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COLLEGE OF SOCIAL SCIENCES
DEPARTMENT OF SOCIAL ANTHROPOLOGY

THE CAUSES AND EFFECTS OF LEPROSY-RELATED DISCRIMINATION AT ZENEBEWORK, ADDIS ABABA, ETHIOPIA

BY
SENAIT DESALEGN

THESIS SUBMITTED FOR THE PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF ARTS IN SOCIAL ANTHROPOLOGY AT THE ADDIS ABABA UNIVERSITY, DEPARTMENT OF SOCIAL ANTHROPOLOGY.

JUNE, 2024
ADDIS ABABA, ETHIOPIA

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A THESIS SUBMITTED TO THE SCHOOL OF GRADUATE STUDIES OF ADDIS ABABA UNIVERSITY IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF ARTS IN SOCIAL ANTHROPOLOGY.

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Declaration

I, the undersigned, declare that this thesis is my original work and has not been presented or submitted either partially or in full by any other person for a degree in any other university. All sources of materials used for the purpose of this thesis have been duly acknowledged.

Name: Senait Desalegn
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Approval Sheet

Addis Ababa University

School of Graduate Studies

This is to certify that the thesis entitled “The Causes and Effects of Leprosy-Related Discrimination at Zenebework, Addis Ababa, Ethiopia” prepared by Senait Desalegn, and submitted in partial fulfillment for the requirements of the degree of Master of Arts in Social Anthropology at Addis Ababa University, complies with the regulations of the University and meets the accepted standards with respect to originality and quality.

Signed by the Examining Committee:

Advisor: ________________________ Signature _________________ Date ____________

Internal Examiner:__________________ Signature _______________ Date ____________

External Examiner:___________________ Signature______________ Date ____________

Department Chairperson: _______________ Signature: ______________Date __________

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Abbreviations and Acronyms

ALERT	All Africa TB Leprosy Rehabilitation and Training Center
BC	Before Christ
BCG	Bacilli Calmette- Guerin
ENAELP	Ethiopian National Association for Ex- Leprosy Patients
FGD	Focus Group Discussion
G2D	Grade 2 Disabilities
MDT	Multi-drug Therapy
MoH	Ministry of Health
NTD	Leprosy is a neglected tropical disease
PWDs	Persons with Disabilities
TB	Tuberculosis
WHO	World Health Organization

Abstract

Leprosy remains a significant public health challenge in Ethiopia due to pervasive stigma and discrimination against those affected. The problem of misunderstanding the root causes of leprosy has contributed to the widespread marginalization of individuals with the disease. The purpose of this study was to explore the socio-cultural factors fueling leprosy-related stigma and discrimination in Zenebework, Addis Ababa in order to inform interventions to promote social inclusion. A qualitative ethnographic research approach was utilized, involving interviews, focus groups and case studies with leprosy-affected individuals, community members, and healthcare workers in Zenebework area. Data was analyzed using thematic analysis.

The study found that among the focus group discussion participants in Zenebework, there were differing understandings expressed regarding the causes and transmission of leprosy. While some biomedical explanations were provided, traditional beliefs surrounding inheritance and supernatural causation were also commonly referenced. Participants affected by leprosy described facing lifelong stigma in their community due in part to these alternative community-held perspectives. The lack of consensus around the disease's origins according to both biomedical and indigenous epidemiological frameworks contributed to a lack of awareness that impacted individuals' social, economic and psychological well-being. Besides, relationships with family, neighbors and friends were described as strained at times due to fears of contagion or views of inherited bad luck according to emic accounts. Further, socio-cultural factors shaping understandings of disease causation and transmission in this community included longstanding religious interpretations linking illness to moral failings or curses. Historical institutionalization practices that segregated those with visible signs of leprosy also influenced spatial expression of stigma. Alternative indigenous nosologies focusing on ancestral sin or airborne miasmas co-existed with biomedical understandings, contributing to the stigmatization of affected groups. A holistic approach is needed to address the complex interplay of factors shaping local disease attribution and resulting discrimination.

Therefore, the study concludes that leprosy and its effect on marriage, employment opportunities, the economy, education, and psychological effects are still causing a double burden on those leprosy-affected communities. Based on these findings, the researcher recommends that conducting awareness-creation trainings for the public at large and health professionals specifically to reduce discrimination against persons affected by leprosy. The government and relevant stakeholders, including associations of persons affected by leprosy, are recommended to prepare and deliver these awareness-creation initiatives.

Key Words: Leprosy, Discrimination, Stigma, Persons affected by leprosy, Socio-cultural factors

CHAPTER ONE

INTRODUCTION

This chapter offers an overview of the study's context, outlines statement of the problem, defines objectives, discusses the significance of the study, presents the research methodology, acknowledges study limitations, and outlines organization of the research.

1.1. Background of the Study

Leprosy is a persistent and advancing bacterial infection caused by M. Leprae, primarily impacting the nerves in extremities, skin, the lining of the nose, and the upper respiratory tract (Ooi, W. W., & Srinivasan, J. 2004). Manifesting as skin sores, nerve damage, and muscle weakness, untreated leprosy can lead to severe disfigurement and significant disability. Also referred to as Hansen's disease, it was named after Dr. Gerhard Henrik Armauer Hansen, who discovered M. Leprae in 1873 (Gelber, R. H. 1993). Hansen's groundbreaking discovery dispelled myths, confirming that leprosy is attributed to bacteria, rather than being hereditary, a result of curses, or linked to sins. (WHO, 2012).

Before Hansen's discovery, debates arose regarding the causes of leprosy. One viewpoint, supported by researchers Leiker and Fischer (1976), suggested heredity as a significant factor. They argued that leprosy was more prevalent among individuals residing in the same geographical area. Citing various studies, Fischer highlighted the high occurrence of leprosy in certain cases in India, leading to the conclusion that heredity could not be entirely dismissed as a cause of leprosy (Leiker and Fischer, 1976).

The second argument proposed in the Philippines suggested a belief that consuming chicken and squash together in a meal or eating rotten fish could lead to leprosy. Additionally, the argument noted a notable prevalence of leprosy was observed among individuals who regularly consumed fish, particularly those employed in the fish canning industry (Maghanoy et al., 2011).In 1873, however, G.H. Armauer Hansen, a physician working in a leprosy hospital in Bergen, Norway, discovered the leprosy bacillus in a sample of tissue from one of his patients. Hansen was able to identify the organism under the microscope because its propensity to collect iron caused it to appear brownish in color compared with the tissue itself. His discovery demonstrated that leprosy is an infectious disease propagated by a specific microorganism (Kazda, 2012).

In the many centuries since leprosy was first described, there were different kinds of thoughts which have been proposed to explain how the bacillus is transmitted. The route of transmission of leprosy remained a matter of debate. The prevailing opinion for many years was that the illness spread via prolonged skin-to-skin contact. Then the theory of respiratory transmission became popular; it posited that the bacillus entered the human body through the lining of the nose. For a time, scientists even entertained the possibility of transmission by insect bites (Kara Rogers, 2011). In the late 20th century, experiments with a mouse model of the disease showed that transmission is indeed possible through the intact lining of the nose and through breaks in the skin but not via the mouth, lungs, or digestive tract or through unbroken skin. Leprosy cannot be transmitted through touch prolonged; close contact over months with someone with untreated leprosy is needed to catch the disease. The disease is not spread through casual contact with a person who has leprosy like shaking hands or hugging, sharing meals or sitting next to each other. Moreover, the patient stops transmitting the disease when they begin treatment. The only known reservoir for leprosy is humans and armadillos (Rees, 1976).

As Grange (2008), leprosy is an ancient ailment documented in the literature of past civilizations, and despite considerable progress, it continues to pose challenges in various nations. Similar to historical periods like prehistory and the Middle Ages, leprosy is still viewed today as the most severe and dreaded affliction for individuals. Unlike many other diseases, there is currently no dependable method for the primary prevention of leprosy it’s important to mention that studying the history of leprosy comes with certain widely recognized challenges. Leprosy's origin is unclear, but ancient evidence from a 4,000-year-old human skeleton in India in 2009 suggests it originated in Europe, with erosion patterns similar to those in Middle Ages Europe and `Thus, there is also evidence that leprosy existed in India by 2000 BC, and this coincides with what is suspected to be the first textual reference to leprosy—in an ancient Sanskrit sacred work known as the Atharvaveda (Roberts, 2020).

According to Roberts (2020), the origin of leprosy is associated with various historical events. The initial concrete evidence of leprosy in Egypt dates back to 200

B.C., as revealed by archaeological findings in the Egyptian oasis of Dakhleh, where four leprous skulls were unearthed. Subsequent indisputable archaeological proof, demonstrating distinct signs of mutilating leprosy, was discovered in the burial site of Coptic Christians at El-Bigha in Upper Egypt, dating back to 500 A.D. The birthplace of leprosy is also attributed to India and the Indus River valley. Additionally, the Persians, who had established strong socio-economic ties with Indians, experienced the prevalence of leprosy. Overall, various historical events such as wars, trade, and pilgrimages are cited as contributing factors to the spread of leprosy among different regions and populations.

Leprosy, categorized as a neglected tropical disease (NTD), continues to be present in over 120 countries, with an annual reporting of over 200,000 new cases. The decline in the incidence of new leprosy cases has been gradual, both on a global scale and within the WHO regions. According to 2019 data, Brazil, India, and Indonesia documented more than 10,000 new cases each. Additionally, 13 other countries, including Bangladesh, Democratic Republic of the Congo, Ethiopia, Madagascar, Mozambique, Myanmar, Nepal, Nigeria, Philippines, Somalia, South Sudan, Sri Lanka, and the United Republic of Tanzania, reported between 1,000 and 10,000 new cases. Notably, 45 countries reported zero cases, while 99 reported fewer than 1,000 new cases (WHO, 2023).

Leprosy is the leading cause of preventable disability in the world; Leprosy-associated disability poses a significant obstacle to public health, as well as social and rehabilitation services in countries where the disease is prevalent. Disability is not only about physical dysfunction but has a broader scope, including stigma, discrimination, and social participation restrictions (Rathod et al., 2020).

In traditional Ethiopian society, there seems to be a lack of awareness regarding the cause of leprosy, with a prevalent belief that it is an inherited condition. Many individuals in this society seek various remedies, which include resorting to prayers, using amulets, applying traditional medicines both internally and externally, and undergoing medical vapor baths and immersion in thermal pools. Despite leprosy not being contagious, individuals diagnosed with the disease often find themselves leading solitary lives or, at best, residing in leper communities scattered across the country (Elizabeth, 2010).

