVIEW OF THE RELATED LITERATURE

Introduction

This chapter discusses the relevant literature, focusing on empirical studies on leprosy. The empirical literature review begins with leprosy from a worldwide perspective, then moves on to Africa and Ethiopia. The first section of the chapter discusses key concepts of leprosy before moving on to the empirical literature and relevant theories.

2.1. Understanding leprosy

2.1.1. Historical background and causes of leprosy

The term leprosy originates from religious translations of Hebrew word "tsara'ath" into Greek which is rendered as "leprosy" in the canonical Old Testament (Hyowon 2022). Leprosy, also known as Hansen's disease, was named after Armauer Hansen, a Norwegian physician who discovered the bacterium that caused the illness in 1873 (Ermias 2019). Leprosy is a contagious disease caused by the bacterium *Mycobacterium leprae*, and leprosy sufferers might have malformations affecting their vision, contact, and manual skills. *Mycobacterium leprae*, an acidic bacterium that survives even in dry conditions, causes leprosy. It grows in vast numbers and has the rare ability to enter neurons (Tessema and Beriso 2016).

In addition, nerve infection is an essential component of leprosy; however, it does not lead to lasting neurological damage for people suffering from the disease (Lidwina and Lusia 2021). The disease mainly causes disfiguring skin lesions, peripheral damage to neurons, osteoarticular imperfection, missing limb dysfunction, vision loss, and stigma (Franco and Rodrigue 2016).

The causes of leprosy are inextricably associated with people's misconceptions, paganism, and erroneous beliefs, thus leprosy is commonly thought to have both biological and mystical causes. The overwhelming majority of individuals believe that leprosy is a retribution for the affected wicked actions (Baseline 2001). According to Baseline the cause of leprosy has been traditionally linked to occult practices punishment of previous sins, consuming specific foods, and genetics. However, studies have shown leprosy is caused by slow-growing bacterium called

Mycobacterium lepra that causes illness predominantly affecting the outer layer of skin and nerves throughout the body (Cheng 2016). Leprosy manifests through a range of distinctive signs and symptoms, such as discolored skin patches, numbness or a loss of sensation in the affected areas, and thickened or stiff skin. Additionally, some individuals may experience muscle weakness or physical deformities, particularly in their hands and feet. Timely detection and treatment are crucial to avert potential complications and disabilities associated with the disease.

2.1.2. Transmission of Leprosy

Leprosy is a contagious disease that can spread from an infected individual to an uninfected person, although the route of transmission is unknown. Leprosy is most frequently transmitted through nasal and oral secretions during direct and continual contact with the affected person (Franco and Rodrigue 2016). People with untreated leprosy are contagious, and the risk of infection increases with close and frequent contact. There are three main forms of leprosy: Lepromatous, Tuberculoid, and Borderline. Lepromatous leprosy primarily affects the skin, eyes, nerves, taste buds, and upper respiratory tract. Tuberculoid leprosy mainly damages the skin of the legs, arms, face, and buttocks. Borderline leprosy is a mix of both lepromatous and Tuberculoid forms, attacking various parts of the body (WHO, 2018).

Jopling (1978) argued that even if an infant is born without leprosy, he or she can easily contract the disease from his mother. Despite continued attempts to stop leprosy spread, an extensive amount of new cases are being reported in numerous endemic locations (Franco and Rodrigue 2016). Despite the scientific findings, in some parts of the world leprosy is widely misinterpreted as hereditary and inoperable, and is viewed as a divine wrath or curse by many communities (Hyowon 2022). It is crucial to confront these misconceptions in order to cultivate a more supportive atmosphere for individuals affected by leprosy, thereby contributing to a significant reduction in the stigma surrounding the disease.

2.1.3. Leprosy Treatment and Control

Leprosy was effectively eradicated as a worldwide health hazard internationally in 2000 and at the national level in 113 of the world's 122 nations by 2005. WHO (2005) defines leprosy elimination as having a point prevalence of less than one in per 10,000 people. Nevertheless, the

number of new leprosy diagnoses remains considerable, with over 200 thousand in 2016 worldwide. In 2021, the World Health Organization (WHO) reported a total of 132,000 new leprosy cases worldwide, resulting in a prevalence rate of about 0.18 per 10,000 individuals. During the same year, efforts to eliminate leprosy continued to emphasize the importance of early diagnosis and combating the stigma associated with the disease. These statistics highlight the persistent challenges in managing leprosy, which while treatable, remains difficult to prevent in a conventional sense (Goulart, 2008).

The World Health Organization advocates for the use of Multidrug Treatment (MDT) for all individuals diagnosed with leprosy. This effective treatment combines three antibiotics: rifampicin, clofazimine, and dapsone, which work together to eradicate *Mycobacterium leprae* bacteria. By reducing the bacterial load in the body, MDT helps transform transmissible cases into non-transmissible ones, thereby minimizing infection reservoirs within communities. MDT is available free of charge due to partnerships between WHO and pharmaceutical companies, greatly enhancing global access to this essential treatment. Individuals are required to follow the MDT treatment for six months to a year, depending on the severity of their condition, while also implementing personal care strategies like maintaining good hygiene, attending regular healthcare appointments, and monitoring for side effects. WHO continues to play a pivotal role in combating leprosy by training healthcare workers, promoting awareness, and integrating leprosy services into broader healthcare systems, ensuring comprehensive support for affected individuals (WHO, 2021).

Finally, the knowledge gap regarding the understanding and perceptions of women affected by leprosy stem from a lack of detailed insight into how they perceive the disease, including its causes, symptoms, and treatment, especially in the Ethiopian context. Although existing studies have investigated public awareness and medical knowledge about leprosy, their findings are often generalized to the broader population, overlooking the specific experiences of women. In particular, there is limited research on the role of stigma, cultural beliefs, and gendered expectations in shaping women's understanding and responses to the disease. This gap is crucial because women's perceptions significantly affect their healthcare-seeking behaviors, access to treatment, and ability to navigate societal stigma. To address this, the current study adopts a

qualitative phenomenological approach to explore the lived experiences of women with leprosy in the Zenebework area. By analyzing their knowledge, sources of information, and the social and cultural factors influencing their views, the study aims to generate valuable insights that can guide targeted educational programs and policy interventions to enhance healthcare access and combat stigma.

2.1.4. Impact of Leprosy on the affected women

Leprosy has wide-reaching biological impacts, primarily affecting the skin, peripheral nerves, eyes, and mucous membranes. The disease's neurological damage is particularly significant, leading to sensory loss, muscle weakness, and deformities, especially in the hands and feet. Nerve damage frequently causes complications like ulcers and infections, which can progress to severe outcomes such as amputations, severely limiting mobility and the ability to perform daily tasks. Early detection and treatment are essential to preventing permanent disabilities, as the disease progresses slowly, making it more challenging to reverse once nerve damage is established (Rao et al., 2019).

The challenges faced by women with leprosy become more pronounced. Women frequently experience delayed diagnosis due to a combination of medical and social barriers, including stigma and limited access to healthcare services. This delay heightens their risk of developing severe physical deformities and disabilities. Socially, women are often subjected to intensified discrimination, which restricts their access to essential resources, healthcare, and social support systems. The resulting nerve damage and physical impairments severely affect their ability to function daily, leading to further isolation and financial hardship (Varkevisser et al., 2009). To improve treatment and rehabilitation outcomes, it is vital to address both the medical and gender-specific social challenges that women with leprosy face.

The psychological effects of leprosy on women are serious, highly brought the stigma and discrimination related with the disease. Women with leprosy often undergo anxiety, depression and serious social exclusion due to being ostracized by their families and communities. The influence increases by the culture and gender-oriented expectations trusted on women who may

practice extra distress due to the loss of traditional roles within their families and communities (Varkevisser et al., 2019).

The influence of leprosy on women often paves the way to high restrictions from social activities as stigma and discrimination bring about seclusion from community life. Women affected with leprosy are often ostracized, restraining their participation in social events, religious gatherings, cultural activities and even daily communications with others. This seclusion is made worse by observable physical deformities and disabilities brought about by the disease, which leads to self-imposed exclusion fearing rejection and humiliation (Rafferty, 2018).

The influences of leprosy on women frequently go down to serious challenges within family and marriage relationships. According to a study by Kumar and Singh (2021), women affected with leprosy often encounter grave marital and familial hardships due to societal stigma and the physical appearances resulting from the disease. The disabilities and observable signs can lead to marital limitation, with many women passing through abandonment or divorce as the direct outcome of their situation.

The stigma and discrimination surrounding leprosy have profound effects on women, amplifying both their social isolation and psychological distress. Visible symptoms and deep-rooted misconceptions about the disease contribute to intensified marginalization, often leading to exclusion from community activities and limiting access to vital services like healthcare and employment (Heijnders, 2004). For women, this stigma is compounded by gender-based prejudice, creating a double burden where they must navigate both the challenges of the disease and the societal biases against their gender and condition (Adhikari & Kaehler, 2020).

The economic impacts of leprosy on women are sizeable, as the disease often hampers their ability to engage in work and participate in economic activities. Leprosy-associated disabilities and stigma highly decrease employment opportunities for affected women. Women with leprosy often encounter economic difficulties due to their seclusion from the labor market. The physical restrictions caused by the disease, such as deformities and sensory loss further limit their ability to participate in productive work, leading to reduced income and increased dependency on

family or social services (Gupta et al., 2019). Consequently, it is vital to address the physical, psychological, and social aspects of leprosy to improve economic prospects and empower women affected by the disease. By confronting these interrelated issues, we can cultivate a more supportive environment that allows women to reclaim their independence and reconstruct their livelihoods, ultimately fostering resilience and self-sufficiency.

Generally, the knowledge gap regarding the personal experiences of women affected by leprosy within their close social networks such as family, neighborhoods, and workplaces and their access to and treatment in public and traditional institutions stems from a lack of targeted research on these interconnected areas. Although existing studies have addressed the broader social stigma surrounding leprosy, they often overlook how this stigma operates within intimate social settings and influences women's everyday roles and interactions. Moreover, little is known about how women with leprosy engage with public services like healthcare, transportation, education or traditional institutions like Edir and Equb, as well as the challenges they encounter in accessing these resources.

This study seeks to bridge these gaps through a qualitative phenomenological approach that explores the lived experiences of women in the Zenebework area. By conducting in-depth interviews and observations, it examines the impact of leprosy on their relationships within close social circles and their engagement with public and traditional institutions. The findings aim to offer detailed insights that can support the development of inclusive policies and community-based interventions to enhance social integration and equitable access to essential services for women affected by leprosy.

2.1.5. Coping mechanisms used by Leprosy affected people

Spiritual and religious practices also play a crucial role in helping individuals with leprosy cope with their circumstances by offering emotional comfort and a framework for interpreting their experiences. Many turn to prayer, religious ceremonies, and spiritual guidance to find strength and meaning in their struggles (White & White, 2013). In Ethiopia, for example, cultural and religious traditions such as the use of holy water and seeking advice from spiritual leaders are particularly prominent. Although these practices might sometimes delay medical intervention,

they remain essential sources of psychological support and are deeply rooted in the cultural fabric of these communities (Molyneux et al., 2015).

Another key coping mechanism for those affected by leprosy involves developing livelihood approaches that address the challenges posed by the disease. Many individuals engage in small-scale businesses, subsistence farming, or home-based crafts, enabling them to generate income while avoiding situations where they might face public discrimination (Peters et al., 2014). Programs such as microfinance initiatives and vocational training tailored to leprosy-affected individuals have proven effective in bolstering financial stability and social involvement. These strategies not only help alleviate economic hardships but also foster psychological resilience by reducing dependency on external support and enhancing individuals' sense of autonomy (Thomas et al., 2016).

Some individuals establish or join self-help groups that provide emotional, social, and financial support. These groups foster a sense of belonging and shared purpose, which helps members rebuild self-confidence and mitigate feelings of isolation. According to van Brakel et al. (2012), self-help groups not only promote social connectedness but also serve as platforms for advocacy and skill development. By engaging in these group activities, members gain economic independence and challenge societal prejudices, thereby facilitating their reintegration into the community.

The knowledge gap regarding the coping mechanisms of women affected by leprosy lies in the lack of detailed research on how they handle the social, economic, and psychological challenges brought about by the disease in their daily lives. While some studies have examined general coping strategies for people with illnesses, there is limited attention on the specific ways women with leprosy, particularly in Ethiopian settings, deal with the stigma, physical impairments, and financial difficulties associated with their condition. Furthermore, the influence of cultural and community-based practices, such as traditional healing methods or support from social networks, is often overlooked.

This study seeks to address this gap by employing a qualitative phenomenological approach to explore the lived experiences of women in the Zenebework area. Through in-depth interviews, it investigates the range of strategies they use, including engagement with traditional institutions, reliance on community support, and personal resilience, to navigate the challenges of daily life. The findings will contribute to a deeper understanding of these coping mechanisms and help inform the development of interventions that empower women and address their complex needs.

2.2.Prevalence of Leprosy: Global Context

Leprosy is an old disease that is still prevalent in many parts of the world, posing a hazard to public health. Currently the disease is more prevalent in parts of Asia, Africa, and parts of South and Central America (Mishra and Gupta 2010). Leprosy continues to pose a severe public health issue on numerous continents, including Africa, Asia, and Latin America (Hyowen 2022).Brazil, India, Nepal, Myanmar, Madagascar, and Mozambique accounted for more than 90% of all recorded cases of leprosy documented globally in 2002, with Brazil accounting for 80% of all leprosy diagnoses in South America(Nyamogoba and Mulambalah 2019).

People with leprosy in Indonesia characterized their situation in terms of their comprehension of the disease and self-image. According to the Indonesian Ministry of Health, there were 16,131 new cases of leprosy recorded in 2014. Inspiration and ongoing support for leprosy affected are required to have a beneficial impact on self-acceptance and a constructive effect on how one perceives oneself about the disease (Susanto and Rahmawati 2017).

In India, for instance, where leprosy continues to be common, the emotional challenges of women with leprosy have been acknowledged and discussed in the literature, but their unique experiences have been largely overlooked. Many leprosy-affected women living in India supported their families by soliciting regularly in their neighborhoods (Yoon 2014).

In 2006 and 2009, an estimated 1500 new cases were reported in Uganda, with the number of new cases with obvious disability increasing from 10% to 19% between 2005 and 2009, respectively. Uganda faces the challenge of ensuring the long-term viability of leprosy prevention measures in order to avoid a resurgence of the disease. The amount of multibacillary

victims across Uganda, who are at higher risk of developing cognitive impairments, is on the rise (Raphael 2017).

Kenya, an East African country, is one of several African countries dealing with a leprosy occurrence, with the disease endemic in the country's maritime strip and western regions (Nyamogoba and Mulambalah 2019). According to the writer the nation's 2015 calendar year report revealed that 124 leprosy sufferers were identified, instructed, and participated in rehabilitation, with females accounting for 67% of diagnoses.

Leprosy disease diagnostic rates range dramatically between men and women all across the world and in practically every part of the world, males outnumber women in terms of discovering cases, at least in clinical symptoms (Grand 1997). Leprosy is frequent in impoverished nations due to the nation's inadequate capability to deliver medical and educational facilities to those in need to lessen disability (Lidwina and Lusia 2021).

In summary, the persistent presence of leprosy underscores the critical need for focused interventions and enhanced resources aimed at improving healthcare accessibility. This is especially vital for women, who encounter distinct challenges within affected communities. Addressing these issues is essential to ensure equitable health outcomes and support for those impacted by this disease

2.3.Leprosy in Ethiopia

Leprosy has historically been prevalent in Ethiopia. It has posed a significant public health challenge in Ethiopia for many centuries, as historical records highlight its profound social and health impact. The distribution of leprosy across the country has been shaped by factors such as population density, socio-economic conditions, and climate. Regions with warmer climates and high population densities, such as Harar, Amhara, and the southern areas, have historically recorded higher prevalence rates of the disease (Mesele, 2014).

The introduction of specialized leprosy hospitals in Ethiopia represented a pivotal development in combating the disease. One of the first such institutions was Borumeda hospital in Dessie,

which catered to the northeastern regions, offering treatment and rehabilitation for those affected. This hospital also played an essential role in reducing stigma by fostering a supportive environment. Similarly, Bisidimo leprosy hospital in Harar, established with assistance from international partners, became a leading facility for leprosy treatment in eastern Ethiopia. Kuyera Leprosy hospital in Shashemane served the southern parts of the country and was notable for combining medical care with community-based rehabilitation initiatives (Mesele, 2014).

Zenebework area in Addis Ababa became a significant settlement for leprosy affected individuals due to a blend of medical, social, and historical factors. In the mid-20th century, as leprosy cases surged in the city, those affected faced intense social stigma and were often cast out by their communities. This prompted missionaries and health authorities to take action, leading to the establishment of leprosy treatment centers, most notably the All Africa Leprosy Rehabilitation and Training (ALERT) hospital, founded in 1934. This hospital specialized in the treatment and rehabilitation of leprosy affected individuals. Over time, Zenebework became a central hub for these initiatives, offering individuals not only medical care but also the opportunity to build supportive communities. The combined effects of isolation, societal rejection, and the need for treatment created a unique environment where those affected could live together, receive care, and mitigate the stigma they faced. As a result, Zenebework evolved into one of Ethiopia's most important settlements for leprosy affected individuals (Ermias, 2019).

Ethiopia is one of the most impacted countries on the face of the earth (Hunegnaw, 2022). Around 2010, the country was among the 17 countries registering up to 1000 new cases of leprosy on an annual basis, whereas between 2004 and 2010, an estimated 4000-4500 new cases were found at medical centers every year (Ermias 2019). According to Ermias, the overall number of people suffering from leprosy recorded in the entire nation reached 5,303, with 4,430 being newly diagnosed, and it was discovered that there were 1,308 females along with 331 children among the newly reported cases.

In Ethiopia, people with leprosy are mostly forced to end marital relationships simply due to the prejudice and discrimination that they face from their in-laws, family, relatives, and the wider society (Yonas 2020). He further stated that people with leprosy have poor incomes and face

prejudice in the workplace due to their medical conditions, and even when they do have jobs; affected people have low incomes due to their choice of simple tasks and physical disabilities.

Despite concerted efforts from various stakeholders, including government health programs, NGOs, and international organizations aiming to control and eradicate leprosy, around 5,000 new cases are reported annually in Ethiopia (Deribe et al., 2018). These initiatives focus on raising public awareness, improving access to healthcare, promoting early diagnosis, and providing free multidrug therapy (MDT) to those affected individuals (Tekle et al., 2020). However, national research on leprosy has declined, highlighting the need for a more thorough analysis of the disease's epidemiological patterns (Negera et al., 2019). Many cases go undetected and unreported, often due to misdiagnosis or limited healthcare access, particularly in remote regions (Lema et al., 2020). The psychosocial effects of leprosy, such as stigma and social isolation, continue to deeply affect the well-being of those suffering from the disease (Henok, 2016).

According to Rahel (2016), the incidence of leprosy is concerning particularly for Ethiopian women who have the disease, due in part to a lack of proper understanding and awareness of the ailment. The social expectations particularly among female suffering from leprosy are comparable to those of leprosy affected in other parts of the world, notwithstanding the lack of sufficient statistics to back this claim. Ramos (2012), on the other hand, claims that the features of women sent to hospitals differ from those of men; they were younger, had an entirely distinct admission description, and died at a greater rate. The information revealed significant gaps in both the treatment and awareness of leprosy in Ethiopia, especially among women. Despite the efforts of the government and health organizations, many challenges persist. Key initiatives, such as setting up treatment centers and implementing referral systems, have played an important role in identifying and treating individuals affected with leprosy. However, early detection continues to be a major hurdle, as the disease remains prevalent, particularly in underserved regions where healthcare access is limited. These insights indicate that tailored approaches to diagnosis, treatment, and support systems are essential to effectively tackle the distinct challenges encountered by women with leprosy in Ethiopia.

Integrating leprosy into the country's overall wellness program has produced both obstacles as well as chances for effective treatment of leprosy individuals, especially those with impairments (Girma 2019). He goes on to claim that it is an opportunity because it enhances the availability of medical treatment for people in need, which would not be conceivable with a vertical arrangement. According to Girma, just 18% of Ethiopia's 601 overall medical personnel from 300 medical institutions and 52 general medical centers could effectively diagnose and treat leprosy affected in general medical services.

2.4.Theoretical Discussions

This research is grounded in several theoretical frameworks that provide a deep and multifaceted understanding of the lived experiences of women affected by leprosy in Woreda 01, Zenebework area. Erving Goffman's theory of stigma and identity is a key tool for exploring how societal attitudes towards leprosy contribute to the marginalization of these women, shaping their sense of self and social interactions. The study also employed phenomenology to delve into the essence of these women's experiences, highlighting their subjective realities and the ways they navigate the challenges associated with their condition. Furthermore, intersectionality theory is applied to investigate the interconnected nature of various social identities such as gender, health status, and socio-economic background and how these elements collectively shape the experiences of women living with leprosy. By synthesizing these theories, the research seeks to reveal not only the individual hardships faced by these women but also the wider societal dynamics that affect their well-being and social integration.

2.4.1.Erving Goffman theory on Stigma and Identity

Goffman (1974) defines stigma as a deeply negative attribute that can greatly affect individuals' lives. He argues that stigma should be seen not only as a source of disgrace but also as a way to connect individuals with society. According to his foundational theory, while those who are stigmatized often view themselves as no different from others, society tends to categorize them as 'other' or distinct. This creates a significant disparity between how individuals perceive themselves and how they are viewed by others, leading to their marginalization. Furthermore, self-stigma can arise when individuals internalize societal judgments, which may lead to lowered self-esteem and feelings of worthlessness. This process, referred to in sociology as

social labeling, highlights how external perceptions can deeply impact a person's identity and social interactions. Goffman's insights encourage us to explore not only the personal experiences of those facing stigma but also the larger social dynamics at play, emphasizing the importance of empathy and understanding in addressing the challenges encountered by individuals with stigmatized identities.

As a result, leprosy has been referred to as an ignored tropical illness and social murderer since it leads to disability, has financial repercussions, and leads to social marginalization when compared to other serial killers such as malaria (Sachs, 2007). Goffman gave the most widely accepted definition and description of stigma, which refers to physiological indications, intended to reveal something uncommon or negative about the signifier's moral position. In this context, stigma is a complex issue that can affect every aspect of the life of people with leprosy.

Our common perceptions of individuals with stigma and our reactions to those who are unwell are thoroughly documented, as these responses are what constructive civic engagement seeks to address and alleviate (Goffman, 1963). Goffman asserts that people frequently view those with stigma as less than fully human, resulting in various forms of discrimination often unknowingly that limit their opportunities in life.

Goffman points out that stigma stems from societal perceptions and established norms, which creates a gap between how individuals perceive themselves and how they are viewed by others. This disconnect can lead to feelings of shame, social isolation, and an urge to hide one's stigmatized identity. For example, individuals with leprosy may struggle with the dual role of being both affected and a member of society, often feeling compelled to conceal their condition to evade negative judgment (Goffman, 1963). The anxiety of being labeled or marginalized can cause considerable psychological distress, further deepening the stigma linked to their condition.

Goffman argues that society creates a stigma theory to rationalize feelings of inadequacy and perceived threats, legitimizing negative attitudes towards individuals with different social or economic backgrounds and fostering discrimination. Language plays a crucial role in perpetuating stigma; terms like "disabled," "bastard," and "imbecile" are often used

metaphorically, losing their original meanings, which heightens societal fears and misunderstandings. For example, some individuals may hesitate to engage with blind people or treat them as if they were deaf or unintelligent. These reactions highlight a societal tendency to stereotype and emphasize the importance of empathy in interactions with stigmatized individuals. Goffman's work encourages a deeper understanding of stigma's societal function and stresses the need for intentional efforts to combat ingrained biases (Goffman, 1963).

Stigma arises when society enforces specific norms that individuals are expected to recognize and follow. Goffman (1963) argues that marginalized groups often feel significant pressure to conform to these societal standards. However, some individuals may disconnect from these expectations, remaining largely unaffected by their inability to comply. Protected by their feelings of estrangement and a strong sense of self, they may view themselves as fundamentally normal, interpreting societal judgments as indications of others' lack of humanity. This viewpoint highlights the intricate relationship between self-identity and societal expectations, suggesting that stigma is not only a result of societal norms but also a deeply personal experience shaped by individual resilience and perspective (Link & Phelan, 2001).

Goffman's (1963) theory suggests that the notion of an "ordinary human being" may stem from a scientific perspective on humanity or from the tendency of large administrative organizations, such as nation-states, to regard all members as equal in certain respects. This concept allows for a description of the stigmatized individual's life circumstances, which can be ambiguously termed as "embrace." Furthermore, a stigmatized individual may seek to improve their situation by investing considerable personal effort to excel in areas typically perceived as out of reach due to psychological or physical limitations.

Erving Goffman's theory of stigma highlights two key aspects: how stigma is perceived by those affected and how it is viewed by the wider community. In this study, women living with leprosy face both internalized stigma, shaped by their own experiences and self-perceptions, and external stigma, reflected in the attitudes and behaviors of community members. Examining these perspectives together reveals the interaction between societal views and personal identity, showing how stigma contributes to both social exclusion and diminished self-esteem. This

approach offers a deeper insight into how stigma operates and persists within the Zenebework community, influencing both individual lives and social relationships.

To put it briefly, Erving Goffman's theory on stigma and identity explores how people with socially devalued characteristics, such as physical disabilities, mental health issues or association with marginalized groups, develop a "spoiled identity," resulting in social exclusion and discrimination. Goffman suggests that stigma is shaped by societal norms and expectations that categorize certain traits as undesirable. This not only influences how individuals perceive themselves but also impacts their treatment in social interactions. To manage stigma, individuals may attempt to conceal or minimize their discredited traits. Ultimately, Goffman emphasizes that stigma is a social phenomenon, deeply rooted in how society defines and regulates deviance.

Goffman underscores that stigma is fundamentally a social phenomenon tied to society's concept of deviance. This viewpoint shapes the research by highlighting the importance of examining not only the personal experiences of women affected by leprosy but also the wider societal factors that lead to their marginalization. By incorporating Goffman's theory, the study seeks to reveal the intricate nature of their lived experiences, particularly the psychological and social obstacles they encounter. The goal is to promote a more compassionate and inclusive understanding of leprosy and its effects. This comprehension is essential for creating interventions that facilitate the social integration and overall well-being of women with leprosy, ultimately fostering a community that honors and appreciates diverse experiences.

Overall, Goffman's theory provides a framework for understanding the social and emotional impact of leprosy on these women. By examining stigma and its influence on their daily lives, healthcare access, and relationships, the research can shed light on the challenges they face and offer valuable insights for improving their well-being and social integration.

2.4.2. Phenomenology

Phenomenology focuses on isolating reality as it is experienced by participants and explaining phenomena using emergent essential themes (Moustakas, 1994). Phenomenology has no a priori hypotheses, which frees the philosopher or researcher from discrimination (Burch 1944). As a

result, the emphasis of this methodological paradigm is subjective experience, with an assessment of participants' detailed lived experiences to make sense of the world. A phenomenological research seeks to unearth the meanings of lived experiences in everyday practice without destroying, distorting, decontextualizing, trivializing, or sentimentalizing them (Colaizzi 1978).

Phenomenology, as a research direction, follows a social constructivist philosophy of human development and encounters sociocultural and past events that are fundamental to one's interpretation of one's existence (Fouche 1993). Through research activities, the researcher explored the phenomena and extracted meaning from the lived experiences of women affected by leprosy (Benner, 1985). As such theoretical framework it is appropriate to achieve this study's objectives for various reasons like prioritizing the perspectives of the participants, the approach enables women to narrate their experiences, promoting a more inclusive appreciation of their struggles and strengths. Ultimately, phenomenology offers a thorough framework for exploring the intricate realities of women affected by leprosy, enhancing our understanding of their situations and guiding the development of targeted interventions.

Phenomenology emphasizes the significance that individuals attach to their experiences. It values the first-person viewpoint, urging researchers to put aside any preconceived ideas and biases in order to immerse themselves in the narratives of the participants. This approach demands methodological precision, employing methods like in-depth interviews, reflective journaling, and analyzing participants' accounts to reveal the essential structures underlying their experiences (Van Manen, 1990).

Phenomenology highlights the personal experiences and interpretations of individuals, enabling researchers to understand the fundamental nature of phenomena as they are encountered in everyday life (Husserl, 1931; Heidegger, 1962). A fundamental principle of phenomenology is the notion of "bracketing," which entails setting aside any judgments regarding the phenomenon under investigation to attain a clearer insight into the participants' experiences (Husserl, 1970). This approach enables researchers to concentrate on the viewpoints of the participants without the interference of their own beliefs or assumptions. The objective is to attain a more profound

understanding of how individuals perceive and interpret their experiences, thereby enriching the overall body of knowledge that can guide practice, policy, and future research endeavors (Creswell, 2013).

In brief Phenomenology is a qualitative research approach that focuses on understanding and interpreting individuals' lived experiences from their own perspectives. This method emphasizes the subjective nature of human experience, aiming to uncover the essence of phenomena as they are perceived by individuals. The goal of phenomenological research is not only to describe these experiences but also to explore the meanings individuals attribute to them, allowing for a deeper understanding of the complexities of human existence (Smith et al., 2009).

In general, a phenomenological approach allows researchers to capture the richness and complexity of the women's experiences with leprosy by focusing on their subjective perspectives; the research can provide a deeper understanding of the social, emotional, and practical difficulties they face. This knowledge can then be used to develop better support systems, address stigma, and improve the overall well-being of women affected by leprosy.

2.4.3. Intersectionality Theory

Intersectionality is a theoretical approach that explores how different social identities such as race, gender, class, sexuality, and disability converge to form distinct patterns of discrimination and privilege. The theory is introduced by Kimberlé Crenshaw in the late 1980s, this concept underscores that individuals do not face oppression or discrimination in isolation; instead they navigate these experiences through the complex and interconnected web of their identities (Crenshaw, 1989).

Intersectionality emphasizes that social categories, such as race and gender, are not separate but interdependent and shape one another. For example, a Black woman experiences racism and sexism as interconnected, not as isolated forms of discrimination. Crenshaw saw the absence of black women in the violence against women projects. She examined as a problem for both the gender equality and anti-racist projects. This framework highlights the complexity of social inequalities and calls for more inclusive approaches in research and policy (Crenshaw, 1991;

Collins, 2000). Furthermore, intersectionality examines how systems of oppression, like patriarchy, capitalism, and colonialism, intersect to perpetuate inequalities (Collins, 2000). It emphasizes recognizing the unique experiences of marginalized groups and addressing their needs in sectors such as social justice, healthcare, and education. This framework broadens analysis and advocates for a more equitable society by giving voice to those often overlooked (Nash, 2008).

Hancock (2007) examines different studies on intersectionality to create a typology of methods that differs from McCall's framework. She categorizes three approaches to understanding diversity: the 'unitary' approach, which analyzes a single, fundamental category; the 'multiple' approach, which considers several stable categories as equally important; and the 'intersectional' approach, which investigates multiple fluid and interconnected categories that interact dynamically and hold equal significance.

In summary Intersectionality emphasizes how various social identities like gender, race, class, disability can combine to create unique experiences of oppression and disadvantage. Women with leprosy likely face a complex web of inequalities. This research can explore how their gender intersects with their illness to shape their access to healthcare, social interactions, and opportunities. By employing intersectionality, the research can move beyond a singular focus on gender and leprosy. It can paint a richer picture of the women's experiences by acknowledging the interplay of various social factors that shape their daily lives and the challenges they face. This knowledge can inform interventions that address not just the disease but also the broader social and economic factors impacting these women's well-being.

Finally, Goffman's theory of stigma, phenomenology, and intersectionality theory collectively offer a strong framework for analyzing the multifaceted social realities of women affected by leprosy. These approaches direct the research toward understanding both the individual and structural aspects of their experiences, providing a comprehensive perspective on the challenges they encounter.

2.5. Conceptual framework of the study

This integrated conceptual framework combines Erving Goffman's theory of stigma and identity, phenomenology, and intersectionality theory to examine the complex lived experiences of women with leprosy. Goffman's theory offers a lens to explore how societal stigma surrounding leprosy marginalizes these women, shaping their social identities and interactions. This stigmatization often results in social exclusion and a "spoiled identity," profoundly affecting their self-perception and societal roles.

Phenomenology complements this perspective by delving into the subjective realities of these women, capturing the essence of their experiences and the personal meanings they ascribe to their challenges. By prioritizing their lived experiences, this approach emphasizes individual voices and highlights the coping mechanisms women adopt to navigate stigma and exclusion.

Intersectionality theory enriches the framework by examining how multiple, intersecting social identities such as gender, health status, and socio-economic background collectively shape these women's experiences. This lens reveals how systemic inequalities and localized cultural norms amplify vulnerabilities and create unique, context-specific challenges. Together, these theoretical perspectives provide a comprehensive understanding of the interplay between societal attitudes, personal narratives, and structural factors. The framework thus bridges individual, social, and systemic dimensions, offering nuanced insights into the multifaceted realities of women living with leprosy and guiding the development of inclusive, stigma-reducing interventions.

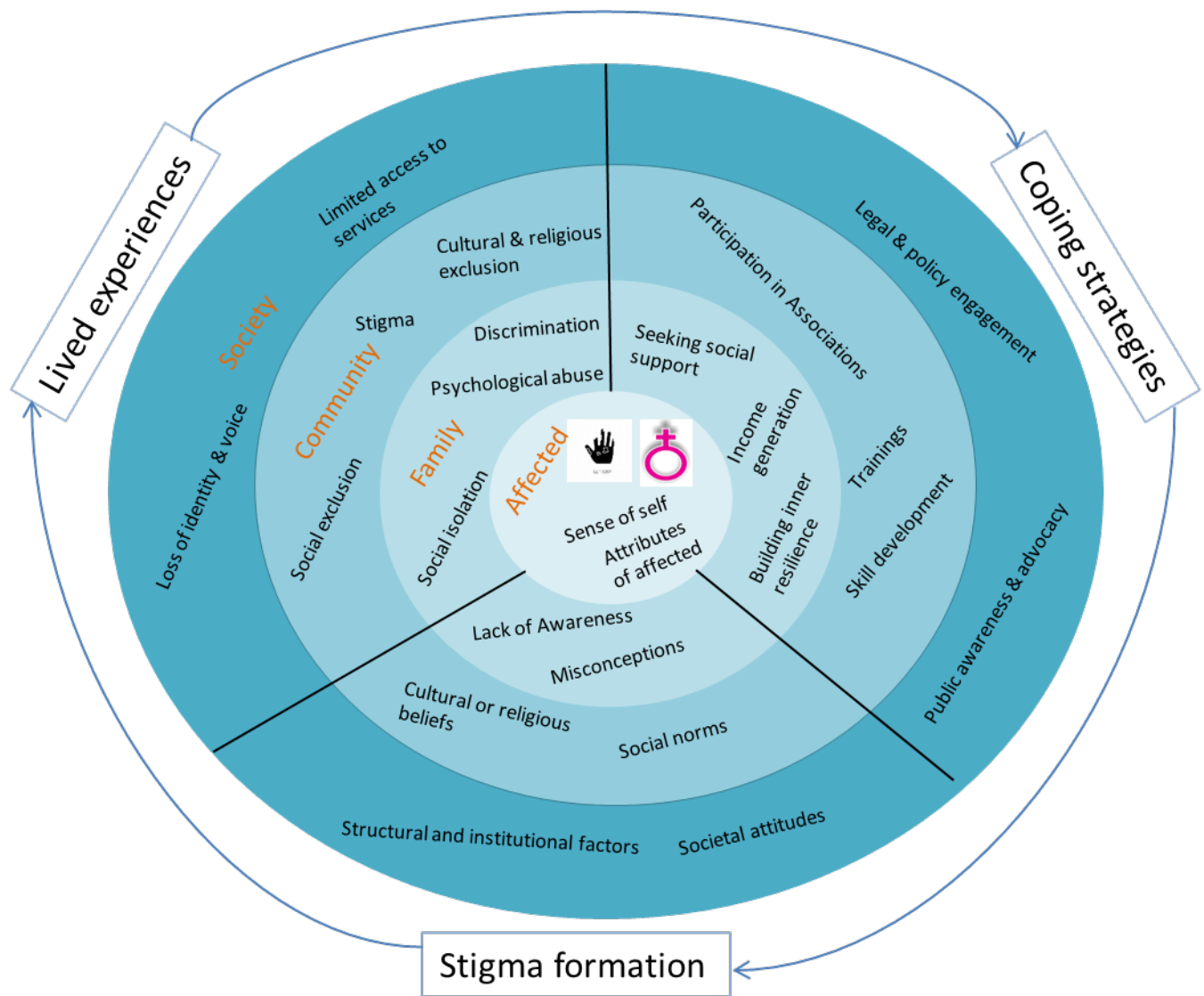


Figure 1: Conceptual Framework of lived experiences of affected individuals

This conceptual framework captures the complex, multidimensional process of stigma formation and its profound influence on individuals, particularly affected person. At its core lies the affected person, whose sense of identity and personal attributes are shaped by interactions within various social layers: family, community, and society. The family layer emphasizes the stigma experienced by family members, while the community layer highlights broader societal discrimination and the influence of cultural norms and values. The society layer encompasses

overarching factors such as societal attitudes, norms and values, organizational support, and legal frameworks that either reinforce or alleviate stigma.

The interconnected arrows illustrate the dynamic relationship among formation of stigma, lived experiences, and coping mechanisms (*see* Figure 1). By offering a holistic view, this framework provides a valuable tool for examining the lived experiences of those affected by stigma, shedding light on how personal identity, familial relationships, societal expectations, and external support systems intersect to shape their realities.

3. RESEARCH METHOD

This chapter describes the method of research that used to complete the study. It goes over the study's methodological details, such as data collection methods, sampling techniques, ethical consideration, and a description of the study area.

3.1. Description of the study area

This research is carried out at Zenebework neighborhood, woreda 01, Kolfe Keranyo sub-city Addis Ababa. This research was conducted in a neighborhood that was established in 1934 in conjunction with the foundation of Alert Hospital. Alert hospital is governed by the Federal Ministry of Health and operated by a board of directors. The hospital's offerings are growing and improving in terms of efficacy and accessibility, and it is transitioning from a leprosy medical therapy facility to a standard hospital (Mesele, 2005).

Alert hospital has been offering healthcare and treatments to leprosy affected individuals from around the nation who do not have referral paperwork from their respective communities of origin. Zenebework neighborhood, where the hospital is situated, is a densely populated area often described as a slum. It is characterized by numerous small businesses, including grocery shops and bars. The area as it is predominantly inhabited by the leprosy affected persons, there are various NGOs which work on leprosy among which Addis Ababa Leprosy Victims Rehabilitation Association (AALVRA), Ethiopian National Association of Persons Affected with Leprosy (ENAPAL), Ethiopian Catholic Church Medhen Social Center are at the forefront. Data was gathered from willing research participants who are currently residing in Woreda 01 Kolfe Keranyo Sub City from AALVRA. People from various parts of the country traveled to the vicinity to seek leprosy treatment. The study site was chosen because it has a high concentration of leprosy affected individuals including women, in contrast to other areas in Addis Ababa.