Leprosy and stigma have been almost two sides of the same coin. Leprosy, historically, has been a dreaded disease, with the very mention of it evoking shame and disgust. Individuals affected by leprosy may face unemployment due to the associated stigma and disabilities, resulting in the loss of their livelihoods and often the respect of their communities. Consequently, this leads to a decline in self-esteem. The mental impact on many leprosy patients is not solely due to the disease itself but is significantly influenced by societal rejection, the fear of being rejected, or the lack of acceptance of their condition. Leprosy stands out as one of the most feared and stigmatized diseases, not only for its physical pain and physiological effects but also for the profound social consequences, particularly through rejection and discrimination (McLaughlin, 2021).

As described by Ocran (2023), stigma is an attribute that subjects a person to disrespect and disregard, stripping them of social advantages and deeming them disreputable. Beyond the impairments caused by the disease, leprosy stigma acts as a hindrance, instilling fear and portraying the victim as a potential threat to society, leading to subsequent rejection.

According to Brown's viewpoint (2006), leprosy is not just a physical malady; it is a social affliction that leaves enduring impressions of mutilation, rejection, and societal exclusion. The impact of the disease extends beyond physical disabilities to encompass psychological and social challenges, largely stemming from the stigma associated with leprosy. In many developing countries, individuals face difficulties in accepting leprosy due to widespread misconceptions, stigma, and superstitions surrounding the illness.

It is self-evident that leprosy has been a persistent public health challenge throughout history, with records tracing its prevalence in various ancient civilizations to which Ethiopia is not exception but one of the countries most impacted by leprosy, with a long-standing history of the disease. The study was conducted in Addis Ababa for several compelling reasons. Adds Ababa in general and Zenebework area in particular is established as a settlement for individuals affected by leprosy reflecting the historical segregation and marginalization of this community, making it a relevant location to understand the root causes and the multifaceted impacts of leprosy-related stigma and discrimination in this context which is crucial for developing effective strategies to address this persistent public health challenges. As a result of the area’s high concentration of leprosy-affected individuals residing in the city, it makes it an important site to explore the socio-cultural factors contributing to the perpetuation of leprosy-related discrimination. The study's focus on the Zenebework community provides an opportunity to contribute to the broader discourse on the sociocultural dimensions of disease-related stigma and discrimination. The strategic focus on the Zenebework area allows the researcher to delve into the historical, socio-cultural, and anthropological dimensions of leprosy-related discrimination, which can inform more comprehensive and effective approaches to addressing this persistent challenge in Ethiopia and beyond.

Therefore, the study by exploring the root causes, beliefs, and effects of leprosy discrimination in this context, it can offer valuable insights that can be applied to the study of other stigmatized diseases or conditions. Furthermore, the findings of the study can inform the development of more effective strategies and interventions to address leprosy-related stigma and discrimination country-wise. Since, the study strives to identify the misconceptions, cultural beliefs, and societal attitudes that perpetuate the problem; it can guide policymakers, healthcare professionals, and community organizations in designing targeted awareness campaigns, educational programs, and support services for leprosy-affected individuals and their communities. Further, it can also contribute to the broader effort to eliminate leprosy as a public health problem in Ethiopia, by addressing the socio-cultural barriers that hinder early diagnosis, treatment, and reintegration of leprosy-affected individuals.

Therefore, the study strives to explore the fundamental socio-cultural factors that contribute to the perpetuation of leprosy-related stigma and discrimination in the area. It also aims to identify the prevailing misconceptions and beliefs surrounding the causes and transmission of leprosy within the local community. Thus, the study by delving into these underlying issues, it seeks to provide valuable insights that can inform more effective strategies and interventions to combat the stigma and improve the quality of life for leprosy-affected individuals and their communities.

1.2. Statement of the Problem

Leprosy, a chronic infectious disease, continues to pose a significant challenge in the world. While it mainly affects the nerves, skin, and mucosa of the upper respiratory tract, left untreated it can cause significant physical impairments and disabilities. Unfortunately, the persistent stigma and discrimination surrounding leprosy impede the timely identification and diagnosis of the disease. Furthermore, self-stigma resulting from leprosy-related disabilities has the potential to curtail individuals' activities, constrain social interactions, and induce physical dysfunction (Urgesa et al., 2020).

Ethiopia is one of the countries most impacted by the burden of leprosy, with a long history of leprosy prevalence. Leprosy patients in Ethiopia often face widespread stigmatization, discrimination, and social isolation, even segregation from non-leprosy communities which in turn exacerbated by the diverse cultural and linguistic perceptions of leprosy, with various derogatory & stigmatizing terms and misconceptions associated with the disease across different ethnic groups and used historically and in some areas today(Ibikunle, 2017; Pankhurst, 1984). This stigma stems from a complex interplay of factors, including misconceptions about the disease, deeply rooted cultural beliefs, and a lack of awareness and education.

In Ethiopia leprosy-related stigma and discrimination have deep-rooted sociocultural origins stemming from misconceptions about the causes and transmission of the disease which often lead to the perception of leprosy as a punishment from God or a curse, contributing to the social exclusion and isolation of individuals affected by the disease. Further, the misunderstandings about the root causes of the illness and how it spreads have perpetuated the perception of those with leprosy as cursed, sinful, highly contagious, and liable to rejection and exclusion from society. Such stereotypes have served to "other" those affected and create an "us vs. them" mentality. As a chronic neglected tropical disease, leprosy also poses significant obstacles to timely identification, diagnosis, treatment, and the provision of rehabilitation services due to the effects of stigma on healthcare access and quality of life. Furthermore, the self-stigma experienced by individuals with leprosy-related disabilities severely hampers their social participation, activities, and overall well-being.

Furthermore, the terminologies and labels used for leprosy across cultures and languages have also contributed to its stigmatization over time. Thus, the use of derogatory terms and phrases associated with leprosy reinforces negative perceptions and perpetuates stigma. This linguistic discrimination further isolates individual affected by the disease and hinders their social integration. Most regions and ethnic groups who live in local areas still have the wrong belief and understanding about leprosy disease, even people living in cities like Addis Ababa don't know about leprosy disease and they are still using derogatory words to call leprosy affected individuals. As a result, this study places a premium on the cause and effects of leprosy related discrimination for those who have leprosy and create some kinds of image and understanding about this disease.

Further, the incorrect public view of leprosy as divine punishment or curse, coupled with deep-rooted social taboos, has led to the widespread avoidance and ostracization of those affected. As a result, individuals with leprosy frequently experience the severing of social connections and familial ties (Ayele, 2022; Melak, 2008). Moreover, the stigma and discrimination can cause severe psychosocial consequences that are even more debilitating than the physical manifestations of the disease itself (Abdul Rahman et al., 2022).

Moreover, misunderstanding the underlying causes of leprosy has resulted in discrimination and stigmatization. Society tends to hold stereotypical views about individuals with leprosy, perceiving them as highly contagious, cursed, sinful, or rejected and unreliable. Such stereotypes lead to a separation between those who are affected and those who are not, creating an 'us' versus 'them' dynamic. Consequently, individuals facing health challenges like leprosy may find themselves reduced to these stereotypes, often resulting in a loss of social status and actual discrimination (ILEP, 2013).

Moreover, the existing literature on leprosy in Ethiopia has primarily focused on the psychosocial, historical, and medical aspects of the disease, with limited anthropological perspectives (Asnake et al., 2000; Anandaraj, 2004; Keweti, 2021; Demerew, 2004; Hunegnaw, 2022). There is a paucity of research that delves into the underlying sociocultural factors driving the persistent stigma and discrimination experienced by leprosy-affected individuals and their communities. As a result, an anthropological approach is crucial to understanding the cultural beliefs, practices, and linguistic nuances that contribute to the stigma surrounding leprosy.

Further, the pervasive stigma surrounding leprosy discourages individuals from seeking timely diagnosis and treatment, hindering efforts to control its spread and prevent disabilities. Moreover, internalized stigma can lead to low self-esteem, limited social interactions, and reduced participation in daily activities, further impacting the well-being of affected individuals. Limited awareness and understanding about leprosy among the general population contribute to its stigmatization and hinder efforts to promote early detection and treatment. This lack of knowledge fuels misconceptions and perpetuates negative attitudes towards individuals affected by the disease.

Therefore, the study strives to explore and investigate the causes and multifaceted effects of leprosy-related stigma and discrimination in the Zenebework area of Addis Ababa. The study by exploring the cultural perceptions, beliefs, and linguistic nuances associated with the disease; it seeks to provide valuable insights that can inform more effective strategies for combating stigma and improving the quality of life for leprosy-affected individuals and their communities.

1.3. Objectives of the Study

1.3.1 General Objective

The general objective of this study is to examine the Causes and Effects of Leprosy-Related Discrimination at Zenebework, Addis Ababa, Ethiopia

1.3.2 Specific Objectives

Based on the above general objective the study has the following specific objectives:

a) To explore the historical and sociocultural context that has contributed to the perpetuation of leprosy-related stigma and discrimination in the Zenebework area.

b) To identify the misconceptions and beliefs surrounding the causes and transmission of leprosy among the local community.

c) To examine the multifaceted effects of leprosy-related stigma and discrimination on the affected individuals and their families, including social, economic, educational, and psychological dimensions.

d) To investigate and suggest the coping mechanisms and resilience strategies employed by leprosy-affected individuals and their communities to navigate the challenges of stigma and discrimination.

1.4 Significance of the Study

The finding of this study serves as an informative document that exhibits the root cause of leprosy discrimination and the effects of the discrimination faced by people affected by leprosy. Furthermore, it endeavors to identify the misperception towards the cause of leprosy, which redounds to the benefit of society knowing the root cause and the impact of leprosy stigma is critical to improve perception of the community toward Leprosy and its associated problems. Moreover, fostering positive attitudes toward individuals affected by leprosy can contribute to the reduction of community stigma and promote early health-seeking behavior, ultimately improving the overall quality of life for those individuals. Consequently, this study has the potential to instigate a positive shift in attitudes toward the stigma associated with leprosy-affected persons.

Through this research, policymakers will be able to use appropriate strategies and methodology to enact legislation that aligns with the fundamental human rights of persons affected by leprosy. Academicians also would be able to use the document as a reference for further study or other relevant purposes. Most importantly, the subject of the study, people affected by leprosy will benefit from the finding of this research since it aims to break down the stereotype, stigma, and prejudice against them.

1.5 Scope of the Study

This study focuses on exploring the root causes and effects of leprosy-related discrimination experienced by the people affected by leprosy in the Zenebework area of Addis Ababa. The study aims to uncover the underlying misunderstandings and stigma associated with leprosy within the local community. Thematically, the study delves into exploring the root causes of leprosy-related discrimination hence it investigates the sociocultural, economic, and institutional factors that contribute to the stigmatization and marginalization of people affected by leprosy in the Zenebework area; impacts of leprosy-related discrimination since it explores the multifaceted consequences of leprosy-related discrimination, including its impact on the physical, mental, social, and economic well-being of the affected individuals and their communities; and misunderstandings and perceptions about leprosy since the study seeks to identify and analyze the prevailing misconceptions, myths, and stereotypes held by the local community regarding leprosy and people living with the disease. Geographically, the study is focused on the Zenebework area, which is located within the Kolfe Keraniyo Sub-City of Addis Ababa. This area was selected because it is one of the leprosaria areas within Ethiopia, where a significant number of people affected by leprosy reside.

The study population comprises individuals living with leprosy in the Zenebework area, as they are the primary stakeholders directly experiencing the issues of discrimination and stigma. Therefore, through investigating into the thematic and geographical scope outlined above, the study aims to provide a comprehensive understanding of the root causes, impacts, and misunderstandings surrounding leprosy-related discrimination in the Zenebework community.

1.6. Methods of the Study

1.6.1. Research Design

The study employed a qualitative research design, with a focus on an ethnographic approach. The use of qualitative methods is well-suited for exploring the complex sociocultural dynamics and lived experiences related to leprosy-related stigma and discrimination. It allows for an in-depth exploration of the root causes and effects of leprosy-related discrimination in the area. The qualitative component involved the use of various techniques, such as interviews, focus group discussions (FGD), and individual case studies. Pseudonyms were employed for the informants to ensure confidentiality.

In this study, a non-probability purposive sampling approach was utilized. The collected data was systematically organized in alignment with the objective of the study. Further, qualitative data analysis procedures were applied, involving the systematic breakdown of information into distinct themes and categories.

1.6.2. Sources of Data

This study employed both primary and secondary data sources. Primary data were collected through interviews, key informant interviews, focus group discussions (FGD), and individual case studies. In addition to these primary sources, secondary sources, including journals, books, published and unpublished reports, and previous researches related to the topic under investigation, were also utilized for a comprehensive understanding of the subject.

1.6.3. Sample Population and Sampling Method

The target population for this study consisted of individuals affected by leprosy and residing in the Zenebework area of Addis Ababa. This population was selected as they are the primary stakeholders directly experiencing the issues of leprosy-related discrimination and stigma.

To identify and engage with the study participants, the researcher employed a non-probability purposive sampling approach. This sampling method was chosen to ensure the selection of information-rich cases that could provide in-depth insights into the research topic.

The researcher initially reached out to local community-based organizations and leprosy support groups operating in the Zenebework area to establish connections with the target population. Through these connections, the researcher was able to identify and contact individuals affected by leprosy who were willing to participate in the study.

In addition to the individuals affected by leprosy, the researcher also purposively selected key informants from the Zenebework community, including: community leaders, healthcare workers and social service providers. These key informants were identified based on their direct knowledge and involvement with issues related to leprosy and the local community. Their participation provides valuable insights and a more comprehensive understanding of the research topic from diverse perspectives.

The sample size for the qualitative data collection was determined based on the principle of data saturation, where the researcher continued to conduct interviews and focus group discussions until no new significant themes or information emerged. Accordingly, the study focused on leprosy affected peoples who live in Addis Ababa Kolfe Keraniyo Sub-City, Zenebework area specifically in Woreda 01; because as per the chairperson of the Woreda, 90% of leprosy affected peoples are living in this area. For that matter the researcher has selected 60 informants who are living in the area purposively. The researcher selected 24 residents for semi-structured interviews, 15 leprosy affected residents for indepth-interview, 2 individual case studies, 2 FGD discussants with 12 peoples six from leprosy affected residence and six from non-affected residence and 7 respondents for key informant interview 2 from leprosy institution in the area, 4 from religious leaders and 1 doctor from ALERT general hospital. Therefore, by employing a purposive sampling approach and engaging both an individual directly affected by leprosy and key informants from the Zenebework community, the researcher was able to gather rich, contextual data to address the objectives of this research.

Further, the researcher employed a purposive sampling technique to select the study participants. This approach allowed for the inclusion of individuals with diverse social strata, genders, ages, marital statuses, health conditions, religions, educational backgrounds, and work experiences, ensuring a comprehensive understanding of the phenomena under investigation. For the in-depth interviews, 15 leprosy-affected individuals were selected from the area, based on their willingness to participate and share their experiences until my data reaches saturation point. The key informant interviews included 7 individuals selected for their expertise and roles within the leprosy-affected community or organizations serving this population.

The FGD participants were also selected using purposive sampling, with 6 individuals (3 leprosy-affected and 3 non-affected) invited to each of the two discussion groups. This heterogeneous composition facilitated the exploration of collective perceptions and experiences within the community. The researcher purposively selected 24 residents from the Zenebework area, for Semi-structured interviews including neighbors of leprosy-affected individuals and family members of those not affected by the disease. This Semi-structured interviewees chosen based on the assumption that these individuals would have a better understanding of the community's knowledge, attitudes, and misconceptions about leprosy.

1.6.4. Data Gathering Instruments

The qualitative data was collected through various methods, including in-depth interviews, focus group discussions (FGD’s), and case studies to capture personal experiences and perspectives.

1.6.4.1 Interviews

Well, in-depth interviews were conducted with 15 individuals affected by leprosy living in the Zenebework area. Interview questions explored participants' experiences, perceptions, and narratives regarding leprosy origins, transmission, and the challenges of stigma and discrimination. Participants were selected purposively to reach data saturation. Interviews were conducted in Amharic, audio-recorded, transcribed and translated.

This study was focused on the interviewees' point of view. Interview questions were crafted to gather data from a group of fifteen individuals affected by leprosy. The selection of this sample size aligns with qualitative research practices, where the determination is often guided by theoretical saturation, reaching a point in data collection where new information ceases to provide further insights into the research questions. The questions adopted a semi-structured format, providing informants with the flexibility to share their narratives and experiences freely. This approach aimed to facilitate a comprehensive understanding of their conditions, allowing the researcher to obtain a broad overview. Throughout the interviews, subjects were questioned about the origins and transmission of their illness, their connections with family, neighbors, and friends, their involvement in social activities, their emotions and attitudes regarding their health condition, reasons for relocating from their original residence, the losses and hardships endured due to discrimination, their current circumstances, and other relevant aspects. All interviews were conducted in Amharic and recorded.

The researcher used seven respondents as key informant, two executive directors from Addis Ababa leprosy association this association was chosen because it has more than 2500 members which make it relevant for this study to get ample information that fit the objectives of the study, and four religious' leaders, two from Abune-Aragawi church and two from Miftah mosques. Two of them are leprosy victims. One is leprosy affected "kes" and the other is leprosy affected "imam" and one leprosy specialist from ALERT General Hospital who is serving as a doctor for leprosy affected people and experienced on the field.

The key informant's interview questions were also developed depending on their position and responsibilities. The interview questions were semi-structured, primarily yielding the data on the cause, the cure and transmission of leprosy and the present situation of leprosy stigma and the discriminatory practices that leprosy affected peoples are facing today, as well as historical and religious practices and misconceptions about leprosy cause and transmission. All interviews were done in Amharic, recorded and translated.

Further, Semi-structured interviews were conducted with 24 residents of Zenebework in order to obtain contextualizing perspectives on socio-cultural dimensions of stigma. Informants included neighbors and family members of those affected by leprosy. While their insights provided useful context.

Therefore, findings from interview discussions are referenced narratively. The primary methodology employed was qualitative ethnographic fieldwork, including participant observation, narrative interviews and focus group discussions.

1.6.4.2 Focus Group Discussions

In addition to the individual interviews, the researcher conducted a series of focus group discussions (FGDs) with residents in the Zenebework area. The researcher conducted two FGDs, each with 6 participants (3 leprosy-affected and 3 non-affected individuals), encompassing participants of various age groups, including young, adult, and elderly individuals, genders as well as individuals affected and unaffected by leprosy, were included.

The FGDs allowed for the exploration of collective perceptions, beliefs, and experiences related to leprosy within the community. The FGDs involved both neighbors of individuals affected by leprosy as well as family members of those not directly affected by the disease. The FGDs allowed the researcher to explore the participants' knowledge, attitudes, and misconceptions about the causes and transmission of leprosy in a group setting. This approach facilitated a more in-depth understanding of the community's perceptions and the underlying social dynamics related to leprosy-related discrimination (participants' knowledge of leprosy, societal beliefs about the disease, experienced stigmas, the resulting hardships, and suggested measures for the future).

The FGDs were structured to encourage open and interactive discussions, with the researcher guiding the participants through a set of pre-determined questions and prompts. The discussions were facilitated using a guide, conducted in Amharic, audio-recorded, transcribed and translated, providing valuable insights not previously identified in interviews. The FGDs lasted approximately 150 minutes on average. This enabled the researcher to gather rich, contextual data on the community's perspectives, beliefs, and experiences regarding leprosy.

1.6.4.3 Individual Case Studies

Case study focuses on the example or few instances of a particular phenomenon with a view to providing an in-depth account of events, relationships, experiences or processes occurring in that particular instances (Darke et al., 1998). The researcher has presents two case studies from people supported by Addis Ababa Leprosy Association because they each had a unique history that revealed the extent of discrimination connected to leprosy as well as the source of misconceptions regarding the illness causes and transmission, which the researcher believed for educating others. Therefore, the two compelling case studies highlighted discrimination's profound individual impacts.

1.6.4.6. Secondary Data Collection

Besides the primary data sources, secondary sources such as printed and electronic documents Journals, books, published and unpublished reports, as well as previous researches related to the topic under investigation, were utilized in this study. Thus, those published/unpublished literature provided context on leprosy history and impacts thereof.

1.6.5 Data Analysis

Since, data collection involved qualitative methods like interviews, FGDs and case studies. All interactions were conducted in Amharic and later translated to English after each day of data collection. The gathered data was systematically organized to align with the research questions and objectives, utilizing a qualitative data analysis method which involves the process of breaking down information into different themes and categories.

The qualitative data collected through interviews, FGDs, and case studies were transcribed, translated, and analyzed using thematic analysis which involves a systematic process of pre-coding, coding, categorizing, and developing themes that aligned with the objectives of the study. First, audio recordings were transcribed while notes were converted into written text. Data was then organized as per the objectives of the research. Then, transcripts and translations underwent iterative coding and categorization to identify common themes. Patterns among interviewees were recognized through pre-coding, coding and theme development stages as per Morse and Field (1995). Ultimately, the significant findings of the study is presented and discussed.