3.2. Research Design, approach, and sampling design

The study follows a case study research design and uses qualitative approach to gather relevant data from research participants. The qualitative research approach is essential for comprehending the everyday lives of individuals because it allows respondents to share their own

experiences. Furthermore, a qualitative approach assists researchers in becoming aware of the actual environments and circumstances on the ground. The primary advantage of qualitative research is that it generates a full account of respondents' thoughts, emotions, and experiences, as well as analyzes the significance of their behaviors (Denzin 1989). The phenomenological approach a form of qualitative enquiry, for example, seeks to discover, evaluate, and comprehend the participants' experiences (Silverman 2010).

Thus, in this study, a qualitative approach was used to collect valuable data on the lived experiences of women leprosy sufferers residing in Zenebework area. In this study, a qualitative method was used to capture women's knowledge and perceptions about leprosy and their relationship with their intimate networks, such as family, friends, neighbors, and the workplace using in-depth interview and observation.

To ensure the collection of rich and relevant qualitative data, careful consideration was given to the selection of research participants, leading to the use of a purposive sampling technique. Purposive sampling is a non-probability sampling technique that is most effective when researching a specific cultural domain with highly qualified researchers (Dolores and Tongco, 2007). The main reason for choosing purposive sampling approaches over other sampling methods is because it allows the researcher to make strategic decisions about who, where, and how to conduct the research. It also helps the researcher determine which groups to interview. The sample size for this investigation thus included 15 women affected by leprosy who have different age cohorts and socio-cultural backgrounds and 7 key informants who have knowledge about the subject matter. The researcher stopped data collection when it reaches saturation level, the point where no new themes, patterns, or insights emerge from additional interviews.

Finally, this study is guided by the interpretivist paradigm, which focuses on understanding how individuals interpret their experiences and assign meaning to their realities. It adopts relativist ontology, acknowledging that reality is socially constructed and varies depending on context. The study's constructivist epistemology emphasizes the collaborative creation of knowledge through engagement between the researcher and participants. Phenomenology, grounded in

Edmund Husserl's emphasis on exploring lived experiences, provides the theoretical framework, facilitating a detailed investigation into how women affected by leprosy understand and navigate their challenges. Erving Goffman's theory of stigma contributes to the analysis by exploring the impact of leprosy-related stigma on identity and social interactions, while intersectionality theory examines the intersecting effects of gender, socio-economic status, and disability. Together, these philosophical and theoretical perspectives support the use of a qualitative, phenomenological approach to explore the participants' complex experiences.

3.3.Data collection

3.3.1.Primary sources

Primary data was collected through in-depth interview, key informant interview, and observation to meet the research objectives and answer the research questions. The primary data collection tool employed in this study was critical for exploring complex social phenomena like social interaction. Furthermore, it enables the researcher to gather detailed information about people's experiences, perspectives, and feelings about leprosy as well as how they handle challenges including stigma and discrimination as members of the community. As a result, this type of data is critical for comprehending the social world and devising effective interventions to address social issues.

In-Depth Interview

In-depth interview was used to obtain data from 15 women affected by leprosy as the study's goal is to identify the lived experiences of leprosy affected women residing in the Zenebework area. When conducting an in-depth interview, the researcher prepared with questions intended for collecting wide-ranging data related to the study's goals. Open-ended questions were used to collect data during the interview because they enable respondents to express their perspective and views freely. The researcher developed an interview guide featuring open-ended questions to explore the lived experiences of women affected by leprosy. The guide was designed to delve into various aspects of their lives, including their knowledge about the disease, social interactions within their close networks and experiences with access to and treatment in public institutions, and the coping mechanisms they employ to navigate the challenges they face. The inclusion criteria for women affected by leprosy in this study included female respondents who

have been diagnosed and living with leprosy. Participants should express a clear willingness to participate in the study and be available during the data collection period. Additionally, participants must reside in Woreda 01, ensuring the research is focused on women living within this specific geographical area. These criteria help to ensure the relevance and accessibility of the data collected in the study.

Key Informant Interview

The researcher conducted a key informant interview with 7 people who have knowledge and experience dealing with leprosy infection in general and women affected by leprosy in particular. 2 social workers and 2 health professionals at Alert hospital, 1 official who work in NGO from Addis Ababa Leprosy Victims Rehabilitation Association and 2 government officials from woreda 01 with in-depth knowledge of the issue served as key informants in this study. Out of the (7 key informants) 3 of them were female and the remaining 4 were male participants. A separate interview guide was used for key informant respondents derived mainly from the exploratory in-depth interview questions. For example, this study aims to explore the specific issues that women affected by leprosy encounter throughout their treatment, as well as the initiatives that are currently underway to help women affected by leprosy in the specific organization. The inclusion criteria for key informants in this study require that participants possess knowledge of leprosy and have relevant work experience in the field. Additionally, only those who have willing were included in the study. These criteria ensure that the insights provided by the key informants are informed, relevant, and contribute meaningfully to the research.

Observation

According to Zohrabi (2013), observation is a prearranged method of inquiry that is carried out on purpose to fulfill the study's requirements and goals. The research used observation because it allows seeing exactly what happens in the study area. In this study, the researcher took on the role of a non-participant observer, aiming to objectively record the daily activities and social interactions of women affected by leprosy while avoiding any direct influence on their environment. By spending time within the neighborhood where these women live, the researcher observed their relationships with family members, friends, neighbors, and coworkers. The observations also included their involvement in social and public institutions, such as religious

organizations. This method provided a comprehensive understanding of the women’s experiences within their natural context. To complement the data collected through interviews, detailed field notes were meticulously recorded during each visit, offering valuable contextual insights into their everyday lives.

Table 1:Summary of the purpose of research methods

Specific Objective	Unit of Analysis	Observation Units	Methods of Data Collection
To explore the knowledge and perception of women affected with leprosy towards the disease	Individual woman with leprosy	Women diagnosed with leprosy residing in Woreda 01 Zenebework area	In-depth interview
To examine the personal experiences of women affected by leprosy within their close social networks, including family, neighborhoods, and workplace.	Interaction between women with leprosy and their social network	Women with leprosy	In-depth interview Observation
To assess leprosy affected access to and treatment in basic public and traditional institutions	Healthcare experience of women with leprosy and treatment service provider institutions	Women with leprosy Medical professionals NGO and government officials	In depth interview, Observation Key Informant interview
To understand the coping mechanisms used by women affected with leprosy to navigate their daily lives	Woman with leprosy in the context of her daily life	Women diagnosed with leprosy residing in Woreda 01 Zenebework area	In-depth interview

3.3.2.Secondary sources

The secondary sources, both published and unpublished, were essential in shaping this research. By examining books, journal articles, reports, research papers and electronic materials, the researcher identified gaps in the existing literature, particularly regarding the representation of women affected by leprosy. This helped refine the research objectives and questions, ensuring that overlooked aspects were addressed. Additionally, insights from these sources influenced the choice of methodology, enabling a comprehensive approach to studying the lived experiences of these women from various perspectives.

3.4.Data collection procedure

Initially, the researcher secured a permission letter from the Department of Sociology at Addis Ababa University, authorizing data collection in the designated study site, Woreda 01, located in

Zenebework area of Addis Ababa. Subsequently, the researcher visited the area to identify key individuals, such as representatives from NGOs and government sectors in Woreda 01 who work on leprosy affected individuals, who could help facilitate communication with potential participants.

During the data collection phase, the researcher outlined the purpose of the study to participants, aiming to build trust, overcome communication barriers, and obtain informed consent from those who met the eligibility criteria. Interviews were arranged at locations convenient for the participants, including their homes or associations who work on leprosy. Appointments were scheduled in advance to agree on suitable interview times. To ensure the process was efficient, the researcher prepared necessary tools, such as notebooks and a recorder.

The data collection process took place from March 26 to May 17, 2024, combining interviews and observations to gather comprehensive insights into the participants' lived experiences. The interview held with research participants was conducted in Amharic and took on average 40 minutes each.

3.5.Data Analysis

The data collected from participants in the current study is analyzed qualitatively. Most significantly, the data is analyzed through the phenomenological analysis method. Phenomenology stresses extracting reality as it is perceived by individuals and explaining phenomena using newly developed core themes (Vagel 2014). Phenomenological research approaches include collecting information about individuals' past and real-world events as they remember them.

In phenomenological research, the interview process is carefully designed to uncover the core essence of participants' lived experiences. It begins with transcribing interviews to maintain accuracy and develop a deep understanding of the data. Researchers then strive to grasp the overall context by thoroughly immersing themselves in the narratives. The next phase involves Horizontalization, where key meaning units are extracted from each participant's account, guided by Moustakas' (1994) criteria: determining if a statement is crucial to understanding the

phenomenon and whether it can be abstracted and categorized as an invariant meaning unit. Redundant, vague, or irrelevant statements are excluded. The identified meaning units are then clustered into relevant themes, which are translated into coherent thematic expressions. Narrative descriptions, known as textural descriptions, are created for each participant, highlighting the essence of their experiences. Essential structures that integrate these descriptions across participants are then identified, refined, and synthesized into a unified framework representing the phenomenon. This methodical approach ensures a thorough and credible phenomenological analysis (Moustakas, 1994).

The phenomenological analysis method is employed to develop themes thus the qualitative data gathered in this study is organized in themes in accordance with the findings of the study. The recorded data through in-depth interviews, key informant interviews and observation was first transcribed and interpreted from Amharic to the English language before analysis. After transcription, the data were carefully coded with similar concepts organized into thematic categories with the aim of identifying themes that reflect key elements of the data. These themes were subsequently analyzed to reflect the core of the participants' lived experiences. The analysis is contingent on the study's findings and greater efforts were made to avoid the researcher's skepticism during the data analysis process using the concept of bracketing in which phenomenology relies on.

3.6. Validity and Reliability

To ensure the validity of the study, various steps were taken to reduce both research and respondent bias. One key measure was practicing reflexivity throughout the research process by keeping a journal to record personal assumptions, beliefs, and biases, ensuring they did not affect data collection or interpretation. Triangulation was applied by drawing on diverse data sources, including interviews, observations, and document reviews, to ensure the findings were validated and information was cross-verified. To minimize respondent bias, questions were carefully designed to be neutral and non-leading, fostering genuine and uninfluenced responses from participants. Additionally, prolonged interaction and strict confidentiality measures were employed, such as anonymizing participant identities by assigning pseudonyms to establish trust

and create a safe, supportive environment, enabling participants to share their experiences openly and without fear of judgment.

For reliability, the researcher focused on consistency in the data collection process. The researcher was transparent about the research purpose and explained the interview process to participants, ensuring they understood their rights, including confidentiality. I also carefully worded interview questions to maintain clarity and neutrality. The researcher worked to build rapport with participants, creating a comfortable environment for them to openly share their experiences. Being mindful of the power dynamics between the researcher as an outsider and the participants, the researcher consciously minimized these by fostering respectful, equal dialogue. This approach helped ensure that the responses were not influenced by the hierarchical relationship between the researcher and the participants.

3.7.Positionality

My position as a researcher had a significant impact on the study. Although I am not personally affected by leprosy, I approached the research with deep empathy and an awareness of the difficulties women with leprosy face. As an outsider, I had to be particularly cautious not to impose my own views or interpretations on the data. I aimed to attune to the emotional and social contexts of the participants' experiences. My social background gave me some understanding of their situation but also required me to constantly reassess my perspectives to ensure the participants' voices remained central. This awareness of my positionality played a key role in maintaining both the validity and reliability of the study.

To ensure the participants' voices were central, I engaged in continuous self-reflection, consciously avoiding the imposition of my views or assumptions on their narratives. This reflexive approach created a respectful and inclusive research environment, where participants felt encouraged to share their stories openly. Building trust and fostering rapport were essential in creating a space that allowed their lived experiences to authentically shape the study's findings.

My positionality also guided the ethical framework of the research. Recognizing the inherent power dynamics between researcher and participants, I emphasized informed consent, confidentiality, and collaborative meaning-making during interviews. I aimed to interpret the data in a way that honored the participants' stories, highlighting their resilience and agency while critically examining the societal and structural forces that sustain stigma and exclusion.

Ultimately, this awareness of my positionality not only enhanced the study's validity and reliability but also reinforced my dedication to centering the voices of women affected by leprosy. This reflective stance enriched the research process, offering a deeper and more nuanced understanding of their lived experiences.

3.8. Ethical Consideration

The informants who took part in this study were thoroughly informed about the primary goal of the study. Participants were able to openly share their opinions and emotions about the problem at hand. The informants were informed that they may turn down or terminate their conversation at any point in time. They were also informed that any information they give will be kept strictly confidential and will not be shared with anyone else outside the purpose of the study. Furthermore, to maintain anonymity, pseudonyms were used throughout the research process to protect their identities. These ethical safeguards not only upheld the integrity of the research but also built trust, encouraging participants to share their experiences openly and without hesitation.

4. Attributes, knowledge, and perception of the respondents

This section discusses women's knowledge and perceptions about the disease including its cause, transmission, and treatment of leprosy and adverse effect of the disease on their health, social and economic life. Their knowledge about the disease was obtained through in-depth interview. Most women living with leprosy are unaware of the disease underlying origin or how it spreads from person to person. The majority of women affected by leprosy have misconceptions or assumptions about the disease. Women with leprosy were able to share their knowledge and impressions of the disease, as well as some of the symptoms they experienced when contracting it. Some of the symptoms they suffered included complete loss of feeling in their palms, vision, and limbs as a result of their illnesses. They also mentioned that their skin was vulnerable to blisters and injury due to a lack of sensitivity. Leprosy-affected women in this study are unaware of the disease's cause or how it transmits from person to person. The majority of leprosy-affected women discovered the condition after visiting a hospital.

4.1. Background information of the respondents

Table 2: Age distribution, marital status and place of origin of respondents

No of respondents	Pseudo name	Age	Marital status	Place of Origin (Region)
1	Mulunesh	65	Widow	Oromia
2	Bekelech	70	Widow	Oromia
3	Kalkidan	15	Single	Amhara
4	Yeshi	70	Widow	Oromia
5	Bekelu	25	Single	Oromia
6	Abaynesh	55	Widow	Amhara
7	Hiwot	55	Widow	Amhara
8	Tigist	30	Married	Amhara
9	Getenesh	35	Married	Oromia
10	Senayit	60	Widow	Amhara
11	Wibit	45	Married	Tigray
12	Sosina	26	Married	Amhara
13	Ayinadis	23	Married	Oromia
14	Mihret	23	Married	Amhara
15	Meseret	Unknown	Married	Oromia

Table 2 shows that the socio-demographic characteristics of respondents who participated in in-depth interview. As shown in the table the age of respondents ranges from 15 to 80. The study

focuses on women affected by leprosy, the age category of respondent's shows that leprosy can affect all age group. The average age of respondents was (45 years), the youngest leprosy affected women being 15 and the oldest being 70 years old. From the interview most of the respondents were first diagnosed at a very young age of (6-7). This means most of the participants were first diagnosed 30-40 years back. During this time leprosy in Ethiopia was largely misunderstood and carried a significant stigma compared to the present day. It was commonly linked to fear and superstition, resulting in extreme social exclusion of those people with stigma which included women with leprosy. Over-all the age distribution reveals that leprosy impacts women at various stages of life, from childhood through to old age. The age distribution of women in the sample suggests participants had lived with the disease for most of their lives. Meanwhile, the inclusion of younger respondent's points to continued transmission or delays in detecting and treatment of the disease among younger individuals, highlighting the importance of ongoing vigilance and support for all age categories.

With regard to respondents' marital statuses, the data shows that 6 respondents were widowed, while 7 women had reported of being married. The remaining 2 respondents had indicated that they were single. Generally, the data shows that marital status significantly affects the ability to manage household finances on a single income. Widowed and single respondents are particularly likely to experience greater financial difficulties due to the loss of a partner or the absence of someone to share economic responsibilities, compounded by the challenges posed by leprosy and leprosy related disability.

Regarding the place of origin, the study discovered that 7 of the 15 participants were from Oromia region, 7 from the Amhara region, and 1 from Tigray. According to the data, most of the affected respondents were from Oromia and Amhara region. In addition to being from the regions, the respondents also came from the rural part of the country. The fact that they are from rural areas shows the difficulty these women face to easily access key information about the disease, its means of transmission as well as available treatment services. Likewise, a previous study by Smith et al. (2015) indicated that leprosy is more prevalent in rural areas due to several interconnected factors such as inadequate healthcare infrastructure, leading to delays in diagnosing and treating. The limited availability of medical facilities and healthcare

professionals in place of origin means that individuals may not receive timely or sufficient care, allowing the disease to advance unchecked. Furthermore, lower levels of health education and widespread poverty in rural areas exacerbate the situation, as residents may lack awareness about leprosy or access to medical services. Likewise, the general and program manager at Addis Ababa Leprosy Victims Rehabilitation Association stated that most affected persons come from Oromia region because Addis Ababa is surrounded by Oromia zones and as a result they come and get registered. As such, the data can be obtained easily if affected persons are registered and available during data collection time.

Table 3: Educational level, occupation and their enrollment status in safety net program

No of respondents	Pseudo name	Educational level	Occupation	Enrolment in safety net program
1	Mulunesh	Illiterate	Unemployed	Enrolled
2	Bekelech	Illiterate	Unemployed	Enrolled
3	Meseret	Illiterate	Unemployed	Enrolled
4	Yeshi	Illiterate	Unemployed	Enrolled
5	Bekelu	Primary	Employed	Not Enrolled
6	Abaynesh	Illiterate	Employed	Not Enrolled
7	Hiwot	Illiterate	Employed	Not Enrolled
8	Tigist	Illiterate	Unemployed	Not Enrolled
9	Getenesh	Illiterate	Unemployed	Not Enrolled
10	Senayit	Primary	Employed	Not Enrolled
11	Wibit	Primary	Employed	Not Enrolled
12	Sosina	Primary	Employed	Not Enrolled
13	Ayinadis	Primary	Unemployed	Not Enrolled
14	Mihret	Primary	Unemployed	Not Enrolled
15	Kalkidan	Primary	Unemployed	Not Enrolled

Education is crucial for obtaining relevant information about leprosy and shaping the health-seeking behaviors of individuals with chronic illnesses. Limited educational backgrounds are acknowledged as key factors that contribute to the spread and delays in the treatment of infectious diseases like leprosy. Table 3, shows the distribution of participants' educational

background ranges from illiterate to primary school. Accordingly, the data shows that out of the 15 female respondents 8 women cannot read or write, while the remaining 7 women have had primary level of education. This indicates that, most of the respondents were not educated and even those that had received formal education; their educational level was restricted to primary level of education. According to the respondents, most women were forced to discontinue their education because their families prefer them to married at an early age. Some of the women have also cited the stigma they encounter from their classmates while attending their lessons as another major factor for discontinuing their education. In conclusion, the limited educational achievement of the respondents not only restricts their economic prospects but also intensifies the difficulties associated with leprosy.