Semi-structured interviews were analyzed using frequencies and percentages, to understand the participants' knowledge, attitudes, and misconceptions about the causes and transmission of leprosy.

Therefore, ensuring rigor, data analysis consistently linked emergent themes back to the research questions and objectives. Significant findings were then compiled and prepared for presentation and discussion.

1.6.6. Validity and Reliability

Well, to ensure the validity and reliability of the qualitative data collected in this study, the researcher employed several strategies. Firstly, the researcher utilized a triangulation of data sources by employing multiple qualitative data collection methods, including interviews, focus group discussions (FGDs), observation and case studies. This approach allowed for the cross-validation of the information gathered, strengthening the credibility of the findings. Additionally, the researcher engaged in member checking, where selected participants were invited to provide feedback and verify the accuracy of the researcher's interpretations and conclusions. This process helped to enhance the internal validity of the study. Furthermore, the researcher provided thick descriptions of the research context, participants, and findings, which can improve the transferability of the study to similar settings.

Further, to address the reliability of the data, the researcher has taken several measures. Firstly, the interview questions were carefully crafted to ensure clarity and minimize potential bias. Secondly, the researcher made frequent visits to the field over a period of five months to build trust and rapport with the participants, creating an environment where they felt comfortable sharing their experiences. This prolonged engagement helped to establish a deeper understanding of the context and the participants' perspectives. Additionally, the researcher was mindful of the potential power dynamics between themselves and the participants, and took steps to create a non-hierarchical and collaborative atmosphere during the interviews and FGDs. This approach helped to mitigate any undue influence on the participants' responses, further enhancing the reliability of the qualitative data. Therefore, by employing these strategies to ensure the validity and reliability of the data, the researcher aimed to strengthen the trustworthiness and rigor of the study's findings, ultimately contributing to a more comprehensive understanding of the root causes and effects of leprosy-related discrimination in the Zenebework area.

1.7. Limitations of the Study

While the qualitative research approach employed allowed for an in-depth exploration of the research topic, certain limitations were present. Due to inherent challenges in qualitative data collection and analysis, the study faced constraints with respect to sample sizes, timeline, and generalizability of findings.

One challenge stemmed from difficulty establishing trust among some respondents, hesitant to openly share experiences on record. Over five months were spent building rapport within the leprosy-affected community. This time-intensive process, coupled with rigorous data analysis, impacted collection and examination timeframes. Furthermore, the investigation focused primarily on the Zenebework area of Addis Ababa. While an important leprosarium, this single context may not wholly represent experiences elsewhere in Ethiopia. Insights thus have limited transferability to other geographic locales. Small sample sizes were also another factor. Though saturation guided participant selection for interviews and FGDs, incorporating broader samples may have unearthed additional themes.

Despite these limitations, the researcher employed various strategies, such as triangulation of data sources, member checking, and thick description, to enhance the validity and reliability of the qualitative data collected. The insights gained from this in-depth exploration of leprosy-related discrimination in the Zenebework area, however, can still provide valuable contributions to the understanding of this critical issue and inform future research and interventions. While generalizability was limited to the defined setting, the illuminative design effectively addressed core objectives.

Insights still offer valuable contributions to deeper understanding of this issue within the researched community and may inform future related work.

1.8. Ethical Considerations

The study was conducted with the utmost care and consideration for the well-being and rights of the research participants. Prior to data collection, the necessary approvals were obtained, and informed consent was meticulously sought from all participants, with clear explanations of the study's purpose and the measures taken to safeguard their confidentiality. The researcher was cognizant of the sensitive nature of the topic and the vulnerability of the leprosy-affected community, and appropriate support systems were put in place to address any emotional or psychological needs that may have arisen. Confidentiality and anonymity were paramount throughout the research process, with participant’s assigned pseudonyms and all identifying information securely stored. The research findings and recommendations are disseminated in a manner that respects the participants' autonomy and prioritizes their well-being, setting a precedent for future research endeavors within this sensitive domain.

1.9. Operational Definitions

- **Leprosy:** A chronic infectious disease caused by the bacteria Mycobacterium leprae that primarily affects the skin, mucosa of the upper respiratory tract, and peripheral nerves. Manifests as skin lesions and nerve damage that can lead to lifelong disabilities if left untreated. Also known as Hansen's disease.
- **Stigma:** Negative attitudes and beliefs; perceptions that the disease is contagious, hereditary, or results from moral failings, held by community members towards individuals affected by leprosy, leading to feelings of shame and social distancing behaviors such as avoidance or discrimination.
- **Discrimination:** Differential and unfair treatment of individuals affected by leprosy, including in matters of employment, health services access, educational opportunities, civic participation, interpersonal relationships etc., resulting directly from stigma towards their condition.
- **Socio-cultural factors**: refers to the diverse elements embedded within a society's culture and social structures that contributes to shaping attitudes, perceptions,

relationships, and behaviors regarding health issues like leprosy which includes belief systems, religious doctrines, linguistic practices, gender roles, social norms, economic circumstances, educational background, historical contexts, political landscapes, ethnic identities, family dynamics, and influences of healthcare providers that collectively influence how a disease as well as those affected by it are understood and treated within a community.

- **Misconceptions:** Incorrect or mistaken beliefs held about leprosy and people affected by the disease. These may include beliefs about modes of transmission, causes, ability to be cured, and level of contagiousness that are inconsistent with scientific evidence.
- **Affected individual/person:** Anyone who has been diagnosed with leprosy at any point in time. This includes people who may have been treated and are no longer actively experiencing symptoms of the disease but still face stigma due to their previous history or diagnoses of leprosy.
- **Family member:** An immediate or extended family relation such as spouse, parent, child, sibling, grandparent, aunt/uncle, or cousin of an individual affected by leprosy.
- **Community member:** Anyone living or working within the geographical locale of the study, including neighbors and acquaintances of individuals affected by leprosy and their families, but not directly affected themselves.

1.10. Organization of the Study

The study consists of four chapters. The first chapter provides a comprehensive overview of the study, including the background, statement of the problem, research objectives, and the methodology employed. It also outlines the scope, limitations, and the overall organization of the research.

The second chapter delves into the relevant literature, examining the existing body of knowledge on topics related to leprosy, discrimination, and sociocultural factors that contribute to the marginalization of individuals affected by the disease. This chapter situates the current study within the broader academic and contextual frameworks. The third chapter focuses on the presentation and analysis of the qualitative data collected through interviews, focus group discussions, and case studies. This chapter systematically examines the emergent themes and patterns that address the research objectives.

In the fourth chapter, the researcher presents the key findings derived from the data analysis and discusses them in the context of the study's objectives and the existing literature. It offers a comprehensive interpretation of the root causes and effects of leprosy-related discrimination in the Zenebework area and then concludes the study by summarizing the main findings and its implications. It also provides a set of recommendations aimed at addressing the identified issues and promoting the social inclusion and well-being of individuals affected by leprosy in the Zenebework community and beyond.

CHAPTER TWO

LITERATURE REVIEW

In this chapter, the thesis delves into the literature review, providing an in-depth exploration of leprosy and the individuals impacted by this condition. It includes concepts, models historical backgrounds of leprosy, different believes in causes of leprosy, leprosy in Ethiopia, the Ethiopian believes about the causes of leprosy, altitudes toward leprosy and finally leprosy related stigma and discrimination are viewed

2.1 Definition, Concepts and Models of Leprosy Disease

The word leprosy comes from ancient Greek [léprā], "a disease that makes the skin scaly", in turn, a nominal derivation of the verb [lépō], "to peel, scale off" (Worman and Wiles 1999). The word came into the English language via Latin and old French. The first attested English use is in the Ancrene Wisse, a 13th century manual for nuns." On the other hand, according to Hasselblad (1963). The terms "library" and "leprosy" share a common origin, both derived from the Latin term "liber." Cooper asserts that leprosy is a generic term encompassing various infectious skin diseases (Cooper, 1976).

Hansen's disease, commonly known as leprosy, has been assigned different names across various languages and historical epochs. In Ethiopia, during the 4th to 6th century A.D., it was identified as 'lamts,' a term reminiscent of the contemporary Tigregna expression "lamtsi." It also bore other designations like "Quesela Segall" (ulcerated body) and "Talak Dewe" (major disease). Among the Oromo people, it is denoted as "Kurchi," sharing a similar meaning with the previously mentioned terms. The frequently used Amharic term, "Qumetena," is thought to have its roots in the Arabic word "Jadham," connoting "cutting" (Tekle-Haimanot et al., 1992).

Currently, the term "Sega Dewe" is the favored expression, but not extensively utilized. Abissinica Amharic English dictionary translates leprosy as ስጋደዌ ቁምጥና Among the Basutos of South Africa, leprosy was referred to as the Bushman's disease (Ibikunle and Nwokeji, 2017). Additionally, in ancient Persia, leprosy was identified as a Phoenician disease. Throughout history, individuals with leprosy have been known as lepers. In the 21st century, this term is falling into disuse as a result of the diminishing number of leprosy patients. Because of the stigma to patients, some prefer not to use the word 'leprosy', preferring 'Hansen's disease'. The term 'leprosy' is still used by the U.S. Centers for Disease Control and Prevention and the World Health Organization.

There are three systems for classifying Hansen’s disease the first system recognizes three types of Hansen’s disease: tuberculoid, lepromatous, and borderline. A person’s immune response to the disease determines which of these types of Hansen’s disease they have: the second system is World Health Organization (WHO) classification based on the type and number of affected skin areas: The first category is paucibacillary. There are five or fewer lesions and no bacterium detected in the skin samples. The second category is multibacillary. There are more than five lesions; the bacterium is detected in the skin smear, or both. The third system is Ridley-Jopling classification Tuberculoid Hansen’s disease, Borderline tuberculoid Hansen’s disease, Mid-borderline Hansen’s disease, Borderline lepromatous Hansen’s disease and Lepromatous Hansen’s disease (Kothari, 2022).

Over the course of history, leprosy has instilled widespread fear globally due to its severe disfigurements, and those afflicted by it have faced harsh societal treatment and isolation. The way people perceive leprosy directly impacts their attitudes toward disability. However, individuals hold diverse viewpoints regarding the physical deformities caused by leprosy. (Olkin, 2002).

2.2 Models

2.2.1. Moral Model

The moral model ascribes significance to deformity based on an individual's or their family's character, actions, thoughts, and karma. As a result, if leprosy leads to disability, it can be accompanied by stigmatization, shame, and blame, particularly when the deformity is interpreted as a reflection of wrongdoing (Adhikari et el., 2014) In a different perspective, disability (or deformity) can be regarded as an indication of honor, faith, or resilience. For instance, individuals with religious convictions may perceive their own or their family member's disability as a deliberate selection by a higher power, reflecting God's trust in them. Additionally, disability can be seen as a positive reminder of successfully overcoming a significant life obstacle, such as enduring a polio outbreak or surviving an encounter with a landmine(Olkin, 2002).

2.2.2. Charity Model

People with leprosy are often treated as objects of charity and pity. The charity model is an older and outdated model of disability. What it looks like: People in your community assume you will always need help and pity you. You are considered a burden requiring charitable resources for support (Alur, 2021).

2.2.3. Medical Model

Within the medical model, disability resulting from leprosy is perceived as a malfunction or impairment in a particular body system or function, inherently considered pathological. According to this approach, the objective is to restore the affected system or function to a state as close to "normal" as possible. The medical model emphasizes the role of professionals with specialized training as the primary authorities on disability. Individuals with disabilities (or deformities) are expected to comply with the guidance provided by these professionals. The language used within the medical model is clinical and medical in nature, employing terms such as "left hemiplegia" or "partial lesion at the T4 level." This viewpoint is often observed in the realms of healthcare, mental health, and education (Shildrick, 2005).

2.2.4. Social Model

The social model considers disability as an integral part of an individual's identity, similar to factors like race, ethnicity, and gender. In this viewpoint, disability arises from a mismatch between the person with a disability and their surrounding environment, encompassing both physical and social aspects. It is the environment itself that gives rise to obstacles and barriers, rather than the disability being the source of limitations. To address disability from this perspective, the focus is on transforming the environment and society, rather than attempting to change individuals with disabilities. Negative stereotypes, discrimination, and oppression act as hindrances to achieving environmental change and full inclusion (Bampi et al., 2010).

This four-part model provides an overview of how society views leprosy patients, particularly those who have disabilities. the researcher used both medical and social model for this study because deformity and disability caused by leprosy are preventable people can be saved from deformity if they get timely medication in one hand and on the other hand when the deformity is already occurred The environment is responsible for generating the limitations and obstacles, rather than the disability itself, so we must have to change the environment and society the Negative stereotypes and discrimination not the deformity or the already occurred disability.

2.3. Historical Background of Leprosy

Hansen's disease, commonly known as leprosy, is a persistent infectious condition that predominantly impacts the skin, peripheral nerves, upper respiratory tract mucosa, and eyes. This disease can result in gradual and lasting harm to these bodily structures (Sorathiya et al., 2020).

Numerous historians propose that leprosy had a longstanding presence in regions such as India, China, Japan, Africa, and the Mediterranean lowlands centuries before the Common Era (Ministry of Labor and Social Affairs report, 1988). While the earliest unequivocal accounts the origins of leprosy can be traced back to 600 B.C., archaeological findings in Egypt suggest the existence of leprosy as early as 4000 B.C. (Volinn, 1989).

With roots extending as far back as 4000 BC, leprosy has a rich historical background and was observed in early civilizations like China, India, and Egypt. The first documented mention of leprosy on Egyptian papyrus dates back to approximately 1550 BC. There is speculation about the disease's origin, with doubts whether it originated in Asia or Africa. Yawalkar and Vischer (1979) suggest that leprosy likely originated in India, with the first authentic descriptions appearing around 600 BC. The disease may have spread to the Mediterranean region through soldiers returning from Alexander the Great's Indian campaign in 327-326 BC. Early textual descriptions of References to leprosy can be identified in Chinese tomb texts dating from the fourth to third centuries, as well as in legal and medical texts from 300 BC. in India link the disease's origin to Egypt.

According to Basch (1999), the origins of leprosy are believed to trace back to Egypt around 4000 BC. The disease later disseminated to the Mediterranean and Europe through the maritime slave trade, which involved the transportation of slaves from India and Egypt between the 4th and 3rd centuries BC. Children, who were more vulnerable to leprosy and possibly sold due to their own affliction or that of their parents, had the potential to spread the disease in confined settings over extended durations or through prolonged contact during domestic tasks. In Germany, evidence of leprosy dates back to 450 to 680 BC, with a higher prevalence among males than females, suggesting varying levels of exposure to the disease. Moreover, a substantial number of individuals lived for a considerable period after contracting the infection (Catalina, 2009).

Leprosy is a contagious ailment characterized manifested by painful white patches on the skin, and the potential destruction of nerves and tissue. This bacterial infection progresses slowly, leading to damage pertaining to the skin and impacting the nerves in the hands and feet, as well as membranes in the nose, throat, and eyes. Nerve damage results in a loss of sensation, increasing the susceptibility of fingers and toes to injury, ultimately causing deformities associated with leprosy. The diminished sensation in the fingers and toes heightens the risk of injury. (Rogers, 2010).

The onset of the disease is marked by distinctive alterations in the skin. These anomalous changes, referred to as lesions, initially appear flat and red. As they progress, they develop rough shapes and a characteristic appearance. The lesions typically exhibit darker hues at the extremities due to the optimal growth conditions for bacilli at lower temperatures (Goodheart, 2008).

A combination of drugs can effectively treat leprosy. According to data from the World Health Organization (WHO) covering 130 countries, the global annual detection rates declined from 2004 to 2010. By the start of 2010, there were 192,246 registered cases of leprosy worldwide. During 2010, 95% of new cases were reported in countries such as Angola, Bangladesh, Brazil, China, Democratic Republic of Congo, India, Ethiopia, Indonesia, Madagascar, Mozambique, Nepal, Nigeria, Philippines, Sudan, and United Republic of Tanzania, indicating a high prevalence in these regions (WHO, 2016). WHO's elimination plan, centered on the widespread implementation of multidrug therapy (MDT), has contributed significantly to the reduction in the prevalence of registered leprosy cases. The impact of MDT is attributed to the considerably shortened treatment duration (MOH, 2008).

Mycobacterium leprae multiplies slowly and the incubation period of the disease, on average, is five years. Symptoms may occur within one year but can also take as long as 20 years or even more. Leprosy mainly affects the skin, the peripheral nerves, mucosa of the upper respiratory tract, and the eyes. The disease is curable with multidrug therapy. Leprosy is likely transmitted via droplets, from the nose and mouth, during close and frequent contact with untreated cases. Untreated, leprosy can cause progressive and permanent damage to the skin, nerves, limbs, and eyes. There were 127558 new leprosy cases detected globally in 2020, according to official figures from 139 countries from the 6 WHO Regions. This includes 8629 children below 15 years. The new case detection rate among child population was recorded at 4.4 per million child population. Among the new cases 7198 new cases were detected with grade 2 disabilities (G2D) and the new G2D rate was recorded at 0.9 per million populations at the end of the year 2020, the prevalence was 129389 cases on treatment and prevalence rate corresponds to 16.7 per million populations (Prasad, 2010).

2.4. Beliefs in Causes of Leprosy

Misconceptions about the cause and transmission of leprosy have led to negative attitudes towards both the disease and individuals affected by it. In China, there was a belief that leprosy was a punishment for engaging in sexual intercourse with a prostitute (Sermrittirong and Van Brakel, 2014). Similarly, in Greece, leprosy was associated with sexual misbehavior. The Car aka Samhita, an Indian medical text, dating from around the first century A.D explained that "antagonistic diet" as well as untruthfulness, ingratitude, blasphemy against the gods, deriding of one’s elder’s sinful actions, and "the accumulated evil acts of past lives" are the factors that cause leprosy" Despite Hansen's identification of Mycobacterium leprae as the causative agent of leprosy in 1873, many physicians were reluctant to accept his findings and persisted in the belief that leprosy was hereditary. In Zambia, there was a belief that leprosy was caused by witchcraft, In Uganda, the maltreatment of a person with leprosy was thought to lead to leprosy through evil spirits. Some cultures implicated certain types of food, such as fish, or the mixing of food, as causes of leprosy. In certain countries, people were reported to avoid using water from a well if a leprosy patient had used it for fear of transmission (Addissu, 1992).

2.4.1. What does the Bible Say about Leprosy?

According to the National Institutes of Health, leprosy is a disease that has been known since Biblical times. Leprosy is mentioned in various literary works, including In the Holy Bible, the sacred scripture of Christianity, numerous references to leprosy and individuals identified as "lepers" can be found are present in both the Old and

New Testaments. Examples of these references can be found in passages like II Kings 5:1 and Leviticus 13:2.

The spiritual significance of leprosy is first established in Leviticus 14, where God gave Moses instructions on how to handle lepers that were healed. The first mention of leprosy is found in Exodus 4:6 when God spoke to Moses out of the burning bush. God used leprosy as one of three signs He demonstrated to Moses that he would use before the elders of Israel to convince them that God would bring them out of Egypt (Exodus 3:16-4:17). Given the terror that leprosy caused because of its incurable reputation, the ability to heal someone from leprosy was a miracle that would make people believe what Moses had to say (McEwen, 1911).

Later, we see the chapters of Leviticus 13 and 14 devoted to handling leprosy according to the Old Testament Law. This brings leprosy into the realm of having not only cultural fallout, but Spiritual implications as well. In Leviticus 13, instruction was given on recognizing and diagnosing leprosy. However, God also instructed 21 times that the person with leprosy shall be declared unclean. This declaration came with the instruction for the person to be publicly identified, isolated, his garments washed or burned if necessary, and sent to live alone outside the camp if he is not healed.

There are also some parts like Chronicles 26:23 23 Uzziah rested with his ancestors and was buried near them in a cemetery that belonged to the kings, for people said, “He had leprosy.” And Jotham his son succeeded him as king, 2 Kings 7:3 The Siege Lifted Now there were four men with leprosy at the entrance of the city gate. They said to each other, “Why stay here until we die? And on Matthew 10:8 8 heal the sick, raise the dead, cleanse those who have leprosy, drive out demons. Freely you have received; freely give. These references, along with others in the Bible, play a role in shaping misconceptions about individuals affected by the disease. Nonetheless, academics contend that the leprosy concept mentioned in the Bible differs from the contemporary understanding of leprosy or Hansen's disease.

2.4.2. What does the Holly Quran say about Leprosy?

Islamic tradition has various perspectives on disabilities and the leprosy disease. According to Ghaly (2009The statement "Allah (God) does not judge based on outward appearance, but rather on the heart and actions" highlights two significant aspects of Islamic values and the experience of living with a disease like leprosy, which can cause both disfigurement and disability. Firstly, it emphasizes that disability is not a divine curse or punishment. Secondly, it conveys the message that those who are more capable and privileged have a responsibility to understand and assist individuals with disabilities.