Table 3 also shows that only 6 of female respondents were employed while 9 respondents were without a job. Out of the 6 women that have reported of having a job, (4 respondents) were beneficiaries of the job opportunities created by Addis Ababa Leprosy Victims Rehabilitation Association. The work includes cleaning, shower and toilet ticketing etc. Their income ranged from 1500 to 2000 birr per month. The remaining 2 women who were beneficiaries from the job opportunities created by the aforementioned NGO had left the job and had started a handcraft business independently. Moreover, the criteria to be employed in the NGO include being a person with leprosy and to proof of absence of any support from any institution. Unemployed individuals in this case will receive such benefits from the NGO whenever donors allocate funds to support the program. To sum up the income women with leprosy receive is not enough to support their daily needs and that of their families as the income does not match high cost of living in the city.

On the other hand, those who are neither members of Addis Ababa Leprosy Victims Rehabilitation Association nor have job in this NGO have been enrolled in the safety net program which is provided by woreda 01. Accordingly only 4 of the respondents had registered in the safety net program. The criteria to engage in the safety net program are severity of disability and absence of any means of support from other sources. Being part of this scheme, the women were provided with 450 birr if they are single and 835 birr if married per month. It is thus evident that such amount of income is not enough to support themselves and their families. Consequently,

since they are unable to cover even their basic needs, participants supplement their income by engaging in begging on the streets.

Data obtained from observation shows that, the living condition of women with leprosy are harsh and difficult. This is more manifested by looking at the houses these women rent. Most of the affected women with leprosy live in narrow houses made of corrugated sheets of iron. This shows that the support provided for women with leprosy is not sufficient to maintain a decent living as they are less likely to meet their basic needs. Thus, greater efforts from the government, NGOs, and other stakeholders are essential to offer the needed support to the women.

4.2. Women's Knowledge and Perceptions of Leprosy

4.2.1. Causes of Leprosy

Regarding the causes of leprosy, the study found out that there exist a gap between the scientific knowledge and the belief of the affected women. The gap is depicted by the fact that the scientific knowledge explains that leprosy is caused by the bacterium, *Mycobacterium leprae*. However, the study further discovered women affected by leprosy traditionally believe that the cause of the disease is superstition and lack of hygiene and sanitation. Accordingly a study conducted by Gebrehiwot and Kebede (2019), found that most women affected by leprosy lacked fundamental knowledge about the cause of the disease and believed it was hereditary or contagious through spontaneous contact, despite leprosy being only slightly infectious.

There are various causes of leprosy according to respondents. Most leprosy-affected women do not have clear knowledge about the cause, transmission of the disease, and while others hold various opinions on the main cause of the disease. For instance, lack of hygiene and sanitation, superstition beliefs were mentioned as the main cause of the disease. Some of the women believed that the cause of the disease is due to curse, gift from a higher power etc.

Lack of Hygiene and sanitation

Hygiene and sanitation are the bedrock of public health, playing a vital role in preventing the spread of diseases such as leprosy. Hygiene involves daily practices like regular handwashing, bathing, and keeping living environments clean, while sanitation refers to the infrastructure and

systems that ensure safe waste disposal, access to clean water, and control of disease-carrying vectors(WHO, 2022).

In the fight against leprosy, maintaining proper hygiene is crucial, as it helps to minimize the risk of secondary infections that can worsen the symptoms and complications of the disease. Equally important is effective sanitation, which plays a key role in halting the spread of *Mycobacterium leprae*, the bacteria responsible for leprosy, though the exact pathways of transmission are not yet fully understood (WHO, 2021).

However, maintaining adequate hygiene and sanitation is a significant challenge, particularly for those living in poverty or in rural areas. These individuals often face barriers such as limited access to clean water, inadequate infrastructure, scarce hygiene products, and a lack of awareness about proper hygiene practices. In Ethiopia, these difficulties are exacerbated by economic constraints, cultural factors, and restricted access to healthcare services.

The hygiene and sanitation practices in Ethiopia are shaped by the country's unique geographical, climatic, and socio-economic realities. In rural regions, where a large portion of the population resides, access to clean water and sanitation facilities is often scarce. This can lead to reliance on unsafe water sources and improper waste disposal, thereby increasing the likelihood of disease transmission (UNICEF, 2020).

Research has shown that poor sanitation and hygiene conditions are closely linked to the spread of leprosy. According to a study conducted by Smith et al (2016),poor sanitation and crowded living conditions have been associated with a higher risk of leprosy transmission in Ethiopia.This highlights the importance of improving hygiene and sanitation as part of broader public health efforts to combat leprosy and other communicable diseases.

Accordingly, Mulunesh a 65 years- old-womanaffected by leprosyhas forwarded her idea as the following:

To be honest, I'm not entirely sure what causes the disease, and most leprosy affected persons including myself, have no idea how it spreads from person to person. When

my brother became ill with leprosy, I learned about the disease for the first time. After that, my father decided to send me to Addis Ababa for treatment. I'm not sure how I became infected with the disease, but I think I contracted the disease through threshing the ripe harvest on my family's field. Additionally I had the contact with the soil in my village in Arsi. I used to walk bare foot and work using my hands. As a result, I became ill and began to experience symptoms such as having cuts on my hands. I believe the disease spreads from person to person as a result of touching dirty things and poor hygiene and sanitation practices.

The respondent's story reveals a notable lack of clarity and understanding about leprosy, which is a common issue for many affected by the disease. Her knowledge of leprosy only surfaced after her brother was diagnosed, demonstrating how information is often acquired within families in response to illness, rather than through proactive public health education. This gap in understanding is further illustrated by her belief that she might have contracted the disease through farming activities and soil contact, highlighting widespread misconceptions about leprosy transmission. Her assumption that leprosy spreads due to poor hygiene and sanitation practices, though partially shaped by general health advice, conflates leprosy with other infections, emphasizing the critical need for more accurate and targeted health education.

Similarly Bekelech a 70 years- old- woman has added the following:

I don't know the cause of leprosy exactly. However, I used to distill "Arake" when I was in the countryside. One day I left my house without washing my body after the distilling of "Arake". So, I came to hold the belief that I contracted the disease owing to my failure to keep myself clean. I mean I should have washed before going outside.

The respondent's narrative reveals a profound sense of guilt intertwined with her efforts to understand her condition. While she acknowledges her lack of knowledge about the exact cause of leprosy, she attributes her illness to a particular incident when she left home without washing after processing "Arake." This story reflects her internalized belief that her failure to uphold cleanliness resulted in her contracting the disease, demonstrating how people often look to their own actions for explanations when grappling with illness. Her expression of regret over not

washing before going outside emphasizes this emotional weight of guilt, as she attempts to rationalize her situation through what she perceives as a lapse in hygiene.

Superstition Believes

Superstitious beliefs are deeply embedded cultural narratives that arise from the desire to comprehend the unknown, especially regarding health and disease. These beliefs significantly influence how individuals view and respond to illnesses like leprosy. In many communities, superstitions serve as coping mechanisms, providing a sense of control or insight in times of uncertainty. As a result, people may turn to these beliefs rather than scientific explanations, particularly in settings where access to healthcare and education are restricted.

The inclination to favor superstitious beliefs over scientific explanations can be influenced by various factors. Cultural traditions, community norms, and historical contexts shape these beliefs, creating a framework through which individuals view their health issues. When it comes to leprosy, prevalent superstitions may include the idea that the disease is a punishment for past misdeeds, is caused by spiritual forces, or is associated with particular actions, such as contact with specific materials or individuals.

A research conducted by Abebe et al. (2015) revealed that in certain Ethiopian communities, leprosy is perceived as a curse or divine retribution, resulting in stigma and social isolation for those affected. This belief system not only perpetuates stigma but also deters individuals from pursuing timely medical treatment, as they fear rejection or misunderstanding from others.

Furthermore, dependence on superstitions can eclipse scientific understanding, particularly in areas with limited health education. When individuals search for explanations regarding their health issues, they are likely to lean towards comforting familiar stories instead of grappling with the intricacies of medical science. These beliefs can deter individuals from seeking traditional medical care, resulting in delays in diagnosis and treatment.

On the subject of the superstition believes, Meseret who is affected by leprosy from Oromia region stated the following:

I caught leprosy when I was a new mother. Back then I went to a river and was hit by “Megagna” (evil spirit) and it was after that I began to get sick. The symptoms were pain, loss of sensation, some white spots on my face; However, I don’t know how the disease transmits from one person to the other.

The quote highlights a notable contradiction in the respondent's beliefs regarding leprosy and its transmission. She attributes her illness to an "evil spirit" encountered at the river, reflecting a prevalent superstition that views leprosy as a result of supernatural influences. However, despite this strong belief, she expresses uncertainty about how the disease actually spreads from one person to another. This inconsistency reveals the intricate relationship between traditional beliefs and medical knowledge, suggesting that while she may see her condition as linked to spiritual elements, there is still confusion about the biological processes of transmission. Such contradictions emphasize the difficulties individuals face in reconciling cultural narratives with scientific insights, ultimately hindering their ability to seek proper medical treatment.

Similarly Ayinadis a 23-years-old woman from Oromia region has said the following:

I don’t know the cause of leprosy exactly. Nevertheless, I got sick as I was a new mother; I was hit by what is traditionally known as “Mich”. Soon after, my face, my ears began swelling and I had no sleep the whole night. I don’t know the ways by which the disease transmits.

The quote highlights the respondent's significant uncertainty about the origins and transmission of leprosy, illustrating her difficulty in understanding the disease within her cultural context. Her difficulty in grasping the disease, paired with a vivid account of her symptoms, highlights the divide between traditional understandings and scientific knowledge, which ultimately impacts her ability to seek effective treatment.

Similarly, Yeshi who is affected by leprosy put forth her idea about the cause of her ailment as indicated:

I went to the “Tsebel” place several times but I was not healed. After several trials thinking that I have “Wukabi”, they took me to the “Kalicha” then he told my families that I caught the disease as a result of my father’s curse.

The quote underscores the respondent's frustration in her pursuit of healing through traditional practices, reflecting her dependence on local methods and her efforts to make sense of her illness within her cultural framework. The mention of her father's curse adds emotional depth, highlighting the difficulties she faces in reconciling medical explanations with cultural narratives as she navigates her experience of illness.

On the contrary, the rest of the participants (11) do not have clear knowledge about the causes of the disease. Among these, Abaynesh from Amhara region stated the following:

Our society terms the disease leprosy as “Tiliku Beshita” meaning “The Great Suffering.” It is termed as such because the disease ends up in the loss of hands, feet and finally ends up in loss of sight. I don’t know the cause of leprosy and even I don’t know where I contracted it from. I don’t also know the way it transmits from one person to the other.

The quote highlights the deep confusion and despair the respondent feels regarding leprosy, known locally as “Tiliku Beshita”. This name reflects the serious physical consequences of the disease, such as the loss of limbs, hands, feet and vision, illustrating that leprosy is viewed not merely as a medical condition but as a significant source of hardship. The respondent's acknowledgment of her lack of knowledge about the disease's causes and how it spreads reveals a significant knowledge gap that many face, especially in communities with limited access to healthcare education. This uncertainty breeds fear and stigma, complicating the individual's experience of the illness as well as reaction in seeking medical treatment from health care providers.

To reinforce Abaynesh's point, Hiwot from Amhara region shared her perspective as follows:

I don't know the exact cause of leprosy, nor do I understand how it is transmitted. However, I believe I contracted the disease as if it were a gift not a genetic one, but rather as part of my fate, as it came from my father who was affected by leprosy. None of my other siblings had been affected, so it feels like bad luck that I ended up with the disease.

The quote reveals the complex relationship between personal identity, family legacy, and the stigma surrounding leprosy. The respondent's uncertainty about the disease's causes reflects societal misunderstandings that perpetuate stigma. By viewing her contraction of leprosy as a 'gift' linked to her father's experience, she expresses resignation to fate and perceives her condition as an unfortunate inheritance rather than a personal flaw. This perspective fosters feelings of isolation, especially compared to unaffected siblings, and highlights the emotional burden of being seen as 'bad luck' ultimately, it sheds light on the coping strategies individuals may use when facing illness and underscores the societal misconceptions that continue to affect those living with leprosy.

According to the study's findings, the majority of women affected with leprosy are unaware of the underlying cause of the disease or how it spreads from person to person. However, even those who claim to know the cause of the disease have misconception depicting a gap between the scientific knowledge and their traditional believes. Their knowledge is based on traditional conceptions entirely having to do with the tradition in the society they grow up in. Some of the affected women attach the cause of the disease to poor hygiene and lack of sanitation because they are compelled to think this way as they caught the disease after performing certain activities like threshing or weeding. Some of the affected women on the other hand relate the cause of the disease with superstition believes such as evil spirits. These are all unproven traditional believes. This shows the gap between the scientific finding and the traditional believes.

These unfounded beliefs not only highlight a lack of understanding but also significantly influence how individuals react to their condition. Such misconceptions can obstruct their ability to seek appropriate medical treatment in a timely manner. For example, if women perceive their illness as a curse or a consequence of poor hygiene, they may be reluctant to pursue scientific treatments, opting instead for traditional remedies or rituals that provide temporary relief. This

hesitation can result in delays in diagnosis and treatment, worsening their health issues and perpetuating stigma within their communities. The tension between traditional beliefs and scientific knowledge creates a complex environment for these women, forcing them to navigate cultural narratives alongside the realities of their health. Ultimately, bridging this gap is essential for enhancing health outcomes and promoting a more supportive community response for those affected by leprosy.

4.2.2. Treatment for women affected by leprosy

Traditional healing practices

This section presents the type and nature of traditional healing practice adopted by women affected by leprosy prior to obtaining modern treatment from a health facility and professional. According to interviews conducted with participants, two main types of traditional healing practices were commonly used to address the effects of leprosy. This includes, treating with “Tsebel” (holy water) and obtaining treatment from a “Kalicha” (spiritual healer).

Traditional healing practices like the use of "Tsebel" (holy water) and consultations with a "Kalicha" (spiritual healer) are deeply woven into the cultural fabric of Ethiopia, far beyond their role in addressing leprosy. These practices are vital to the daily lives of many Ethiopians, symbolizing a broader dependence on spiritual and religious rituals for various health concerns. "Tsebel," revered for its divine qualities, is utilized by most followers of the Ethiopian Orthodox Church not only for physical healing but also for spiritual cleansing and protection against malevolent forces.

Similarly the "Kalicha" who acts as a bridge between the spiritual and physical worlds, is sought for both medical and personal guidance within the community. The significance of these traditional practices lies in their accessibility, cultural relevance, and holistic approach that addresses both physical and spiritual needs. In rural areas, where modern healthcare is often scarce, these methods serve as the primary means of addressing health crises. Consequently, they play a pivotal role in shaping how Ethiopians manage their health and interact with

contemporary medical systems. Recognizing the importance of these practices is crucial for effectively integrating traditional and modern healthcare approaches in Ethiopia (Assefa, 2010).

Correspondingly, three affected women tried to get treatment by going to “Tsebel” with the help of their family. Among them one woman even visited what is traditionally known as “Kalicha” or “Wukabi” but unfortunately the “Kalicha” couldn’t find any solution for her sickness. One of the three women mentioned encountered several ups and downs before reaching hospital and receiving treatment. Yeshi was from Wolliso, Oromia region. She had to say the following:

I went to the “Tsebel” (holy water) place several times but I was not healed. After several trials thinking that I have “Wukabi”, they took me to the “Kalicha” then he told my families that the disease caught me as a result of my father’s curse. However, he could not also cure me from the disease. My family could not help me further for fear that the disease may transmit to them and for fear that they might face insult from the society if they are seen with me. I further continued to look for treatment and went to “Kobi” hospital in Wolliso where I met a certain female doctor who was foreigner who told me that it was leprosy and she gave me 6 injections. Then she told me to go to Addis Ababa for better treatment. In the meantime, I heard information from a certain person about Gebre-Kiristos in Addis where I can get medical treatment. Hence, I escaped from my family to come to Addis alone. Before reaching Addis Ababa, I had to pass through hard ships such as going on foot from Wolliso to Ambo and again going on foot from Ambo through Holata to Addis Ababa. In all of this, I had to beg different persons for lodgings. On a certain day, a day which I couldn’t remember, I arrived at Addis Ababa bus-station. There, when I asked for information I accidentally found a woman affected with the disease. She then took me to Alert hospital.

This narrative captures the profound struggles faced by women with leprosy in Ethiopia, shedding light on issues of community perception, misinformation, and barriers to treatment. The woman’s reliance on traditional healing methods, such as “Tsebel” (holy water) and seeking advice from a “Kalicha” (spiritual healer), underscores the strong cultural beliefs surrounding the illness. The Kalicha’s claim that her disease stemmed from her father’s curse reveals the

damaging effects of such beliefs on family ties, exacerbating feelings of guilt and isolation. These spiritual explanations further obscure her understanding of the disease, causing delays in seeking appropriate medical care. The stigma associated with leprosy further forced her family to withdraw out of fear, leaving her even more isolated and alone.

To add further idea on the traditional treatment, Ayinadis had to say this.

When I was in the countryside, I didn't know anything about leprosy. Nonetheless, my family thought that I was possessed by an evil spirit; they used to take me to "Tsebel". However, I did not get better with the "Tsebel" and my aunt took me to Alert hospital.

The story highlights the entrenched misconceptions and cultural beliefs about leprosy in rural areas. The respondent's unfamiliarity with the disease underscores the pervasive lack of awareness within her community, where her symptoms were erroneously linked to an evil spirit. Her family's dependence on "Tsebel" (holy water) as a remedy reveals the powerful grip of traditional practices, even when they prove ineffective in addressing her illness.

Likewise, key informant nurse Zerihun, who has been working on leprosy at Alert hospital for more than 30 years, has shared his experiences encountered during his treatment.

The first reason for the increase in the number of the affected individuals with leprosy is the lack of societal awareness about the disease. The awareness of our society is very low. This means that people when observing something alien marks on their body, do not go to the health center quickly. This is so because the disease is not ailing but it slowly catches and does not take root at once. Hence the society doesn't take swift action thinking that it will get cured soon. Among those things I come across, during treatment, the affected person start to take other options. These options include going to sorcery, and if it doesn't get better they go to holy water "Tsebel" and eventually the illness gets serious.

The nurse's reflections from his extensive tenure at Alert hospital illuminate key themes surrounding the obstacles in leprosy treatment and societal attitudes. Foremost among these

is lack of awareness, which he identifies as a major factor contributing to the increasing prevalence of leprosy. He emphasizes that community ignorance often leads individuals to postpone seeking medical assistance when they notice unusual symptoms, as the disease's gradual progression fosters a false sense of security. This issue is further complicated by a reliance on alternative treatments, such as sorcery and "Tsebel" (holy water), which the affected often pursue out of desperation or cultural conviction. The nurse's insights underscore how these misconceptions can worsen health outcomes, as delays in receiving appropriate medical care allow the disease to advance unchecked.

Medical and psychosocial treatment

After being diagnosed with leprosy, the affected individuals receive a variety of treatments from doctors and nurses at Alert hospital. This renowned facility has been treating affected individuals with leprosy in Ethiopia since its establishment in 1948, making it one of the oldest hospitals dedicated to managing the disease in the country. Located in Addis Ababa, Alert hospital has become a critical resource for both men and women affected by leprosy, offering not only medical treatment but also it offers comprehensive psycho-social support to individuals with leprosy, focusing on their mental and emotional well-being. This support includes raising awareness, providing counseling, and facilitating community reintegration programs, all aimed at combating the stigma surrounding leprosy and enhancing the quality of life for those affected.