Within Islam, various terms have been used in the Quran and hadiths to describe leprosy. For instance, the term "baras" is exclusively used in the Quran to refer to leprosy. Another commonly used term is "judham," which can be found in hadith and sira literature. Interestingly, the verb form of "judham" (jadhama) means "to cut off or amputate," which is believed to be the origin of its association with leprosy in Arabic. For example, one Arabic dictionary mentions that judham causes the skin to "crack." The term "majdhum," derived from the same root, refers to a person afflicted with judham. It is possible that the terms "abras" and "judham" suggest two distinct forms of leprosy (Sierra, 2011).

There are three widely recognized hadiths that discuss Prophet Muhammad's interactions and guidance concerning individuals with leprosy. These hadiths, which hold significant theological importance, have had a profound impact on the social, medical, and legal perspectives regarding leprosy across the Islamic world for many centuries (Dols , 1983).

Regarding individuals with leprosy, there is a well-known prophetic tradition that advises people to distance themselves from a person afflicted with leprosy, comparing it to fleeing from a lion. This implies that associating with a leper could pose a risk to one's life (Rispler-Chaim,2006Another authentic hadith recounts an incident where a person with leprosy came to the mosque to pledge allegiance to Islam. In this narrative, Prophet Muhammad requested the individual to maintain a certain distance, but he did acknowledge and accept the man's allegiance (Al-Tabari et al., 2000). In another hadith, which is considered of questionable authenticity, there appears to be a cautionary message advising healthy individuals to maintain a distance of one or two spear-lengths from those affected by leprosy. In a separate, reliable hadith, it is narrated that Prophet Muhammad invited an individual with leprosy to share a meal with him. The Prophet proceeded to hold the person's hand and placed it in a dish, instructing him to eat in the name of Allah, trusting in Allah and relying on Him (Laila Muhammad and Ragab Eslim, 2021).”

To summarize, while one hadith suggests keeping a distance from people with leprosy, another hadith portrays Prophet Muhammad's compassionate gesture of sharing a meal with and offering support to an individual affected by leprosy (The Islamic view is closer to the modern views held by Judaism—namely, that all events, including disease, are caused by the Divine Will alone, for reasons not always known, and therefore are not necessarily expressions of punishment.

The Quran clearly states that individuals who are blind, lame, or sick are not at fault or to be blamed for their conditions. While the Quran emphasizes refraining from blaming the ill, the presence of these three hadiths, which advise physical distance from those with diseases, may initially seem contradictory. However, they collectively reflect the belief among Muslims that all diseases are a result of Allah's will, while also acknowledging the potential for contracting diseases through close contact with those who are affected. Mohamed (1985) the first two hadiths demonstrate Prophet Muhammad's understanding that leprosy can be transmitted through close contact, likely based on his own observations and experiences. This awareness is reflected in his advice to maintain distance. On the other hand, the third hadith highlights his firm belief in the will of Allah. It signifies his confidence that he would not necessarily contract leprosy through close contact unless it was the will of Allah. Moreover, it emphasizes the belief that contagion is not an independent force but rather subject to the control of God.

Early Islam demonstrated acceptance towards individuals with leprosy, as evidenced by the significant leadership roles entrusted to them. One notable example is Mu'ayqib, a prominent early Muslim from the tribe of Daws who had leprosy (referred to as judham). Like many early converts, Mu'ayqib faced persecution for his faith until he managed to escape from Mecca and, along with fellow believers, seek refuge in Abyssinia. Eventually, when the Muslim community found sanctuary in Medina, Mu'ayqib returned. Prophet Muhammad then appointed him as the custodian of his official seal, a responsibility that he continued to fulfill even after the Prophet's passing (Hasnain,2019).

2.5. Leprosy in Africa

Leprosy has a significant historical presence in Africa, remaining a persistent public health challenge until recent times. Historical evidence, such as Schram's findings, suggests the prevalence of leprosy in Nigeria dating back to 200 BC (Schram, 1971). In the 18th century, South Africa also experienced the common occurrence of leprosy (Laidler, 1971). During the apartheid era, South Africa implemented segregation policies for leprosy patients, separating African and non-African patients in different leprosaria. According to Ralph Schram (1971), Africa accounted for approximately A significant portion of the world's leprosy cases, estimating the total cases between 2-5 million. Nigeria was identified as having the greatest number, around 650,000, with other countries like Sierra Leone, Congo, and Nigeria exhibiting high prevalence rates (48/1000, 22/1000, and 19/1000, respectively).

Even when the effective multidrug therapy became available, there were an estimated 3.5 million people with leprosy in the region. The health infrastructure of many countries continued to be poor. General health workers knew little about leprosy and its control, and stigma persisted. Today, there are still about 30,000 new cases being detected in the African region each year. Leprosy complications which result in irreversible disabilities still affect about one million people in Africa, often, the most vulnerable people living in poor areas. The disease persists as a source of social stigma, discrimination and poverty. Ninety percent of beggars in the cities of Africa are cured of leprosy but have irreversible disability (History of Leprosy, 2000).

2.6. Empirical Literature Review

Well, the review of existing literature reveals that significant research has explored various historical, epidemiological, clinical, and rehabilitation-related aspects of leprosy. However, limited anthropological studies have explored the underlying sociocultural factors perpetuating leprosy stigma.

Historically, societal perceptions of leprosy were largely shaped by religious teachings that associated the disease with sinfulness and uncleanness (Lewis, 1987; Catalina, 2009). Early policy and approaches toward leprosy, including incarceration of individuals in leprosaria, were also informed by these moralizing conceptualizations of the disease (Grange, 2008). However, with Hansen's identification of Mycobacterium leprae as the causative agent in 1873, the medical understanding shifted to recognizing leprosy as an infectious condition (Hansen, 2000).

Subsequent research explored leprosy transmission routes, showing close and frequent contact over extended periods is necessary for infection rather than brief encounters (Premdas et al., 1996). While the exact mechanism remains debated, evidence supports leprosy transfer through respiratory droplets expelled during coughing or sneezing by untreated multibacillary cases (Ramakrishnan et al., 2020). Untreated paucibacillary cases are non-contagious (Comstock, 1980). Contact does not ensure infection as vast populations remain unaffected despite exposure (Addis, 1942).

Despite recognizing leprosy's biological origins, stigma persists due to fears rooted in historical perceptions. Negative attitudes enable continued social avoidance and ostracization. Even in cured individuals, the threat of stigma lingers, fueled by disability visibility (Catalina, 2009). Stigma proves remarkably resistant to change, with societal perceptions persisting despite medical advances (Van Brakel, 2006).

Globally, stigma has profound impacts including social isolation, loss of relationships and self-esteem, economic deprivation and mental health issues like depression (ILEP, 2013; Elizabeth, 2010). Stigma also impedes healthcare through delays in diagnosis and treatment adherence due to fears of discrimination (Van Brakel, 2012). Deformities compound stigma impacts, provoking revulsion and reinforcing perceptions of contagiousness (Gostin, 2008). Effective strategies require targeting underlying causes rather than symptoms alone.

In Ethiopia, despite medical advances against leprosy, stigma and misconceptions remain significant issues (Melaku, 2016). Discrimination towards affected persons pervades daily life, restricting social participation in marriage, employment and community events (Elizabeth, 2010). Reintegrating affected individuals requires holistic programs tackling stigma root causes through community empowerment and education (Nihon Leprosy Association, 2012). This literature review provides context on historical perspectives, transmission mechanisms, perceptions and impacts of leprosy stigma globally and within Ethiopia to inform the current study.

While studies like Demerew (2004) and Rosalijn (2007) examined psychosocial impacts of leprosy in Ethiopia, gaps remain regarding the causal relationships and interactive dynamics between leprosy stigma and discrimination. Similarly, while Melese (2001) touched on popular attitudes, limited research delves into beliefs fueling stigma.

Studies focusing specifically on stigma in Ethiopia, such as Anandaraj (1995), are dated and don't examine underlying sociocultural contributors. More contemporary work like Melaku et al. (2016) surveyed health professionals but did not investigate community perceptions or lived experiences.

Despite Tekle-Haimanot et al.'s (1992) documentation of tolerant historical views towards leprosy in Ethiopia, limited research explores how evolving socioeconomic trends impact stigma. The relationship between stigma and reintegration challenges is also underexplored.

Therefore, by taking an in-depth qualitative approach, this research aims to fill gaps in understanding the root sociocultural drivers of leprosy discrimination. It also aims to generate insights through diverse data sources and methodology to inform culturally appropriate interventions. It explores collective attitudes to stigma alongside lived individual experiences. Further, by delving into historical context and belief systems, the study provides a holistic grounding to examine discrimination's causes and impacts. It seeks to identify misconceptions fueling stigma while illuminating coping strategies. Therefore, the goal is to create an evidence base to reduce leprosy stigma and promote community inclusion of affected individuals through targeted interventions.

2.7. Leprosy in Ethiopia

Leprosy has a long history in Ethiopia, with evidence suggesting its origin from neighboring regions like Nubia and Egypt due to Ethiopia's extensive trade connections with these areas. Research, including "Leprosy, Leprosaria and society in Ethiopia" by Terecha (2010), indicates that Ethiopia's enduring trade and cultural relations with leprosy-affected regions, such as Egypt, the Orient, the Greco-Roman world, and the Arabian Peninsula, position leprosy as one of the oldest diseases in Ethiopia.

Ethiopia has suffered since time immemorial from a high incidence of leprosy, and is indeed said to have been one of the country’s most seriously affected by the disease.' Its existence is well documented in the rich travel literature of the area. The Portuguese priest, Francisco Alvares, the first foreign observer to write a comprehensive account of the realm, testified in the sixteenth century that it was inhabited by "many lepers". The more numerous observers of the nineteenth and early twentieth centuries indicated that little had changed in the intervening years. Nathaniel Pearce, a British resident in the north of the country, declared in 1831 that infection was "very common among the lower class", and that there were "thousands who had lost their fingers and toes", and whose bodies were "covered all over with large white spots" (Pedrotti, 2022).

The first tentative estimate of the country's leper population was made early in this century by Capuchin missionaries at Harar, who put it at 8,000. A decade later, Merab suggested a substantially higher figure. Arguing that there must have been between one and three lepers per thousand of the population, he estimated that there were at least twenty thousand among the country's ten million inhabitants. In support of this view, he asserted that some of his Ethiopian friends, who believed that many lepers concealed their disease, estimated that there were between five and ten per thousand, or a total of at least 50,000. The emperor’s interpreter, Hayla Maryam had indeed spoken of no less than 100,000 but Merab considered this an exaggeration. Merab's conservative figure of 30,000 was nevertheless considerable, for it compared with an estimated 130,000 in all India, 40,000 in Japan, 15,000 in Indochina, and 8,000 in Madagascar (Pankhurst, 1984).

2.8. Ethiopians Beliefs about the Causes of Leprosy

There were diverse beliefs regarding the cause and transmission of leprosy, as observed across various regions globally. Some viewed leprosy as a punishment for sin, as indicated by Tekele Haimanot. Additionally, evil spirits were commonly held responsible for causing leprosy. Certain actions, such as engaging in open sexual intercourse, exposing one's body outdoors, being in the sunshine after coming from a hot environment, approaching a river, or washing with uncovered water at night, were connected with evil spirits and were variously attributed to leading to leprosy.

Leprosy was also considered a warning sign signaling the imminent end of the world (Cherkosie, 1973).

Despite the diverse beliefs about the causes of leprosy, the strong faith in miraculous cures and the belief in the non-contagious nature of leprosy played a role in reducing negative social attitudes. The relative social tolerance towards leprosy in Ethiopia was influenced by the widespread belief in the hereditary nature of the disease (Pedrotti, 2022). In Ethiopia, leprosy has been historically linked to individuals known as "Lalibellas," also referred to as "Haminas" or "the great beggars," believed to originate from Wello, a Northern Province of Ethiopia. It was commonly thought that the earlier "Lalibellas" were leprosy patients, and there is a perception that they, like the present-day "Lalibellas," engage in begging as a preventive measure against leprosy. Both past and contemporary "Lalibellas" could be observed across the country, often seen in pairs, singing loudly at house gates before sunrise, with the belief that the cold morning air helps prevent deformities (Yohannes, 1973).

There exists a folk tale connecting the belief in the inheritable characteristics of leprosy among the "Lalibellas" to a boy who, against his friend's advice to beg and avoid his father's disease (leprosy), ended up deformed (Han et al., 2009). In contrast, leprosy is perceived by some to be a divine test of faith or a demonstration of God's grace, chosen for a particular person. These beliefs, whether directly or indirectly, trace back to the history of St. Gebre Christos. Beyond the general populace's understanding of hereditary transmission, historical accounts from the turn of the century suggested a higher prevalence of leprosy among the Amharas compared to the Oromo people, a viewpoint that gained further support in 1969 with Price suggesting potential genetic susceptibility among the Amharas (Price, 1973).

2.9. Attitude toward Leprosy

Biblical concepts significantly shaped the Ethiopian societal perceptions of leprosy, playing a pivotal role in fostering compassionate concern for patients. The culture of Christian charity became prominent, encouraging handicapped individuals, typically hidden in other African societies, to openly display their suffering to seek assistance. This explains the frequent presence of people affected by leprosy near churches, seeking alms and hoping for miraculous cures.

The Fetha Nagast, containing Ethiopia's traditional laws, significantly contributed to the country's tolerant stance towards leprosy by adopting a humanitarian perspective on this debilitating disease. Notably, the code challenged the notion that leprosy constituted a disability, affirming that the decision to marry an individual with leprosy rested entirely with the prospective spouse. However, the situation differed if the disease emerged after marriage, permitting a man to separate from his wife, provided he offered her a full outfit and dowry. (Gobena, 2016).

Apart from the benevolent principles promoted by the law and the Church, the general population held diverse opinions about leprosy, influenced by widespread illiteracy and limited knowledge of the disease. Ethiopia's people embraced numerous beliefs regarding leprosy's origins, including influences such as a demonic attack, extramarital relations under moonlight, intercourse during menstruation, spirit possession, and hereditary factors. Notably, contagion was not considered a significant cause, contributing significantly to the prevailing tolerant mindset. However, attitudes shifted during the 20th century as perceptions of leprosy's contagious nature evolved, altering the public's stance from pity and sympathy to a more nuanced perspective (Gairhe, 2014).

2.10. Leprosy Stigma and Effects of the Stigma

Stigma, a multifaceted phenomenon with various origins, is frequently tied to the cultural setting in which it manifests. Nevertheless, Leprosy-related stigma exhibits notable similarities across various countries and cultures, presenting opportunities for the formulation of targeted interventions. The stigma associated with leprosy can be defined as the erosion or tarnishing of the patient's authentic identity. Early diagnosis of leprosy can prevent visible deformities or functional impairments. However, in many endemic regions, the norm is to conceal early lesions until disfigurement occurs. By this stage, irreversible disability has often set in (Prochazka et al., 2020). This perpetuates the enduring image of leprosy as a condition leading to lifelong disability, reinforcing the perceived necessity of concealing the diagnosis until it is too late for comprehensive intervention (Chace, 2019).

The stigma of leprosy has three distinct roots: the historical legacy of its being a curse or the result of sin, the physical deformity and disability that result from the disease, such as leonine facies, loss of eyebrows and eyelashes which give away the fact that the individual had leprosy, loss of fingers or toes, and foot drop and the leprosy ulcers have an unmistakable appearance and natural (Singh and Nahato, 2019).

Van Brakel distinguishes between two types of leprosy stigma: public and self-stigma. Public stigma manifests as avoidance or evasion of individuals with leprosy, maintaining a significant physical and social distance between those with leprosy and others in society. It also involves expressing deep repulsion towards the deformities caused by leprosy and a lack of social support in terms of acceptance, employment, financial security, and social connections. Simultaneously, individuals affected by leprosy may experience self-stigma, leading to feelings of self-hatred and loathing. This self-stigma can manifest as low self-esteem, a reluctance to socialize, possibly driven by the belief that others do not accept the knowledge of leprosy, and avoidance of contact with loved ones, either directly or indirectly (Van Brakel, 2006). The stigma associated with leprosy unfolds through various stages. Initially, societal perceptions of leprosy shape the emotional reactions to learning that an individual has the condition. Negative emotional and cognitive responses to leprosy translate into adverse behavior towards the affected individual, stemming from the perceived loss of social value. The culmination of this stigmatization process results in discrimination against individuals with leprosy, coupled with the erosion of their previous societal standing and worth.

Studies suggest that individuals experiencing stigma may encounter emotions such as fear or shame, contributing to anxiety and depression. Consequently, individuals with leprosy might withdraw from social engagements and participation due to anticipated stigma. This social exclusion has economic ramifications for those with leprosy and their households, ultimately leading to impoverished conditions (Somar, 2020).

Individuals facing stigmatization encounter challenges in their marital relationships, face obstacles in securing employment, and experience difficulties in establishing or maintaining employment. Their community interactions, including social connections and companionships are, are negatively impacted. Families affected by leprosy may experience limited access to educational opportunities, leading to disparities and inequalities between individuals with leprosy and those unaffected by the disease. These adverse consequences stem from the community's inadequate understanding of the illness and the widespread misunderstandings surrounding it (Luka, 2010).

The impact of stigma is more pronounced among educated women and within extended families. Women, apprehensive about transmitting the infection to family members, endure persistent isolation and express ongoing concerns about divorce (Chaturvedi et al., 2005). Individuals affected by leprosy often experience feelings of unhappiness, confusion, negative reactions from others due to their distinct appearance, feelings of inadequacy, diminished motivation, and social isolation resulting from stigma (Lusli et al., 2015).

Chingu and Amosun (2013) have documented the deprivation of essential rights for individuals with leprosy, including the right to reside in their birthplaces, access education, and secure employment. This deprivation primarily stems from Individuals affected by leprosy often endure social isolation and grapple with psychological repercussions. Society, driven by a lack of understanding about the true nature of the disease and an exaggerated fear of its consequences, tends to segregate and marginalize these individuals.

The baseline survey carried out in various regions of Ethiopia revealed instances of rights deprivation among individuals affected by leprosy. In Jimma, those with leprosy face restrictions in using river water alongside others. In Addis Tesfa Hiwot, access to religious services, including funeral ceremonies, is denied to individuals with leprosy. In Shashemene, they experienced forceful displacement during the fall of the Derg regime, being compelled to abandon all their possessions (Banchiamlack, 2016).

Hiletework (2016) defines social exclusion as the comprehensive isolation of an individual from various facets of social connections within society. This phenomenon involves a lack of normative integration, restricted social participation, material deprivation, and insufficient access to social rights. Consequently, individuals affected by leprosy are characterized as a marginalized and stigmatized group subject to multifaceted exclusion.

The notion that leprosy is hereditary is deeply ingrained, prevailing widely regardless of individuals' educational backgrounds. This entrenched belief contributes to the stigmatization and isolation of individuals living with leprosy in society. Moreover, those disabled by leprosy face an additional challenge as society perceives the disease both as contagious and hereditary. This exacerbates the shame and tendency to conceal experienced by the family members of individuals disabled by leprosy compared to those disabled by other causes (Nasir et al., 2022).

Leprosy is burdened with deeply ingrained societal stigma, causing fear and prompting the migration of numerous Ethiopians who abandon their homes and loved ones. Common misconceptions, such as the belief in leprosy's hereditary nature or its association with divine calamity, contribute to the erosion of social dignity for those affected. Begging has become a socially accepted practice among individuals with leprosy and in society at large for an extended period (Lancet, 2019). Within communicable diseases, Leprosy is the foremost cause of long-term physical disability. When newly diagnosed leprosy patients exhibit a high disability grade, it suggests a delay in their diagnosis, often stemming from either late arrival at healthcare facilities or misdiagnosis caused by healthcare workers lacking sufficient competence in identifying the signs and symptoms of leprosy.

As the introduction and literature review make clear, leprosy is an ancient disease that has given rise to a number of false beliefs throughout history and different religions. Misinformation about the causes and transmission of leprosy contributes to negative attitudes and discrimination throughout the world. The researcher wants to focus on the root causes and impacts of leprosy discrimination to close the knowledge gap regarding the causes and transmission of this disease as well as the impact it had on the leprosy affected community because in Ethiopia leprosy disease is still believed to be a curse and the work of evil spirits, and as a highly contagious disease as a result leprosy affected people are still discriminated from different social, economic religious and other activities.

CHAPTER THREE

DATA PRESENTATION AND INTERPRETATION

The main goal of this study is to explore the underlying socio-cultural factors and the far-reaching effects of leprosy-related stigma and discrimination in the Zenebework area of Addis Ababa. This chapter presents the accumulated data, achieved from the interviews, FGD and individual case studies. To fulfill this aim, the study developed the following themes: socio-demographic profiles and general information about informants, encompassing both individuals affected by leprosy and those unaffected, causes of leprosy, beliefs in causes of leprosy, leprosy associated stigma and discrimination, and the effect of the stigma/discrimination. All thematic areas were devised in alignment with the objectives outlined at the study's outset.

3.1. Socio-Demographic Background of Study Participants

In terms of gender composition, both sexes (female and males) were included; from leprosy affected informants 9 of them were female and 16 of them were male, and from non-leprosy affected respondent 20 of them were male and 14 of them were female. The informants' ages ranged from 21 to 78, and they included youth, adults, and elderly persons which engaged with pinpointing the root causes and effects of leprosy-related discrimination.