Modern treatment as opposed to the traditional one is based on approaching from modern way of treatment and scientific evidences. Modern treatment presupposes the treatment of the disease through the use of medicine for the treatment of the disease. The study findings showed that affected women with leprosy visit Alert hospital for their diagnosis as well as for treatment. A research on the modern treatment of leprosy emphasizes the efficacy of multidrug therapy which involves a combination of antibiotics, typically including rifampicin, dapson, and clofazimine in controlling and curing the disease. Furthermore a study by Scollard et al. (2019) assessed the success of MDT, highlighting its role in significantly reducing the global predominance of leprosy.

Many women in this study shared their experiences and opinions about the leprosy treatment they received at Alert hospital, highlighting its role as a vital support system for those battling the disease.

Sosina a 26-years-old affected woman from Amhara region stated the following:

I first visited “Borumeda” hospital which is found in Wollo. Then when I underwent checkup, the hospital informed me that it was leprosy. They referred me to Alert. However, before going to Alert I lost hope and tried to commit suicide once by throwing myself into a river and another time I tried to hang myself with rope. In both cases, people reached and saved my life. Soon after, I came to Alert hospital where I obtained treatment free of charge. The medicine was provided for free and I also received free therapy. The other thing I freely received from Alert hospital was to treat the disease and how to nourish myself. In this regard, I was made aware not to touch hot things, not to go near fire so that I may not suffer another physical disability.

Sosina’s story depicts the emotional and physical challenges faced by an individual diagnosed with leprosy, highlighting key themes of despair, resilience, and recovery. After receiving a diagnosis at Borumeda hospital, Sosina descends into profound hopelessness, leading to two suicide attempts that illustrate the psychological burden of the illness. Yet, community support becomes a lifeline during their healing process, particularly during their transition to Alert hospital. Here, they receive free medical treatment and vital education on self-care, which not only empowers them but also nurtures resilience and personal growth. This experience emphasizes the critical role of compassionate care and community in transforming despair into hope and fostering healing.

Likewise, key informant Mikiyas, a social worker at Alert hospital, also indicates the importance of holistic support to people with leprosy.

The first thing we do beside medical treatment, giving awareness for those affected persons who come to our hospital. As most of the persons who visit our hospital come after facing disability, they lose hope and opt to commit suicide therefore, in

order to avoid such feelings, we provide them awareness telling them that even though they are handicapped they can continue life and move around by using artificial materials.

The idea forwarded by the social worker, is also supported by the nurse working on leprosy at Alert hospital who states:

Annually, up to 3500 new cases come to Alert hospital and receive treatment. Whenever they come to the hospital they receive treatment free of charge. Moreover, we give them awareness as to what care they should take. After they become affected, they may not feel any sensation in their limbs and may not feel burning sensations as well, so we advise them to take care. However, we think that the number of victims is increasing currently. This is evidentiary from the fact that new cases of children are becoming victims and are coming to our hospital presently. No matter how the awareness is given, women are the most affected ones because women after receiving treatment have home responsibilities which include preparing food for their children. While preparing food they are susceptible to burning from fire, hot water and even they walk long kilometers on foot. Not only this, even if there is availability of food the chance of eating is very unlikely. They feed on the leftovers of their husbands and their children. These things aggravate the disease and eventually lead to disability. This is what I experience during treatment and these situations make affected women different from the men.

Alert hospital treats people affected by leprosy annually, offering free care and vital education on self-management to the affected who often lose sensation, leaving them prone to burns and other injuries. Despite these efforts, the hospital is alarmed by a rising number of cases, particularly among children. Women, however, bear the brunt of the disease due to their domestic roles, such as cooking and traveling long distances on foot, which increases their risk of injury. Adding to their challenges, women frequently eat last, often only consuming leftovers, worsening their condition and increasing their likelihood of disability. These gender-specific issues underscore

the profound and unique impact of leprosy on women, distinguishing their experience from that of men.

The Women's Social Affairs Coordinator from Kolfe Keranyo sub-city Woreda 01, with 10 years of experience, explained that to address stigma and discrimination against women with leprosy, they collaborate with stakeholders. One key initiative is the assault combatting committee (3C committee), which includes affected women, religious leaders, village elders, and non-affected community members. The committee works with the police to ensure justice for women who face verbal or physical assault, such as beating and rape, by gathering information and applying for legal action when needed.

Moreover, there is NGO like Addis Ababa Leprosy Victims Rehabilitation Association around Zenebework committed to assisting those affected by leprosy, with a special emphasis on empowering women. It provides a wide array of services, including medical care, vocational training, and psychological support; all aimed at helping women restore their independence and enhance their quality of life. In addition, AALVRA actively promotes leprosy awareness to combat stigma and discrimination, facilitating the reintegration of affected individuals into society. Beyond simply providing initial awareness, the association has a dedicated program to continually expand this knowledge. The organization engages in various advocacy efforts, such as organizing sporting events that promote community involvement and hosting informative meetings. It utilizes various platforms including mass media like radio, television, newspapers, and booklets, to further enhance and spread awareness.

The awareness is not only provided by associations but also by health professionals. However, there is a knowledge gap about leprosy among the health professionals themselves. The idea is further supported by Fikirte, a medical doctor from Armauer Hansen Research Institute (AHRI) working for 30 years in the area.

The reason for the increment in the number of the leprosy affected is attributable to the lack of knowledge about the disease among medical professionals. Even if there is knowledge among the professionals, the number of such professionals with the knowledge about leprosy is very few. This is so because there are different diseases

similar to leprosy. Among such, Vitiligo, Psoriasis, Leishmania. Therefore the health professionals may fail to provide accurate diagnose properly. Owing to this, the knowledge gap is observed not only among the affected but among the health professionals as well. The second reason for the increase in the number of affected persons with leprosy is the replacement of vertical leprosy control program by the horizontal one which is at work currently. Vertical leprosy control program promotes giving awareness and diagnosing by going door to door, market centers, shades, prison centers and schools. However, the horizontal leprosy control program limits the awareness to hospitals. This leprosy control program is believed to have played a role in increasing the number of affected individuals with leprosy.

According to the respondent, the rise in leprosy cases is also linked to a concerning lack of awareness about the disease among healthcare professionals. Although some medical workers have a basic understanding of leprosy, there is a striking shortage of those with specialized expertise. This problem is further complicated by the presence of other skin conditions such as vitiligo, psoriasis, and Leishmania that can easily be confused with leprosy. As a result, healthcare providers often find it challenging to make accurate diagnoses, leading to critical gaps in support for the affected. This lack of knowledge not only leaves leprosy affected untreated and uninformed but also underscores a significant challenge within the medical field, highlighting the urgent need for improved training and education on leprosy to enhance overall healthcare outcomes. Moreover, the transition from a vertical leprosy control program, which actively promoted awareness and conducted door-to-door diagnoses in community areas, to a horizontal program that restricts awareness efforts to hospitals, is reported as a key contributing factor. The vertical program's more proactive strategy, which involved outreach in schools, prisons, and markets, was more effective in early case detection, and its discontinuation has resulted in an increase in undiagnosed or late-diagnosed cases.

Overall, different associations provide awareness for those affected with leprosy. However, the awareness is provided after they encountered disability. Therefore, there remains knowledge gap between those awareness providers and the affected women. The presence of the knowledge gap is observed from the collected data as well as the majority of the affected women neither know

the cause nor the transmission. According to the social worker, this is so because the awareness focuses on the non-affected surrounding the study area. Moreover, the awareness creation program is often emphasizes completing reports and securing funding, rather than centering the needs of those affected by the disease. On the other hand, the data collected from health professionals shows that there is also a knowledge gap about leprosy among the health professionals themselves.

Material support

Alert hospital offers essential material support to individuals affected by leprosy, addressing their medical needs. This support includes providing protective footwear, mobility aids, and wound care supplies, which are vital for preventing complications like ulcers and disabilities.

Wibit from Tigray region forwarded the support she got as follows:

When I first came from my birth place to Addis Ababa Alert hospital, I not only received medical treatment, but I also received food, bed, Vaseline, paraffin used to soften my sore and shoes which perfectly suits me. All these were provided free of charge by the hospital.

Providing physical supportive materials is also another way of treating the affected persons. The second key informant, social worker Habtamu from Alert hospital, has stated the following regarding the subject matter.

We give them physical supportive materials for instance, if the affected feet are amputated, we provide with crutch, and wheelchair. All the treatments in Alert hospital are for free including the above mentioned materials. However, with regard to shoes, we charge them 20 birr to create a sense of belongingness and so that they should not develop sense of dependency and in order for individuals use the shoes properly and come and ask if the shoes are worn out.

In the discussion about the material support offered by Alert hospital, the social worker highlighted that while affected individual receive crucial items like crutches and wheelchairs at no cost, they are required to pay 20 birr for shoes. This nominal charge serves several important

purposes: it cultivates a sense of ownership among the affected ones, reduces dependency, and promotes responsible use of the shoes. The social worker's observations underscore the hospital's commitment to not only providing physical assistance but also empowering them in their journey toward rehabilitation.

In support of the above issue, the key informant, a medical doctor from Armauer Hansen Research Institute, added the following idea:

Alert hospital was primarily established to treat affected persons with leprosy. Armauer Hansen Research Institute was founded to engage in research on leprosy. Therefore, there are both treatment and research work. With regard to treatment there are medicines, physiotherapists, machines, and all the necessary materials. Our doctors participate in various researches on leprosy. Hence we think that everything necessary for the affected is available here. The department is different to the other departments as it provides treatment free of charge.

The above quote highlights several key themes regarding the mission and operations of Alert hospital and Armauer Hansen Research Institute. It emphasizes the hospital's primary purpose of providing specialized treatment for the affected, supported by the research initiatives at the institute aimed at enhancing understanding and treatment of the disease. The comprehensive care offered at the hospital is also underscored, featuring a variety of resources, including medications, physiotherapy, and essential medical equipment. Importantly, the availability of free services distinguishes the leprosy department from others, showcasing a strong commitment to accessibility and support for affected individuals. Collectively, these themes reflect a holistic approach to leprosy care that combines effective treatment with ongoing research to enhance good outcomes.

Besides a social safety net and reform officer who works for 6 years from Woreda 01, Woman and Children Association Affairs office said the following regarding material support provided to leprosy affected at Alert hospital.

Whenever the affected are encountered with health problems, we facilitate free health insurance card by conducting discussions with health bureau and health

centers so that they can visit Alert hospital and receive free medical treatment using the free health insurance card. In addition, if need arises for other materials like wheelchair we will also provide them.

The health insurance card scheme primarily targets individuals affected by leprosy, but it also extends support to individuals with other health conditions, thereby broadening access to essential healthcare services for a wider population. This free health insurance card enables the affected to receive medical treatment at Alert hospital without any direct costs, covering everything from consultations and medications to necessary medical equipment like wheelchairs. Currently, thousands of individuals benefit from this initiative, highlighting its effectiveness in reducing financial barriers and promoting health equity. By collaborating with health bureaus and local health centers, the program ensures that those in needs can readily access the services offered by Alert hospital.

The services mentioned above are provided for all affected persons with leprosy. Nevertheless, there are situations where affected women are prioritized. According to the information gathered from the second social worker Habtamu from Alert hospital, the hospital places a strong emphasis on supporting affected women, especially those who are breastfeeding. The hospital recognizes that frequent visits are often not necessary. For instance, when it comes to providing shoes, the hospital ensures that lightweight, attractive, and well-fitting pairs are ready in advance, allowing these women to avoid long waits. This thoughtful approach enables affected women to receive their essential items quickly and efficiently.

Affected women get priority not only in receiving treatment and receiving materials assistance, but they also get priority in being empowered, in getting skill training, job opportunity based on their types of disabilities. The kind of disability determines the kind of job they hold. For instance if their hands and feet are not affected by the disease they open beauty salon shops, or take up sewing clothes according to the informant from Woreda 01.

The general and program manager at Addis Ababa Leprosy Victims Rehabilitation Association, as a key informant, highlights why women affected by leprosy are given priority in receiving support from their association.

The affected men in our association outnumber the women because women often remain unseen in public, limiting their access to information and preventing them from becoming members. In contrast, men are more likely to receive information and join the association. Women face additional challenges, including cultural attitudes and the compounded burden of disability, which makes their situation more complex. To address this, our association prioritizes women affected by leprosy by providing direct assistance, clothing, other materials, financial support, and opportunities to enhance their economic capacity. When advocating for members' rights or allocating resources, women receive special attention for instance, the majority of financial assistance is directed toward them. This ensures that despite their lower numbers, women are the primary beneficiaries of our support.

The quote highlights several sub-themes concerning gender disparities in the association's approach to people with leprosy. First, it notes the significant representation gap, with affected men outnumbering women due to societal barriers that restrict women's visibility and access to information and consequently membership to the association. This lack of exposure prevents affected women from joining the association, leading to increased isolation and exclusion from important benefits. Secondly, the quote highlights the dual challenges that women encounter, as their disabilities intersect with cultural attitudes referring to patriarchal system, resulting in a complicated array of obstacles that impede their empowerment. In response, the association focuses on supporting these women by offering direct assistance, including clothing, financial support, and resources designed to improve their economic situation. Importantly, the association makes sure that most of the financial aid goes to affected women, demonstrating a dedicated effort to tackle gender inequalities.

Moreover, women affected by leprosy are assigned with different leadership responsibilities. According to the general and program manager at Addis Ababa Leprosy Rehabilitation Association, affected women have not had leadership responsibilities for a long time. However,

these days the association has accommodated such women in different parts of the association with various responsibilities. Among such responsibilities they are represented in the general assembly of the association and made members of the board of the association.

Lastly, the study findings reveal that there are two types of treatments: traditional and modern. Affected women tried to get healed by traditional way of healing which was really unsuccessful. Nonetheless they finally opted to get the modern treatment which has different dimensions. After failing with the traditional treatment, the affected women faced a number of challenges to reach the modern medical treatment. The modern treatment treats not only with medicine but there are different services which incorporate getting food free of charge, supportive materials used to support their disabilities. Additionally awareness programs are offered to avoid further psychological harm.

4.2.3. Adverse effect of leprosy on the health of affected women

The adverse effects of leprosy on women's lives are various, impacting their physical health, mental well-being and social status. These effects vary based on factors such as age, disease severity, and education. Younger women may struggle with health issues and societal pressures related to marriage and motherhood, while older women face more intricate health problems and less support. The severity of disability from leprosy can lead to greater social and economic isolation, particularly for those with advanced conditions. Additionally, educational background affects women's access to information and resources, as well as their ability to advocate for their own care. Understanding these differences is essential for addressing the unique needs of women affected by leprosy.

In the same manner, studies show that leprosy triggered by the bacterium *Mycobacterium leprae*, mainly affects the skin, peripheral nerves, and mucous membranes, paving the way to serious health difficulties if not treated at all. One of the most known adverse effects is nerve damage, which can result in a loss of sensation, mostly in the extremities such as the hands and feet. This makes individuals susceptible to injuries, burns, and infections that may go unobserved, ultimately guiding to ulcers, deformities, and in grave cases, the loss of fingers and toes (Britton

& Lockwood, 2004). Additionally, leprosy can result in blindness due to complications like corneal damage and chronic inflammation of the eye (Saini et al., 2019).

Moreover, the adverse effects of leprosy on the health of the affected women vary from woman to woman. Meseret said that:

I didn't get medical treatment on time therefore, the disease ended up in the deformity of my feet. It didn't stop here but the deformity included my hands as well. At the same time I also lost my sight. I also faced hearing disability. I mean I have encountered partial hearing incapacity as a result of the disease. Moreover, I once got sick with tuberculosis. The medicine given to heal the disease had also other negative side-effects. In my case, the medicine brought about gastric illness.

The quote clearly demonstrates the escalating impact of leprosy, revealing how delayed medical intervention resulted in several severe disabilities. The individual's account emphasizes the progression from deformities in the feet and hands to more serious conditions, such as loss of vision and partial hearing loss. The severity of disability and the presence of additional illnesses intensify the difficulties encountered, underscoring the importance of addressing both the primary disease and any related conditions.

Bekelu has also told the effect of leprosy on her health in the following way.

I lost my feet. My hands are deformed. The other is my nose is also deformed. Additionally, the disease had left some cuts in parts of my ears particularly on the edges of my ears. These are the observable health effects. However, there are unobservable health effects caused by the disease. These include permanent headache, loss of sleep, which was finally treated after I went to the hospital and took the medicine.

The above statement illustrates the profound physical and psychological impact that leprosy can have on an individual. The visible symptoms such as the loss of feet, deformities in the hands, a disfigured nose, and cuts on the ears demonstrate the severe physical disfigurement caused by the disease. Additionally, the interviewee draws attention to the less visible but equally harmful

effects, including chronic headaches and insomnia. These unobservable symptoms highlight the often-overlooked mental and emotional challenges associated with leprosy. The reference to seeking hospital care and receiving medication underscores the critical role of accessible healthcare in addressing both the physical and psychological aspects of the disease.

This individual experience reflects the broader patterns observed in the study where 13 out of the 15 respondents reported similar observable physical disabilities and deformities, along with unobservable harms that were revealed through detailed interviews.

5. Social Experiences and Institutional Access of Women Affected by Leprosy

Affected women navigate complex relationships within their families, neighborhoods, and workplaces, often facing stigma in these contexts. This section also investigates how women affected by leprosy access and receive treatment through both public and traditional institutions. It addresses the challenges these women encounter, such as barriers to accessibility and societal attitudes.

5.1. Loss of family support and stigma

A diagnosis of leprosy frequently leads to a breakdown in family support systems. This deterioration can stem from factors such as stigma and fear surrounding the disease, which often causes family members to withdraw from the affected individual. As a result, the emotional and social support typically offered by families may decline or disappear entirely, leaving those affected feeling isolated and vulnerable as they navigate the physical and psychological challenges posed by the illness. This underscores the wider implications of leprosy, affecting not just health but also personal relationships and family dynamics. According to the findings of this study, the loss of family support does not end in isolating the affected women from social gatherings and events but it extends to the materials they use. Further the stigma which brought about the loss of support goes to the extent of wishing death for their off-spring.

Likewise, a study by Brakel (2006) indicated that the loss of family support stems from the effect of the disease. The loss of family support and the associated stigma are the well-known

challenges faced by the persons affected with leprosy including women. Rejection and isolation from the family for fear of transmission and societal abuse are the most common practice faced by the persons affected with leprosy. The rejection and isolation ends up finally in exclusion of themselves from the family as well as from the society and making the reception of medical treatment much more difficult. In addition a study by Rafferty (2018) looked at how leprosy-related stigma leads to isolation and rejection, with many individuals losing the support of their families due to fear and misconceptions surrounding the disease.

Regarding the relationship and loss of family support, Yeshe narrated her story as follows:

The relationship I had with my family was the worst. They didn't even take me to health centers for fear that if they go with me they might contract the disease. The other thing is they give me food but they don't allow me to eat with them. Moreover, they don't even eat food on the same plate I used and don't even touch the item with their hands. I wash the feeding utensils myself. They even don't touch with their hand the clothes I wear. I sleep alone. Regarding decision making, on family matters, I didn't have any say in family affairs. They always regard me as inferior. I don't know they gave me less respect than a dog. "Dogs are better respected" than I was. For your surprise, there was Saint Mary church in front of our house in Wolliso. My mother and I used to go to this church. I just stand and wait for her in the very nearby place just some inches from her. She talks alone begging her creator to kill me rather than seeing me cut my legs and hands. She would like to see my burial as she would be relieved instead of seeing the community changed the attitude towards her. She would pay what we traditionally call "Silet" if I die. So there is nothing surprising if any other person hates you because my own mother hated me. I have lots of relatives in Addis around Zenebework. They are my brothers but none of them dared to approach me. They don't want to have relationship with me even after I settled here.

The participant's statement expresses feelings of isolation and abandonment resulting from leprosy diagnosis, highlighting the profound effects of familial and societal stigma. The interviewee portrays a family environment marked by fear and rejection, where relatives avoid

seeking medical help due to fears of contagion and enforce rigid boundaries that strip them of basic dignity, such as eating alone and having to clean their own dishes. This treatment illustrates themes of inferiority and dehumanization, with the participant feeling they are regarded as less valuable than an animal. Furthermore, her mother's wish for her death to relieve her shame further emphasizes the intensity of this stigma, indicating that the participant's presence is perceived as a burden. Additionally, the lack of support from nearby relatives underscores a widespread societal exclusion.

Regarding rejection and isolation as well as hatred by the family, the same woman has narrated another affected male's story which is even much worse than her.

There was a man affected with leprosy whom I know in the nearby. He was highly affected by the disease and his legs and hands were incapacitated. After he received treatment from Alert he went back to Wolliso where his family resides. As he got back he faced isolation from his family and they made him a separate hut. He started living there alone and his mother takes food for him. In the meantime his sister and brother were plotting to kill him by burning the hut down during night. However, his mother heard their conversation. Afterward his mother told the man what she heard and advised him to escape before he got burnt with the hut. He soon left Wolliso and started living around Zenebework area until now.

This quotation highlights that rejection and isolation begin at home, as it is reflected in separating common household items that is used by those affected with leprosy. This rejection is multi-faceted and in some cases, can escalate to extreme actions, including plots to harm those affected. Both men and women experience this rejection and isolation; however, women's situations are particularly challenging due to societal gender roles, which add to their burdens. Women face the dual challenge of being marginalized due to their gender and the expectations placed upon them in the division of labor. Additionally, the complexity of their circumstances is exacerbated by the physical disabilities associated with the disease, making their lives considerably more difficult compared to men affected with leprosy.

Regarding rejection and isolation from the family another affected respondent from Sadan Sodo, Oromia region remembers her story of rejection and isolation as follows:

The relationship I had with family members and relatives was not good. My brother used to insult me telling me that I am the only unique person among the family. He insults me saying "Komata". He tells me that because of me they are not able to get married.

The quotation shows that an affected woman rejection starts from family members. The participant remarks convey a profound sense of conflict within the family and personal anguish linked to their leprosy diagnosis. The brother use of the term "unique" in a derogatory manner indicates that he perceives the participant's condition as a source of shame or a burden. By referring to her as "Komata," which is a derogatory term employed in Ethiopian communities to describe individuals affected by leprosy, he reinforces societies negative perception and exclusion of the women due to her illness. It carries connotations of stigma, dehumanization, and social exclusion, revealing the entrenched biases against those with the disease. This term suggests that affected individuals are not just marginalized but also perceived as inferior and unworthy of social acceptance, profoundly affecting their self-esteem and interpersonal relationships. Furthermore, the claim that the participant's presence hinders the family's prospects for marriage underscores a wider societal stigma surrounding leprosy against people with stigma and their family members, suggesting that the participant is viewed not merely as someone with a disease but as a liability that threatens family honor and social reputation. This situation illustrates the significant emotional impact of stigma on relationships, as the affected individual encounters blame and ridicule instead of support. Ultimately, the statement emphasizes themes of rejection, shame, and the damaging effects of societal perceptions on family dynamics.

Additionally, Hiwot who is affected by leprosy from Gondar, Amhara region said the following about rejection and isolation from her family:

My family did not know about leprosy. Due to the lack of knowledge they used to insult me saying "yihechi Ekekam". They isolate me saying or using such isolative words. My family when they give me "Injera" I had to eat alone. I even slept alone.

At that time there was no mattress and I used to sleep on something like a table called Zeng. Moreover, they don't even wear my clothes. Even when they asked me to carry my younger siblings, I had to wrap them in multiple layers of cloth to avoid transmitting the disease. Therefore the relationship I had with my family was bad. They think that the disease itself would run on foot and catch them. Hence, they even don't talk with me.

The narration highlights the significant disruption to her ability to fulfill key family duties due to her leprosy diagnosis. The word yihechi Ekekam is a derogatory term used in a local context to describe someone as untouchable or filthy. It conveys a strong social stigma, often associated with ignorance about contagious diseases such as leprosy, contributing to the isolation and emotional abuse faced by the affected individual. The enforced isolation being required to eat and sleep alone and having her clothes shunned reveals the deep-rooted stigma that permeated their family relationship. Although the participant was still expected to carry out tasks like caring for her younger siblings, these duties were heavily influenced by fear and misinformation, resulting in excessive precautions aimed at avoiding perceived contagion. The family's lack of knowledge about leprosy led to a breakdown in communication and support, further alienating the participant and limiting her involvement in family responsibilities. This emphasizes the severe emotional and social impact of stigma, especially in its ability to disrupt core family relationships and duties.

Likewise, Mihret from Merabete, Amhara region narrated her rejection and isolation from her family in the following way:

The relationship I had with the rest of my family members was not good. After I caught the disease, I used to eat alone and sleep alone as well. One day they took me to the "Tsebel" (holy water) where I don't know the place, they left me there warning me that I should not return home until I get cured. They left me there and went home. Then I didn't return home. I met someone at the "Tsebel" place who told me to go to Addis Ababa in order to get medical treatment. Sooner I didn't waste time I left the place and came to Addis. Even after I received the medical treatment my family did not want me. They didn't watch out for me.

The quote illustrates the central idea of abandonment and the profound loss of both home and family support after being diagnosed with leprosy. The family's decision to isolate the woman, forcing her to eat and sleep apart, marked the start of a deepening rejection. Their choice to take her to a holy water "Tsebel" and abandon her there with the command not to return until healed, symbolized a complete severing of ties. Left to navigate an unfamiliar environment alone, she had no choice but to seek medical treatment in Addis Ababa without any support from her family. Even after receiving treatment, her family's continued refusal to welcome her back highlights a deep and painful loss not just of a physical home, but of the vital emotional and social support that family should offer. This narrative exposes the destructive impact of stigma and fear on family bonds, leading to a profound sense of abandonment and a loss of belonging for the affected individual.

The significance of loss of family support and its impact is also reiterated by doctor Fikirte from Armauer Hansen Research Institute.

Discrimination and stigma start from family. For instance, let me tell you what I came across the day before. There was a girl from rural area and was affected by leprosy. Her father after buying rope went to the bush and told the girl to tie the rope on a tree and to commit suicide because her family was being abused by the community. Because of her illness, the rest of her siblings were unable to get married. While the man was taking this action the mother of the girl who was at the nearby place helped the girl to escape from that community and saved her life by coming to our hospital.

The study findings from the quotations show that there is a high rejection and isolation from the family before and even after the diagnosis. This is illustrated in the quotations, which shed light on the emotional and social ramifications of stigma within family dynamics. Among the 15 women interviewed, 11 indicated that their relationships with family members are strained or non-existent, highlighting a widespread atmosphere of discrimination. Such rejection takes many forms ranging from emotional neglect to social exclusion and results in a significant lack of support during critical times. These findings imply that stigma not only undermines the affected

women's self-esteem and mental health but also disrupts the essential family bonds that are meant to offer care and protection.

5.2.Loss of community support and stigma

Neighborly relationships form the foundation of community life, offering a blend of emotional, social, and practical support that nurtures a deep sense of belonging and security. In Ethiopia, where communal ties run especially deep, neighbors are fundamental in daily life, providing help in times of need and ensuring that everyone is included in important social gatherings like holidays, weddings, and funerals. For women affected by leprosy, the loss of this vital support is particularly devastating, as it amplifies their social isolation and heightens their vulnerability. The stigma surrounding leprosy often leads neighbors to distance themselves, causing the exclusion that may begin within the family to extend outward into the broader community, further isolating these women. This not only deprives them of the practical help neighbors usually offer but also cuts them off from the crucial social connections that are essential for their well-being and sense of self.

The loss of neighbors support considerably influences individuals with leprosy particularly women aggravating their social seclusion and susceptibility. In many communities, mistaken beliefs and deep-rooted fears about the transmission of the disease compels neighbors to reject those affected with leprosy. This ostracism is especially severe on women, who most of the time depend on their social network for psychological and material support. The social stigma attached to leprosy ends up in women being segregated from communal activities, traditional institutions and deprived of assistance, increasing their feelings of loneliness and helplessness.

Moreover, the lack of neighborly support can hinder access to healthcare and economic prospects, vital for handling the disease and sustaining livelihoods (Cross & Choudhary, 2005). Concerning the matter here is the different affected women's idea narrating the loss of neighborly support. Among such women Mihret expressed her idea in the following manner.

When I was in “Merabete” I had the worst relationship with my neighbors because even for holidays, they never extended invitations tome. They even don't consider me as human being. They rather opt to ask me saying “where did you get this disease

from or where did you buy it from”? Even if I was invited to go by one of my neighbors, I would totally reject the invitation because I had injury in my hands. Whenever I take the “Injera” in to mouth, they just look at my hands and when the “Injera” falls from my hands they laugh at me. Therefore I do not go when I am invited to events. There is no one who helps me other than having negative attitude towards me. However, after I came to Zenebework, I met people who were like me and I started exchanging conversation, chatting with them and the relationship is better here in Addis Ababa.

The quote underlines the deep psychological toll that stigma and mistreatment inflict on individuals affected by leprosy. The respondent shared how her neighbors in her place of origin not only excluded her from social activities like holiday gatherings but also dehumanized her with cruel remarks, questioning how she contracted the disease. This harsh treatment generated intense feelings of shame and humiliation, severely damaging the respondents’ self-esteem and leading her to withdraw from social interactions, even when invitations were extended. However, after relocating to Zenebework in Addis Ababa, things have gotten better because there are a number of women affected with leprosy. This shift in community enabled her to rebuild her social ties and regain lost confidence by freely exchange her idea with hercommunity members. She can get the psychological and material support she was deprived of when she was at home in the countryside. Generally, the quote illustrates how negative attitudes and exclusion from neighbors can drive individuals into social withdrawal, while a more supportive and inclusive community can be a powerful force for healing and belonging.

Due to the pervasive stigma from neighbors, women affected by leprosy are often excluded from important social events like weddings, feasts, and funeralsfurther shrinking their social circles. Accordingly, Sosina narrated her story as follows:

When I was in my hometown Desse, the relationship I had with my neighbors wasterrible as the community was very discriminatory. For instance, when I go to wedding and eat “Injera” people just look at my hand and then the “Injera” in my hand will fall from my hand with fear. Then they come and ask me as to what my hands are and further asks me where I brought the disease from. At this point, I feel

inferiority and I exclude myself and stay indoors. I neither go to mourning nor wedding. Nevertheless, after I came to Addis Ababa, most of my neighbors are affected with the disease and if they invite me to their home I will go. Even here around Zenebework area, those that are not affected by the disease have better attitude towards leprosy and towards the affected persons.

On the other hand Getenesh narrated what she encountered in the following manner:

When I was in Sodo, the relationship I had with my neighbors was very bad. People insult me saying “Komata” they even insult my lineage using this word. My brothers and sisters even insult me taking the community as a bad example. Here in the surrounding Zenebework, the people residing are persons affected with leprosy therefore, there is some discrimination and stigma but it is much better than the one in my hometown. Here, we invite each other during holidays, we chat together we eat together. I have even better relationship with those non-affected persons here. I remained here around Zenebework and I couldn't go back and attend the funeral ceremony of my father and mother because of the negative attitudes of the community. Not only this, when I sent my daughter to my home town to attend the funeral ceremony of my family, they insulted her saying here comes the daughter of that “Komata” woman. Imagine if they insult her being non-affected, it is not that difficult to assume what they would say to me. Consequently, I preferred to stay here and opted not to move anywhere.

The quote illustrates the deep effects of stigma and discrimination on the affected woman's relationships and sense of belonging as well as their family members. The use of the word “Komata” suggests that affected individuals are not just marginalized but also perceived as inferior and unworthy of social acceptance, profoundly affecting their self-esteem and interpersonal relationships. The prevalence of such language underscores the wider societal attitudes toward leprosy and the significant challenges that those living with the condition and their immediate families encounter. In Sodo, she faced intense ostracism from neighbors, enduring not only insults about her condition but also attacks on her family lineage, underscoring the entrenched societal biases against the condition. This mistreatment affected her immediate

family, her daughter as well, demonstrating how stigma can erode familial bonds. In contrast, moving to Zenebework provided her with a more nurturing community of individuals who share similar experiences, fostering a spirit of camaraderie through communal meals and celebrations.

Hence, the data shows that for all of the women living with leprosy the relationship tends to get better when they relocate to Zenebework area. Additionally, there is better relationship with individuals who are not affected by leprosy residing in and surrounding Zenebework neighborhood. This is so because awareness work has been undertaken around the area. Yet, despite this supportive environment, the lingering scars of her past keep her from attending important family events, like her parents' funerals, due to the fear of humiliation and continued stigma. The hurtful remarks directed at her daughter highlight the intergenerational impact of discrimination, suggesting that the effects of stigma extend beyond the individual to affect their immediate family members as well.

On top of the above story Yeshe from Wolliso stated the following:

In Wolliso, no one acknowledged me as a human being. My neighbors insulted me, asking where I got the disease and calling me “Zer Asedabi,” meaning “someone who gives a bad name to the family.” They told me to leave, so I decided to move to Addis Ababa and settled in Zenebework. However, the community’s attitude there hasn’t changed much. When I revisit Wolliso, I still find the culture isolating, with unchanged perceptions about the disease. In Zenebework, I interact with affected neighbors, and we share daily struggles, borrowing items when needed. Most residents here live in poverty, which limits our quality of life. Relationships with affected individuals are better than those in Wolliso. However, I avoid non-affected people, fearing insults if conflicts arise. As a result, my social interactions remain limited to others affected by the disease.

The quote provides important insights into the support networks for individuals affected by leprosy, illustrating the sharp contrasts between the respondent's experiences in Wolliso and Zenebework. In Wolliso, she faced deep isolation and dehumanization, as neighbors not only disregarded her humanity but also subjected her to taunts calling her “Zer Asedabi”. The term

"Zer Asedabi" reflects Ethiopia's entrenched social hierarchy, where discrimination based on lineage denies people certain rights and status. It symbolizes exclusion that continues to shape community interactions. Labeling women with leprosy as "Zer Asedabi" underscores their double marginalization, as they face both the stigma of their illness and ancestral biases, deepening their isolation and limiting their access to healthcare and social acceptance. This hostile atmosphere compelled her to seek a more supportive environment in Addis Ababa. Although she found some sense of connection in Zenebework, where shared struggles foster a bond among those affected, the specter of stigma still looms large. The respondent's acknowledges that her social interactions are primarily with others who share her experiences, driven by a fear of rejection from those unaffected. This highlights the complex dynamics of social relationships shaped by stigma, showing how the desire for acceptance and support leads individuals to seek help among those who truly understand their challenges, even as economic difficulties affect everyone's quality of life. Ultimately, the quote captures the ongoing struggle for dignity and a sense of belonging in the face of societal prejudice.

In addition Kalkidana 15-years-old affected girl from Motta, Amhara region added the following:

When I was in the province, I had no relationship with the neighbors because I was unique. I felt afraid of insults that may come from them. Hence, I stayed indoors. However, when I came with my father for medical treatment, as there was no lodging, when we went to get accommodation, the receptionist at the hotel looking at my hands told me that I could not rent the bed and chased me away. But she was more than willing to rent the bed to my father alone. So, we went together to find another bedroom.

The quote depicts the severe social isolation and discrimination faced by a person with leprosy. In the countryside, people with leprosy avoided neighbors due to fear of rejection, leading to self-imposed isolation. This stigma persists in the city, where they are denied accommodation due to their appearance. This situation highlights the challenges women with leprosy encounter in accessing services and the widespread stigma that isolates them.

Most of the relationship of women with leprosy had in this study is largely negative. However, there are cases where the relationship between people with leprosy and the community is positive. An example of such relationship is described by Wibitas follows:

I do not remember the relationship I had with my neighbors in my place of origin as I was a child. However, Zenebework is our territory. I mean most of the residents are composed of people affected with leprosy. The non-affected ones even come to our neighborhood and it is not just us who go to their dwellings. On holidays, we call each other, we borrow utensils. For instance, when I don't have "Injera" I just borrow from my non-affected neighbors and by the day I make "Injera" I return the "Injera" I borrowed. I participate with community members in local associations but I don't get special support or treatment from my neighbors because of I have leprosy.

The quote reveals the distinctive dynamics of community and belongingness in Zenebework, where many residents are affected with leprosy. The respondent conveys a strong sense of ownership over their neighborhood, observing that non-affected individuals come into their area rather than the other way around. The practice of borrowing items, like utensils for making "Injera," cultivates a spirit of solidarity and belongingness among neighbors, showcasing the cooperative nature of the community.

Likewise, Senayit who has good relationship said the following:

I can say I have good relationship with my neighbors. We call each other any day to chat together. I am serving in the leadership position in the local association. I carry out my work and I don't get any special support or treatment from my neighbors.

The quote highlights the speaker's favorable view of their relationships with neighbors, emphasizing a strong sense of community and connection. They engage in frequent conversations and interactions that cultivate camaraderie among them. Her role in a leadership position within the local association reflects a proactive commitment to community involvement. The respondent's focus on personal responsibility demonstrates resilience and independence but

also highlights a potential shortcoming in the community's support network for those who may need extra help.

The two quotes tell us that there are positive cases of good relationships and interaction among people affected with leprosy and their neighbors. However, such cases are insignificant when compared to the negative relationship.

The study findings show that there are two different stigmas. The first one self-stigma emanates from the affected women themselves. According to Corrigan and Watson (2002), self-stigma is the process by which individuals with a stigmatized condition absorb and accept society's negative views, leading to feelings of shame, low self-worth, and reduced self-esteem. They exclude themselves from neighbors in particular and from the community in general. This preclusion may come from the fear that the affected women might be insulted by their neighbors or by the community at large. The second exclusion stems from the insult that comes from the community, social stigma. Social stigma involves the unfavorable attitudes, beliefs, and actions aimed at individuals or groups who are seen as different or unworthy by the larger society (Link & Phelan, 2001). That is the community excludes or segregates the woman affected with leprosy from community activities.

Accordingly, the study findings indicate that only a small number of women affected by leprosy (2 out of 15) reported having positive relationships with their neighbors, while the majority faced negative interactions. Specifically, 7 out of 15 women experienced negative relationships primarily due to the stigma from their neighbors. Additionally, 6 out of 15 women withdrew from social interactions due to self-stigmatization. Despite these challenges, the findings reveal that relationships with neighbors in Zenebework, including those with non-affected individuals, are generally better compared to their place of origin. The improvement is attributed to cultural factors and awareness-raising programs that have led to greater acceptance within the community. This does not mean in any measurement that there is no stigma but the stigma becomes lesser when the women came to Zenebework.

5.3. Marginalization in marriage against women affected with leprosy

Women affected by leprosy often experience deep marginalization before and within marriage due to inherent societal stigmas. The stigma is encountered before and after marriage. The stigma before marriage is caused from the long-lived and deep-rooted wrong belief about the disease. Before marriage, the stigma surrounding leprosy often surfaces as discrimination in partner selection, with misconceptions leading to restricted courtship opportunities and social rejection. Consequently, women affected by leprosy may experience feelings of isolation and diminished self-worth, which can hinder their confidence and desire to seek out relationships. The latter one is restricted to partner selection and courtship prior to the marriage. The stigma in turn, results in the abandonment of women affected by leprosy by their partners, which further deprives them of their rightful share of marital property. To cope with these challenges, many affected women choose to marry others who share similar experiences, creating a sense of solidarity and mutual understanding.

In the same vein a study conducted in India, by Kumar et al (2021) examined the experiences of women affected by leprosy, showed that affected women with leprosy often experience deep marginalization before and within marriage due to inherent societal stigmas. Before marriage women with leprosy encounter refusal and omission from potential marital prospects, as leprosy is considered as a hereditary blasphemy and impurity. This stigma leads to complications in finding a spouse, with many women being either denied absolute or forced into marriage with substantial power imbalances. Once married the marginalization remains, as these women are often divorced or subjected to abuse by their spouses. The social isolation they face paves the way for another continued marginalization as they are often seen as a burden both by their family and society.

To illustrate this experience, Getenesha 35-years-old affected woman narrated her story of marginalization among married women with leprosy as follows:

My husband and I were not affected when we first got married. I contracted the disease when I gave birth to my second child. It was after this that my husband and his family began to isolate me. All the rejection and isolation forced me to leave my birth place without having to share the common property we had as husband and

wife. Nonetheless, he has married another woman with the property we acquired together. Now I am facing hardship along with my child here in Addis Ababa.

The isolation and rejection extend to her husband and her in-laws. This kind of rejection even deprives women with leprosy the rights to share the common property acquired during the marriage intensifying their vulnerability. Moreover, the weight of this rejection frequently drives women like Getenesh to leave their home community, adding another layer of complexity to challenging circumstances.

Likewise, Wibit from Tigray remembered her marriage relationship:

It wasn't difficult for me to find a partner because my partner also had the disease. My disability wasn't too severe, and there was a non-affected person interested in marrying me. However, I hesitated to marry him because I feared that if we ever had a falling out, he might insult me. I was also concerned that he might abandon me after I gave birth to children. That's why I chose to marry someone like myself. Additionally, since my child is not affected by the disease, I would be happy if my son married a girl from a similar background. As a parent, I want to protect him from the stigma of being insulted as the son of a "Komata". Therefore, it is better for him to marry someone who shares the same condition.

The quote highlights the complex dynamics of partner selection among women affected by leprosy, emphasizing her need for safety and empathy in their relationships. The respondent chooses to marry someone with the same condition to shield herself from the stigma and emotional risks associated with marrying a non-affected partner. Her concerns about potential insults and abandonment after childbirth reveal her vulnerability in the face of societal expectations. Furthermore, her wish for her son to marry someone from a similar background showcases her protective instinct against the stigma of being labeled a "Komata." This illustrates how stigma influences family dynamics and relationship choices, promoting a preference for connections within the affected community to foster emotional security and mitigate the likelihood of social rejection.

Yeshe added about marriage relationship the following:

I was asked by a non-affected person for marriage since my disability was not that much serious. However, I feared that he might insult me when we have some misunderstanding and feared that his families might not be willing to accept our partnership. I thought about my future life beforehand. I was pessimistic if I married such a man what will happen after bearing children. That's what always preoccupied my mind. So, I married a man who had leprosy. I gave birth to one child but the father of my son died after the birth. He passed away as a result of the disease. I am raising my son alone.

The quote highlights the deep-seated anxieties faced by women affected by leprosy when it comes to partner selection and future stability. Although the speaker received marriage proposals from non-affected individuals, her concerns about potential mistreatment and familial rejection led her choosing a partner who also had leprosy, illustrating her need for shared understanding within a stigmatized community. Her apprehensions regarding motherhood and the risk of insults reveal her vulnerability and skepticism toward relationships with non-affected partners. After the loss of her husband to the disease, she navigates the complexities of single parenthood while raising a child in a society steeped in stigma.

The above two quotes indicate that women with leprosy tend to isolate themselves even if they are wanted by non-affected persons fearing that if they quarrel with their partner may lead to insults and discrimination. Additionally, they also fear that the family of their partner may not be as accepting their marriage. Furthermore, such fears also extend to the kind of life their children may lead once they become adults.

Similarly, Bekelech a woman with multiple disabilities told her marriage story as follows:

For me, it was not difficult to get partner because he was also affected by leprosy. The non-affected persons are not willing to marry us looking at our bodies. For example in my case since my disability is multiple, the non-affected person did not want to marry me. So, the option I am left with is to marry a person affected with the disease.

The quote implies that when non-affected individuals consider marriage with someone who has leprosy, they weigh several factors like the type, severity, and number of disabilities involved. This highlights how the decision is largely shaped by the visibility and functional limitations of these disabilities. For example, more pronounced or severe disabilities, such as noticeable physical deformities or those requiring substantial care, often carry a higher social stigma and present practical challenges, leading to greater reluctance in marriage decisions.

Likewise, multiple disabilities can heighten concerns, as they may be seen as an added burden or a more complex situation to navigate within a marriage. This underscores a societal mindset where the ease of managing the disability plays a crucial role in determining marital choices.

Concerning the stigma that encounters women affected with leprosy, nurse Zerihun states the next idea:

There exists stigma on both men and women. However, the stigma becomes strong on women rather than men. For instance, in our country the family structure is patriarchal, favoring men and relegating women to a subordinate role. Consequently, even if a woman affected by leprosy has no visible deformities and is fully cured, society continues to label her as having been marked by "kumtina" (a local term for leprosy). This persistent stigma makes it challenging for her to find a husband. From my work experience, I have frequently observed how these women are excluded from marriage prospects because of enduring societal biases. The women are much more influenced by the disease than men because the patriarchal system favors the men rather than women. Additionally, what makes women different from men is that women affected with leprosy during pregnancy experience hormonal change which is natural. However, when the bacteria are added to the hormonal change things get worse and the impact for women may become stronger and far worst.

The above quote sheds light on the profound stigma that women with leprosy face, a stigma intensified by the patriarchal structure of society. While both men and women encounter discrimination, women bear a heavier burden due to cultural norms that favor men and

marginalize women. Even without visible signs of the disease or after being cured, women can still be ostracized and deemed unfit for marriage solely because of their history with leprosy. This deep-seated bias reflects a broader societal pattern where women disproportionately suffer the social repercussions of the disease. Additionally, the quote highlights the unique challenges women face, particularly during pregnancy, when hormonal changes worsen the effects of leprosy, further complicating their physical and social well-being. This interplay of societal discrimination and biological factors greatly intensifies the struggles of women with leprosy, making their experience far more challenging than that of men.

The study's findings indicate that many women with leprosy often choose to marry others with the same condition, driven by societal stigma and fears of future mistreatment from both partners and their families. Even when these women marry individuals with other type of disabilities unrelated to leprosy, they frequently encounter abandonment, sometimes losing marital property, highlighting the economic vulnerability common among marginalized groups. Additionally, the displacement of these women from their communities illustrates the intersection of social exclusion and forced migration, reinforcing the study's findings on the geographic and social isolation faced by those stigmatized due to their health conditions.

5.4. Discrimination against affected women at work places

Affected women with leprosy often face serious stigma in workplace highly influencing their relationship with their work colleagues. Women affected by leprosy who secure employment frequently take on low-paying, informal roles, such as street vendors or small-scale home-based entrepreneurs. Many women opt for these positions as they allow for greater independence, reducing their exposure to the stigma and discrimination often encountered in more formal employment settings. Nevertheless, even in these environments, the visible signs of leprosy like skin lesions and physical deformities can evoke fear and bias from both colleagues and customers, intensifying their social isolation.

Likewise a study by Sarkar et al (2020) demonstrated that the stigma related to leprosy goes beyond direct interactions having impact on the overall insight of a workplace. Work colleagues may avoid relating with affected women with leprosy fearing the social consequences or

believing that the presence of individuals affected with leprosy may harm the good name of the organization.

On the other hand, the fear of discrimination by affected women with leprosy themselves can hinder from seeking employment, further aggravating the social and economic marginalization (Cross & Choudhury, 2005).

With respect to discrimination at workplace Tigista 30-years old affected woman shared her experience as follows:

I want to work but when I go to seek employment, they turn down my question looking at my hands. When I first came from the province, I settled at a place called Sendafab because I did not have any relatives in Addis Ababa or knew anyone in the city. I was living around a mosque and in order to survive I started selling potatoes on the street. I brought potatoes of 1000 birr to sell but the potatoes got rotten because no one would buy them from me. I became inconsolable because once they look at my hands, people refused buying from me. They just change their facial expression when they look at my hands. Then I heard information from people about people with similar conditions like mine vastly reside in Addis Ababa. Then I came to Zenebework.

Tigist's response reveals the entrenched societal prejudice against trading with women affected with leprosy. This prejudice is fueled by visible physical deformities, which mistakenly lead people to believe that the disease can be transmitted through the products or utensils these women handle. Such unfounded fears drive potential customers away, deepening the women's poverty. As discussed in chapter two, intersectionality theory shows that overlapping social identities like disability, gender, and economic status exacerbate stigma and discrimination. Tigist's situation exemplifies this, as she endures increased marginalization and exclusion due to her poverty, disability, and identity as a woman further making her vulnerable to live in poverty. Another participant, Hiwo also stated the following regarding discrimination at workplace:

The people at my workplace had a negative attitude towards me. I was assigned to the task of solid waste disposal, which was physically demanding and often made me

sick. When I tried to rest during work, the supervisors and other workers would tell me that the workplace wasn't a place for rest, and if I needed a break, I should go home. They would harshly ask me to leave, with stern expressions on their faces. Whenever I asked for permission to rest, they would rudely insist that I just do my job, denying me my rights. The discrimination and pressure eventually forced me to quit. There was no special support provided to me at that job. Currently, I work for the Addis Ababa Leprosy Victims Rehabilitation Association, earning 1400 birr per month. I live in government-provided kebele housing because of my illness. Without it, I couldn't afford rent. But the 1400 birr is not enough given the skyrocketing cost of living. Sometimes, I can't even afford a cup of coffee, and I have to borrow 20 birr from someone just to have one. In fact, just before meeting you, I borrowed 20 birr to get a coffee.

The respondent's narrative highlights pervasive themes of workplace discrimination, physical and emotional strain, and financial instability. The harsh treatment and lack of empathy from colleagues and supervisors, particularly the legal rights such as taking rest from the demanding work, reflect deep-seated biases. This discriminatory behavior, coupled with the absence of support or accommodations, ultimately forced the respondent to quit her job. The need to borrow small amounts for everyday needs starkly illustrates the ongoing economic vulnerability she endures.

The study finding shows that 9 out of 15 affected women are unemployed, while 6 are employed. However, even those who are employed did not actively seek higher paying jobs. They face discrimination and are not hired by others. Instead, they are employed by their own NGO, the Addis Ababa Leprosy Victims Rehabilitation Association. This also raises the issue of sustainability of income. In the event of the NGO closing or lack of available funding, employees with leprosy may be without a job further making them vulnerable to economic insecurity. The study also highlights that women affected by leprosy experience severe economic instability, living below the poverty line.

5.5. Access and treatment in public and traditional institutions

This section investigates how women affected by leprosy access and receive treatment through both public and traditional institutions. It addresses the challenges these women encounter, such as barriers to accessibility and societal attitudes.

5.5.1. Transportation services

Misunderstanding about the disease's transmission has led to discriminatory behaviors from other passengers and transportation staff against people discrimination of those having observable symptoms of leprosy. They may frequently encounter avoidance, exclusion, and derogatory words significantly hindering their mobility. These discriminatory practices limit access to essential services like healthcare and employment and reduce opportunities for social engagement and economic mobility. The impact of this stigma is particularly harsh on women, who often contend with additional gender-based barriers, further isolating them and intensifying their economic and emotional struggles. This cycle of exclusion perpetuates vulnerability, making it increasingly challenging for women with leprosy to navigate their everyday lives.

In the same manner a study by Adhikari et al (2013) showed that stigma associated with leprosy highly influences the use and access to transportation for those affected leading to greater social and economic marginalization.

Regarding access to transportation and treatment Yeshe shared her experience as the following:

During the Derg time, we used to use only bus number 7. This bus was nick named as the bus of the "Komatas". We couldn't even use other buses except bus number 7. The non-affected persons would not use the same bus with us because when he or she gets off the bus, and see people with leprosy using the same bus as; they might get insulted saying 'she went with the Komatas'. And eventually they might isolate him or her from the community. Thus, no one except people who had leprosy used bus number 7. Not only that, when the bus passes by, the non-affected persons rigidly fold their hand saying that the bus of the "Komatas" is passing by. But now days, after EPRDF came to power we were made equal with other people. We can use any transport service like any other persons paying the price of the transportation.

The quote highlights important themes regarding the influence of government policies on the rights and social integration of individuals with leprosy. During the Derg era, the exclusive reliance on bus number 7, known as the "bus of the Komatas," exemplified the profound segregation and stigma experienced by these individuals, restricting their access to public transport and subjecting them to verbal abuse and potential ostracism. The respondent's insights into the changes that occurred after the EPRDF came to power reveal the positive impact of government initiatives in fostering equality and mitigating stigma. The newfound ability to use any form of transport represents a significant advancement toward inclusivity, underscoring the essential role of government support in safeguarding the rights and dignity of marginalized communities. Overall, the response highlights the intersection of social stigma, government policy, and the ongoing journey toward equality for individuals with leprosy.

On top of that Ayinadis from Oromia region has to tell the following as to what she faced in accessing public transport.

When I use transport for instance, like taking a bus, the non-affected people look at my hands and my feet and ask me where I was going. When I tell them, that I am going to Zenebework, they tell me that Zenebework is the village of the "Komatas". Soon after, I began to feel bad. When people ask me where I live, I started changing the name of my neighborhood. For example I would tell them I am from Hana Mariam. I used to do this in order to avoid being insulted by people.

The quote underscores critical themes of stigma and identity for those living with leprosy. The respondent describes how her experience on public transportation is tainted by the scrutiny of non-affected passengers, who closely examine her hands and feet and react unfavorably when they mention Zenebework, referred to as the "village of the Komatas." This negative reaction triggers feelings of shame, prompting the respondent to change her village name to Hana Mariam to evade ridicule and preserve her dignity. Such actions reveal a profound fear of discrimination that shapes her self-perception and social interactions, highlighting the significant impact of societal attitudes on her everyday life.

Erving Goffman's theory of stigma and identity, as discussed in chapter two, offers valuable insights into how stigmatized individuals navigate their social environments and how societal

perceptions shape their identities. Goffman posits that those who experience stigma often feel the need to hide their true selves to enable smoother social interactions. Ayinadis's choice to alter her locality when asked about her destination on the bus serves as a clear illustration of this principle. By distancing herself from Zenebework, a place associated with leprosy, she aims to avoid the daily insults and protect her well-being from negative reactions linked to her identity. This deliberate change in her narrative reflects her efforts to normalize her interactions within society, showcasing the lengths to which stigmatized individuals will go to safeguard their dignity and seek acceptance. Ultimately, Goffman's theory highlights both the internal and external challenges faced by those living with stigma, emphasizing how societal attitudes can deeply affect personal identity and social behavior.

Hiwot, who is affected by leprosy, also narrated her access to transport and the treatment as follows:

The discrimination on public transport comes following the kind of disability suffered by people with leprosy. For instance sometimes when people look at my body, some passengers are either afraid or disgust by me. Other times, when I sit beside them and my clothes touch theirs, they will give me a disapproving look and drag back their clothes to their side. They think that the disease can run from me and catch them. Apart from this, I pay the set price to use public transport and I don't receive any special support on the transportation.

The quote highlights the close connection between discrimination experienced using public transport and the specific disabilities associated with leprosy. The respondent describes how passengers often react with fear or disgust, reflecting deep-seated stigma towards visible disabilities. This leads to social isolation, as individuals instinctively distance themselves to avoid contact, driven by unfounded beliefs and lack of knowledge about disease transmission. Despite paying the same price as others, the lack of support or accommodations underscores the inequities faced by those with leprosy and other forms of disability. Overall, this situation illustrates how societal attitudes not only hinder mobility but also contribute to the ongoing marginalization of individuals living with stigma.

On the other hand during the time of my data collection, I have observed that they have the access to transportation like any other person. Such acceptance not only improves their mobility but also facilitates their social integration, helping to challenge and reduce persistent stigma.

To conclude, the study findings for the most parts, shows that women with leprosy face limited challenge accessing transport service. However, there are discriminations based on the type and multiplicity of disabilities as they further away from Zenebework area.

5.5.2. Participation in traditional institutions

This section presents the impact of leprosy on women's participation in traditional institutions like Edir and Equb. Edir and Equb are essential social institutions that play vital roles in community life. Edir acts as a mutual aid system, organizing funerals and providing financial and emotional support to grieving families, while Equb functions as a rotating savings and credit group where members pool resources for financial gain. Edir emphasizes social responsibilities, requiring women to contribute funds, attend meetings, and participate in funeral rites. In contrast, Equb is economically focused, helping women save money and access financial resources for personal or business needs. The primary distinction between the two is their purpose. Edir offers social support during mourning, while Equb facilitates financial collaboration.

Accordingly, the section presents those having participation in Edir but not in Equb. The other category includes women with leprosy who neither participate in Edir nor in Equb. The last group of the respondents includes those who participate in both institutions.

To further illustrate these categories, insights from individual women provide a deeper understanding of their experiences.

Among those participating in Edir but not in Equb, Meseret has the following to say about on her experience.

I do have Edir but not Equb. I pay the required membership fee for Edir from the payment I earn from Woreda 01 safety net and not because I have the financial capacity to pay for it. But regarding Equb, I have no the capacity to pay. So I do not participate in Equb. Even though I am a member of an Edir, I don't have any

responsibility. I am just an ordinary member. There is no Edir for persons with leprosy only so I participate with any non-affected persons. The benefit I get from Edir is, whenever there is a death in the family, I receive money from the Edir. There is no any other special support for the family.

The quote sheds light on the economic difficulties women with leprosy encounter in engaging with traditional institutions such as Edir and Equb. The respondent's participation in Edir is sustained by a safety net program, while financial limitations keep her from joining Equb. Despite her modest role in Edir, it offers crucial support during times of loss. Her involvement alongside non-affected individuals suggests a degree of inclusion. This analysis shows how economic vulnerability and limited institutional support affect the participation and benefits received by women with leprosy.

Furthermore, Mulunesh added the following about her participation in Edir.

I have Edir. I joined Edir by paying the membership fee just like any other person. However, I am simply an ordinary member and not entrusted with any responsibility. There is nothing Edir for persons with leprosy only. I participate just like any other non-affected person. The Edir helps us whenever there is mourning and there is no special support. On the other hand, I don't have Equb. I myself live on the money I earn from Woreda 01 safety net program.

The respondent shares her experience with Edir, highlighting that she joined by paying the same fee as other members but regards herself as merely an ordinary participant without any special responsibilities. She notes the lack of a dedicated Edir for people affected by leprosy, which underscores her similar involvement with non-affected individuals. Although Edir offers support during mourning, she emphasizes that there is no extra assistance for those impacted by leprosy. In contrast, she does not take part in Equb and depends entirely on the income from Woreda 01 safety net program to sustain.

The above two quotations indicate that both of the participants are limited to one traditional institution. This is so because they do have shortage of money. They both live on the money they

earn from Woreda 01 safety net program. The limitation to one traditional institution clearly shows the economic condition in which they live.

On the contrary, Sosina having no participation in both Edir and Equb has expressed her idea as follows:

I don't have Edir and Equb. I even make my daily bread from the income I earn by begging. I sometimes think about my death and as to who may bury me as I don't have Edir. But since I can't do anything about it, I don't participate in both institutions.

The quote underscores the respondent's significant struggles, highlighting her inability to participate in Edir and Equb, essential social institutions. Relying on begging for daily sustenance reflects her economic vulnerability and marginalization. The lack of access to these institutions not only deprives her of social support but also leads her to confront her mortality and lack of burial arrangements, intensifying her feelings of isolation and despair. Her situation exemplifies the broader effects of poverty and social exclusion on women affected by leprosy, revealing how economic barriers hinder access to crucial support networks and contribute to existential anxieties and hopelessness.

Regarding this issue, Ayinadis a 23-years-old woman from Oromia region stated the following:

I don't have Edir or Equb because I don't have a job. I live on the assistance given to me by Addis Ababa Leprosy Victims Rehabilitation Association. Participation in these institutions is considered as a "luxury" for me. I, as a person who waits for help, I don't have the capacity to participate in such institutions. I even have to wait for help even for my daily consumption.

The quote portrays the respondent's reality, showcasing her exclusion from Edir and Equb due to unemployment. She relies entirely on aid from the Addis Ababa Leprosy Victims Rehabilitation Association, highlighting her vulnerable position and reliance on external support. By describing participation in these institutions as a 'luxury' she underscores her feelings of inadequacy and disconnection from community life. As someone who must wait for assistance even for basic

necessities, she reveals her inability to engage in social structures that require financial contributions, emphasizing the profound effects of poverty and social isolation. This analysis illuminates the economic barriers that prevent individuals affected by leprosy from accessing vital support networks, further entrenching their vulnerability and marginalization in society.

The above two quotations show that these affected women are living in hard economic situation. The poverty severity compels them to avoid participating in the two traditional institutions. The first woman lives by the money she gets from begging while the other woman lives by the assistance she receives from Addis Ababa Leprosy Victims Rehabilitation Association. By abstaining from institutions like Edir and Equb, these women lose crucial social support networks that could offer emotional and financial assistance in times of need. This exclusion not only heightens their economic vulnerability but also intensifies their social isolation, hindering their ability to forge meaningful connections within their communities. For women, this disengagement can severely affect their self-esteem and sense of belonging, deepening feelings of inadequacy and marginalization. Ultimately, the inability to participate in these traditional institutions deprives them of essential resources that could enhance their livelihoods and facilitate their social integration.

In contrast to these struggles, there exists another category of women who actively participate in both traditional institutions, Edir and Equb. Among them Senayit states:

I am working in Birke Kibinesh and their Friends Hand Craft work association. I am doing the handicraft work and I am earning income from the work. Therefore I am part of both Edir and Equb groups and even have my own saving. I am entrusted with high responsibility in these institutions. I serve as a secretary; I participate in auditing in addition to being a member. I also serve in the saving as a chairperson. I didn't face any problem to participate in these institutions and I don't receive any special support because I have leprosy.

In the same manner Wibit added her participation as following:

I have both Edir and Equb and savings as well. The participation I have in these institutions is the same with those non-affected persons. I don't have special support from these institutions owing to me being affected. The Edir will support my family with burial expenses when I die. I use my saving for the services I need when the money comes in, and the same applies to the Equb. There is no special support I received to join these institutions.

The two quotes show both women are self-sufficient and as such they both participate in the two traditional institutions. Moreover, they have saving which is used for living. This indicates that they are in good economic standings. In summary, these quotes reveal that engaging actively in Edir and Equb can significantly empower women affected by leprosy and promote their social integration. Their stories emphasize the crucial role of inclusivity and support within community frameworks, demonstrating that when provided with appropriate opportunities, women with leprosy can break down barriers, achieve financial stability, and cultivate a strong sense of belonging within their communities.

In addition to involvement in informal institutions, during my observation, I have found that, the women also participate in religious institutions freely without any restrictions. They participate like any non-affected persons. They go to church and mosques whenever they want. There is no special support they receive from the religious institutions.

The study finding shows that 9 out of 15 interviewed women have Edir but not Equb. 4 out of the 15 women are not part of both Edir and Equb. 2 out of the 15 have both Edir and Equb and additionally have their own savings. The study findings also indicate that the first and the second category of respondents, those participating in Edir and but not in Equb and those having no participation in both institutions, have financial problems. This financial limitation either restricts them to participating in only one of the institutions or completely hinders their ability to engage in both types of institutions. The study finding also shows that there is no societal discrimination in participating in the two traditional institutions. Most of the respondents are able to participate alongside other non-affected people from their community.

6. Coping Mechanisms among women affected with Leprosy

Persons affected with leprosy regularly make use of several coping mechanisms to manage the psychological, social and physical problems related to the disease. Due to the stigma associated with leprosy, women encounter social isolation, discrimination and emotional distress. To overcome these problems, they may depend on the support of family members and intimate friends for the provision of emotional and financial support. Moreover, religious and spiritual practices are habitually used as important source of comfort. Involvement in self-help groups plays important role, giving a sense of harmony and empowerment by linking women with others who share similar experiences. Furthermore, some women implement avoidance strategies, such as hiding their situation or abandoning social interactions to reduce the influence of stigma. Nevertheless, these strategies may come up with short-term solutions, while these strategies themselves may in turn pave the way for further isolation and aggravate psychological distress in course of time (Nicholls et al., 2003).

Consequently, in this study religious and spiritual practice like conducting prayers is one of the coping mechanisms to overcome the stigma and discrimination. The other means of coping mechanism is just keeping silent to the stigma and discrimination they receive from service providers. This mechanism is sought as there is no other option. The rest of the coping mechanisms include migrating from the place of origin to Zenebework, and engaging in begging on the street to solve their economic pressure which resulting from the stigma and discrimination.

In connection with coping mechanism, Tigist forwarded her idea as follows:

Whenever I face any problem, I just cry to the almighty going to the religious institutions and conducting prayers to the creator for instance I go to mosque and conduct "Solat" and then come home renewing myself. It is in this way that I comfort myself. People say degrading things to persons with leprosy. So I think the solution is to just pray to the creator.

The quote highlights the vital role of spiritual and religious connections for women enduring the challenges of leprosy. By seeking relief in religious institutions and engaging in prayer, the respondents receive comfort; feel a sense of renewal during difficult times. This practice serves not only as a coping strategy to alleviate emotional confusion but also strengthens her sense of identity and resilience against societal stigma. Through prayer, she finds a source of comfort that empowers her to face the devaluation imposed by others. Ultimately, this spiritual bond significantly enhances her mental well-being, enabling her to tackle her struggles with newfound hope and strength, and fostering a profound sense of empowerment in the midst of discrimination.

Another coping mechanism used by women suffering from leprosy includes migration. For example, according to Sosina a 26-years-old woman from Amhara region, Desse moving to Addis Ababa served to escaping the challenge she faced at her place of origin:

The way I coped with the negative influences from my family and relatives was by escaping from my place of origin and finding a community where there are many individuals affected by leprosy. In my previous community, I was the only person affected by leprosy and as a result, I faced a lot of negative attitudes. However, in Zenebework, I find comfort in the presence of others who are also affected by leprosy, especially those with more significant disabilities. This comparison helps me feel a sense of solace.

The quote highlights the respondent's effective coping mechanism to lack of acceptance from her family and community regarding her condition. By moving to Zenebework, she connects with a supportive community of individuals affected by leprosy, which provides her with a sense of belongingness and empathy she lacked in her previous environment. The presence of others facing similar challenges, particularly those with more severe disabilities, reassures her and alleviates her feelings of isolation. This shared experience fosters solidarity and empowers her to face her struggles with renewed strength, underscoring the importance of community in promoting emotional resilience and well-being during difficult times.

The next participant's coping mechanism is distinct from the previous ones, as she actively engages in educating others about leprosy as a means of overcoming stigma and misunderstanding. Wibita 45-years-old woman states her experience as follows:

First of all, I solve problems that I encounter by explaining about the disease and by giving awareness about the disease. I tell them how I contracted the disease full-heartedly. I do so in exposing myself then I talk about the problem I face with confidence and being committed and give proper answer and I stand firmly for my goals. Generally it is possible to pass challenges throughby having a determinant attitude.

The quote emphasizes her proactive approach to managing the challenges of her condition and the stigma associated with leprosy. By openly sharing her experiences and educating others about the disease, she addresses misconceptions and combats discrimination. Her confidence and commitment to raising awareness empower both herself and her community. This willingness to be vulnerable allows her to confront obstacles head-on and reinforces her determination to achieve her goals. Ultimately, Wibit's perspective highlights the critical role of education and self-advocacy in overcoming adversity and fostering a supportive environment.

Another woman affected by leprosy shared her coping mechanism, which differs from the previous participants. She addresses the challenges posed by her community by begging on the streets and religious institutions, where she receives food and money from compassionate individuals. She describes this practice as follows:

I solve the problem I face from the community by either going to religious institution or by going to the street and begging. In doing so, I get food as well as money from the righteous. Moreover, I escape the problems I encounter from service providers by keeping silent and by crying because I can't do anything.

The quote highlights the participant's coping strategies in response to her condition and the stigma from her community. She seeks comfort in religious institutions and resorts to begging on the streets to deal with her economic situation, emphasizing her dependence on communal support for essential resources like food and money. This approach reflects her survival instinct

and need for immediate relief. However, her silence and emotional reaction when facing challenges with service providers reveal a profound sense of helplessness and isolation, indicating her struggle to advocate for herself.

The findings from the study show that the affected women with leprosy have various coping mechanisms. 9 out of 15 the study participants cope with the problem of stigma and discrimination coming from the community by devoting themselves to religious practices in their respective religious institutions. The same group responds to challenges from service providers by remaining silent, as they lack any alternative coping mechanisms. The study finding additionally shows 2 women cope with the problem by giving awareness about the disease with confidence. They are fully committed to explain about the disease and giving proper answers for any question they face, with the hope of reducing stigma, fostering understanding, and ultimately gaining acceptance and support from their community. The study finding also revealed that most of the women affected by leprosy use migration or escaping from their place of origin as a coping mechanism, even if they may not recognize it as such. By moving to areas like Zenebework, where they find a larger community of people with similar conditions, they seek to escape the stigma and difficulties they faced in their original communities. This approach helps them find a sense of belonging and alleviates the social isolation they previously endured.

Furthermore the study findings reveal that 3 out of 15 women affected by leprosy rely on begging as a survival strategy to secure basic necessities like food and money. This dependence highlights their economic struggles and social exclusion, reflecting the lack of viable livelihood alternatives. To address this issue, implementing programs that offer vocational training, microfinance, or community support is essential. Such initiatives would help these women achieve financial independence, reduce their reliance on begging, and promote their reintegration into society with dignity.

7. CONCLUSION AND RECOMMENDATION

7.1. Conclusions

The main objective of this study was to understand lived experiences of women affected by leprosy residing in Woreda 01 Zenebework area, Addis Ababa, Ethiopia through a phenomenological lens. It specifically aimed at exploring (1) knowledge and perception (2) interaction they have with close social networks (3) access and treatment the women have with in public and traditional institutions and (4) coping mechanisms.

This study examines the intricate relationship between poverty, disability, stigma, and social exclusion experienced by women with leprosy in the Zenebework neighborhood of Ethiopia. The findings reveal significant gaps in knowledge about leprosy, with many women holding misconceptions about its causes and transmission. These misconceptions, as discussed in the literature review, align with Erving Goffman's theory of stigma, wherein the social stigma surrounding leprosy exacerbates the isolation of affected individuals. This limited understanding perpetuates the stigma, hindering timely medical care and increasing the risk of disability. Goffman's concept of "spoiled identity" is evident, where women with leprosy are marginalized not just physically but socially, diminishing their sense of self-worth.

The research further highlights the persistence of stigma, not only from society at large but also from close social networks, including family. This discrimination reflects the intersectionality concept, where multiple forms of oppression, including gender and disease-related stigma, converge to uniquely impact women. The findings indicate that such discrimination can lead to severe consequences, including violations of legal rights and human rights abuses, ultimately fostering feelings of isolation, despair, and even suicide. These results emphasize the urgent need for advocacy and the implementation of human rights protections for women affected by leprosy.

The study also reveals barriers to broader social integration for women with leprosy, with their participation in public and traditional institutions largely confined to the Zenebework area. This limits their access to broader institutional support that could enhance their social integration and overall well-being. This highlights the need for expanded and accessible institutional support

networks to improve their lives and reduce the isolation caused by both physical and social disabilities.

Additionally, the study explores the coping strategies adopted by women with leprosy, such as religious practices, silence, migration, and begging. While these strategies offer short-term relief, they reveal the ongoing struggle against societal perceptions and demonstrate the resilience of these women. However, as highlighted in the literature on coping and resilience, these mechanisms alone cannot overcome the structural barriers created by stigma and limited access to resources. These findings suggest the need for stronger community support structures and policy interventions.

The primary contribution of this study lies in its comprehensive understanding of the lived experiences of women affected by leprosy, framed within both theoretical and empirical contexts. By integrating Goffman's theory of stigma with the lived realities of leprosy patients, the research offers valuable insights into how stigma influences individual identity and community dynamics. Furthermore, it underscores the importance of strengthening educational campaigns, expanding social support systems, and ensuring the effective implementation of policies to reduce stigma and promote the dignity and inclusion of women affected by leprosy.

In conclusion, this study advocates for a multi-faceted approach to address the challenges faced by women with leprosy, calling for both institutional and societal reforms. Enhancing education about leprosy, improving social support systems, and ensuring the effective implementation of policies that guarantee equal access to services is vital steps toward building a more inclusive society for these women. By addressing the stigma and structural barriers identified in this study, Ethiopia can ensure that women affected by leprosy are afforded the dignity, care, and social inclusion they deserve.

7.2.Recommendations

The study findings highlighted a significant gap between the scientific understanding of leprosy and the knowledge possessed by the women affected by the disease. This gap has led to social isolation, economic hardship, and widespread stigma, all of which hinder their ability to engage with society. To address this, it is crucial to launch extensive awareness campaigns about leprosy, its symptoms, transmission, and treatment. These campaigns should extend beyond local organizations to actively engage religious institutions, community leaders, and families. Religious groups and family networks hold considerable influence in communities, making them vital partners in changing societal attitudes and offering emotional and social support. By utilizing these channels, campaigns can align with cultural values, promote empathy, and dispel misconceptions, thereby reducing stigma and fostering community unity. This approach aligns with the participants' experiences of marginalization and emphasizes the need for a collaborative effort to reshape societal perceptions of leprosy.

Additionally, financial dependency and limited opportunities for self-sufficiency were major challenges faced by women affected by leprosy. Many participants expressed difficulty in securing stable income, which worsened their economic and social exclusion. To address this, local authorities, NGOs, and community organizations should work together to promote and support income-generating activities. For example, initiatives that help women create and sell handmade goods, such as crafts, clothing, or food products, could provide practical and sustainable solutions. Offering access to microfinance programs, vocational training, and market opportunities would not only empower women to gain financial independence but also restore their dignity and sense of purpose. These actions are vital for alleviating the economic disadvantages these women face and supporting their social reintegration.

Lastly, the ongoing stigma faced by women with leprosy in the workplace was a significant issue identified in the study. Many participants shared experiences of rejection or marginalization in professional environments, which intensified their economic struggles and damaged their self-worth. To address this, it is essential to implement educational programs that promote workplace inclusion and challenge discriminatory practices. These programs should target employers, colleagues, and broader professional networks, emphasizing the rights and capabilities of

individuals affected by leprosy. In addition, enforcing anti-discrimination policies and offering incentives for employers to hire and support these women can help create more equitable opportunities. Building supportive workplace environments will not only dismantle harmful stereotypes but also empower women to regain their dignity and confidence. These actions are critical for ensuring the social and economic reintegration of women affected by leprosy and promoting a culture of respect and inclusion.

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ANNEXES: INTERVIEW GUIDES

Addis Ababa University
College of social sciences
Department of Sociology

Dear Interviewee,

My name is Biftu Jemal. I am pursuing my Master's degree in Addis Ababa University Department of Sociology MA regular program. As part of my study, I am required to conduct research and write a thesis paper. To this end, I selected the topic entitled "Exploring the lived experiences of women affected by leprosy residing in woreda 01 Zenebework area". As a result, I kindly ask that you serve as my informant. The objective of this study is to collect information on the life experiences of women affected with leprosy living in Woreda 01 Zenebework area. I require your assistance because the information obtained from this study may help leprosy-related social welfare agencies and other health professionals to learn more about the lived experiences of leprosy-affected women. As a result, I encourage you to take part in this study.

You were chosen purposively to participate in the study, and I assure you that everything you are about to say or divulge will be kept confidential. I don't need your actual name or address to remain anonymous. Furthermore, some of the questions may be highly personal and challenging to respond to or discuss. So, please make every effort to answer all of the questions. There is no correct or incorrect answer. You are simply asked to share your experience. Finally thank you for your assistance.

An interview guide for Women's who are affected by leprosy

Section I: General

1. Socio-demographic profile of the informants
 - Age
 - Education
 - Occupation
 - Marital status
 - Place of Origin

Section II: knowledge and perception of the women about the disease

1. Could you please tell me what you understand by leprosy in relation to the following points?
 - Cause
 - Transmission
 - Treatment
 - Adverse effects of the disease on health, social or economic
2. Can you tell me about how you first learned about leprosy?
3. When did you come to know that you were infected with Leprosy? Who helped you to identify it?
4. Could you please tell me what you felt when you first heard you were infected with Leprosy? What measures did you first take?
5. How do you describe your personal experiences in your family, compared to other members?
6. How do you describe your relationship with your neighbours, compared to other members of your family?
7. Can you tell me about any situations where you are treated differently because of your leprosy diagnosis in workplace?
8. Can you describe your journey from the onset of symptoms to receiving diagnosis?
9. How do you describe your marriage relationship?

10. Have you treated differently compared to other individuals? How do you describe your access to transportation system?
11. How do you describe the attachment that you have with traditional institutions like Edir and Equb?
12. Can you tell me the participation you have in religious institutions?

Section IV: Coping mechanisms used by the survivors

1. What coping mechanisms do you use to overcome the challenges you encounter from close networks?
2. What coping mechanisms do you use to overcome the challenges you encounter from different service providing institutions?

Annex II: Interview guide for medical professionals

1. Socio-demographic profile of respondents

Sex _____

Position in the institution_____

Years in services_____

2. How many leprosy affected individuals do you treat every week or month?
3. What are the factors contributing to the rise or decline in the number of the affected individuals?
4. What is your Preparation to provide services for the affected including budget, human resource, equipment and reagents? Is this different from other department in the hospital?
5. Describe your understanding of the specific challenges faced by women affected by leprosy during your care.
6. How do you address stigma and discrimination toward leprosy affected in your practice?
7. What role do you play in supporting the psychosocial well-being of women affected by leprosy?
8. What improvements should be made to healthcare services for women affected by leprosy?
9. What do you recommend for the future to mitigate the effects of leprosy?

Annex III: Interview guide for NGOs and Government Bodies

1. Socio-demographic profile of respondents
 - Sex _____
 - Position in the institution _____
 - Years in services _____
2. What are the programs and measures that have been taken to tackle leprosy in the area?
3. What initiatives are in place to support women affected by leprosy in your organization/department?
4. How do you address stigma and discrimination toward leprosy in your programs and policies?
5. How can your organization/department collaborate with other stakeholders to ensure comprehensive and holistic care for women with leprosy?
6. What are the challenges and limitations of existing support systems for leprosy affected women?
7. What recommendations do you have for improving the lives of women affected by leprosy residing in Woreda 01 Zenebework?