Table 1. Demographic Characteristics of Semi-interview Informants

Variables	Variables Category	N	% of Total N
Sex	Male	14	58.3%
	Female	10	41.7%
	Total	24	100.0%
Age	15-20	3	12.5%
	21- 30	4	16.7%
	31- 40	11	45.8%
	41- 50	5	20.8%

	51-60	1	4.2%
	Total	24	100.0%
Marital Status	Married	10	41.7%
	Unmarried	10	41.7%
	Divorced	4	16.7%
	Total	24	100.0%
Religion	Orthodox	18	66.7%
	Protestants	2	13.3%
	Muslim	4	20.0%
	Total	24	100.0%
Educational background	Secondary Education	2	8.3%
	Tertiary Education	22	91.7%
	Total	24	100.0%

As shown in the table above, 58.3% of the respondents to this semi-interview are men, and 41.7% are women. When it came to age, the majority of interviewees (45.8%) were between the ages of 31 up to 40, while among interviewees marital status, 41.7% were married, 41.7% were single, and 16.7% were divorced. Orthodox Christians make up 66.7% of the population; Muslims and Protestants make up the remaining 40%. All of the interviewees to this question are educated; 91% have degrees, master's degrees, or other tertiary credentials. This data shows the researcher used inclusive data with the aim of acquiring detailed information about the knowledge and misconceptions of leprosy disease in the study area. The researcher used inclusive data from religion, marital status, sex and educational background perspective as can be seen almost all of the interviewees are literates have degrees and living at zenebework area and all of them are the neighbors of leprosy affected individuals.

All of the interviewees, FGD1 discussants and individual case studies informants are originally from rural Ethiopia, outside of Addis Ababa, and had to relocate due to leprosy. And they belonged to three different religions; Orthodox, Muslim, and Protestants although most of them (15) were Orthodox Christianity followers. In terms of marital status, 7 are married, 12 are unmarried, and 4 are divorced. 6 informants are uneducated, and those who are educated span from primary school to the tenth grade. Some informants make a living through trades and small enterprise, but the vast majorities rely are engaged in begging. From the observation and explanation of informants, deformities are present in various parts of their bodies, including their hands, legs, noses, and eyes, all of which have become septic. In contrast, two individuals show no signs of any physical disability.

3.2. Understanding Leprosy

3.2.1. Leprosy and Its Causes

Leprosy, caused by bacteria, stands as one of the oldest diseases affecting humanity called ‘mycobacterium leprae’. The germs are similar to tuberculosis; however, the bacteria’s that cause leprosy are less powerful to infect than TB. The disease affects the skin, the peripheral nerves, mucosa of the upper respiratory tract, and the eyes (Bampi, et al., 2010). According to Centers for Disease Control and Prevention (2019), the disease can cause skin symptoms such as: Discolored patches of skin, usually flat, that may be numb and look faded (lighter than the skin around), Growths (nodules) on the skin, Thick, stiff or dry skin, Painless ulcers on the soles of feet, Painless swelling or lumps on the face or earlobes, Loss of eyebrows or eyelashes. Symptoms caused by damage to the nerves are: Numbness of affected areas of the skin, Muscle weakness or paralysis (especially in the hands and feet), Enlarged nerves (especially those around the elbow and knee and in the sides of the neck), Eye problems that may lead to blindness (when facial nerves are affected) Symptoms caused by the disease in the mucous membranes are: A stuffy nose, Nosebleeds

As key informant Dr. X explained:

> *When someone notices discolored patches of skin nodules like, Painless ulcers on the soles of feet, hands or on their other parts of their skin and muscle weakness they should go to a nearby hospital because mostly this are the signs of leprosy disease. To be honest the transmission of leprosy disease is not*

> *sufficiently studied yet but the current level of understanding on these disease shows it is transmitted more of through breathing droplets from nose when there is prolonged contact with leprosy affected patient.*

Pickersgill (2006), similarly support the above; The exact mechanism by which Mycobacterium leprae is transmitted from one person to another is not entirely clear. Nevertheless, evidence suggesting the bacillus's ability to survive outside the host has led to the current understanding that leprosy is transmitted through the respiratory tract. In cases with a high bacillary load, the mucous lining of the respiratory tract contains numerous bacilli, which can be expelled through activities like coughing and sneezing.

Leprosy is curable disease. The leprosy bacterium exposes only on 5% of world population 95% of the world population immunity can resist the bacteria even the bacteria caught them. From 5% the 15% are able to transmit the disease. The rest 85% can’t transmit the bacteria even if they stayed for prolonged time with any person. Leprosy is a less contagious disease than others. It is also possible to remove this disease from our country, as has been done in other countries. Due to its curable nature, it can be eliminated even from the globe. For instance, there are over 300 leprosy patients receiving treatment at this hospital, yet none of them can spread the illness because patients immediately stop spreading when they begin the treatment (WHO, February 2022)

During the interview, informants have extensively informed and discussed their initial situation in detail. Based on the study's findings, all informants, and discussants were asked about the cause of leprosy disease. The researcher discovered that there is huge misconception about the cause and transmission of leprosy disease among both non-affected and affected individuals. All of the informants and discussants of FGD1, and case studies used to reside in remote and rural areas. They had no access to any health institutions where they could learn more about this type of disease and raise awareness of it. Even though they are aware, they are financially enabled to travel to town for medical treatment.

All informants agreed that they first noticed a small patch before it spread across their bodies. According to discussants from in the first focus group discussion (FGD1), the majority of participants (4 individuals) recalled experiencing the initial symptoms of leprosy during childhood. Despite the passage of time, they vividly remember the appearance of signs such as rashes and nodules on their bodies. And simply treated by their families at home by using various traditional cures like "Tsebel, Emnet," and traditional medications which did not work and they remained at home for an extended period of time without going hospitals. Then their situation became worse and they got physically damaged.

As informant Demke explained:

> *I get infected by leprosy around 14 or 15 years old, and at that time, I had no knowledge about the disease I never heard or seen leprosy affect before. First I noticed white scratches on my legs initially, which later developed into wounds. Despite my condition worsening, my mother took me to 'tsebel bota' (holy water) for a period exceeding three months. As time passed, the problem escalated, and the infection spread to my hands.*

On the other side, three FGD1 discussants and two interview informants stated that as soon as they detected the above-mentioned symptoms, they went to the nearest health station and were told they had skin illness, and the doctor gave them skin cream.

As Tesfaye from the interview mentioned:

> *My problem began around 1965. First, I noticed black and red patches; I thought it is a skin disease. I chose to wait and see if my skin problem would go away on its own; but it didn't. Because of that I want to the nearest health center and the doctor gave me ointment to apply on my skin. I did as the doctor said but there was no change in my body.*

As can be observed, some of the informants, such as Tesfaye, went to the clinic in the early stages of the disease, but a lack of understanding among health professionals became the cause for his deformities.

Semira also mentioned;

> *I was first infected by leprosy when I was nine years old and I had no knowledge of the condition. What I remember is that my mother took me to the nearby health center, and they did not conduct a*

> *comprehensive examination, and they failed to accurately diagnose my disease at that time. They told for my mother that I had a kidney condition and needed to stop eating salty foods, and my mother feed me for more than 2 months without salt but my condition became worse.*

Other FGD1 discussant strength the above idea by saying:

> *When I was a teenager, my ear began to ache for no apparent reason, and there was no visible injury. Over time, the ache worsened, and my parents took me to a clinic and gave me medications, but the medication they gave me couldn't relieve the pain, so I went to a new hospital, where they told me it was leprosy and referred me to ALERT hospital.*

In contrast, Feyesa, Belaynesh, and some FGD1 Discussant used to see a number of leprosies affected peoples in their community the leprosy affects which live far from the town with bounded territory, because of this they keep their symptoms hidden from even their family and become highly deformed.

Discussant

> *Before I was sick I used to see leprosy affected peoples around that lost their hands and feet's and they are named "dhukkuba juuzam or qurcummaa", and most of them were begging sitting around the church. Because of that when I saw the same symptoms on my body I got scared and hidden at home for long time without showing the patch on my body for anyone and I became deformed like you see know.*

Whereas, Tafese, and Aster were aware of the disease because knowledgeable peoples who now about leprosy disease advised them. Consequently, they managed to obtain timely medication and became free of physical disability. Tafese, for example, narrated his condition.

> *While I was shepherding there, a foreign tourist came across me and asked to speak with my family. He informed my father about the leprosy disease and recommended him to take me health center. My*

> *father brought me to ALERT Hospital when I was 12 years old, and I took eight months of medication and became healthy. Thanks to that white person who saved me from deformity.*

On the other hand, informant Merhawit said:

> *After time had passed, a woman who came to visit families from Addis Ababa observed and suggested that I seek medical treatment at the hospital. She said I might be contaminated* by *what we call it in our Area 'ድውየት' so, she advised me. And based on her advice, I went to HAYDER referral hospital. They wrote me a referral to Addis Ababa Alart Hospital and I started leprosy medication. However, after some time, when I became healthy, I stopped taking medicine and lived happily for 10 years. But after ten years the disease recovered and the infection has spread to my body.*

Oppositely, Ayalew narrated his story;

> *I was listening to the radio and they were talking about leprosy and explaining about the symptoms of leprosy and suggesting if you have white patches on your skin you should go to hospital and other facts about leprosy then I realized my skin has the same patches but because of my previous knowledge about leprosy as hereditary disease I didn't pay that much attention to the condition and started living my life but after a few years my condition became worse and I became deformed like you can see.*

As can be learned from informant Ayalew and interviewee Merhawit explanations, The cause of the deformity was not solely attributed to the delay in seeking treatment, sometimes it's because of the wrong believes related to the disease and there are also some people who discontinue the medication after using it for a certain period.

In general, the informants and participants remarked that when they first acquired leprosy, they were at a tender age and the location the place they resided in was secluded and rural. Getting health care was difficult. Even when some of them went to a nearby health center, the health officers were unfamiliar with leprosy and gave them useless ointment or body cream; that worsen the condition. In addition to these obstacles, extensive social isolation and fear of neglect pushed affected individuals to conceal their symptoms and hold off from seeking health care.

Data obtained from those interviewed and participants in the first focus group discussion revealed that their understanding of leprosy was generally inaccurate. This lack of accurate knowledge had significant consequences, leading individuals to perceive themselves as unequal and sinful. Prior to being diagnosed with leprosy, most individuals lacked awareness of the disease, being unfamiliar with its signs, causes, transmission, and treatment. Six interviewees explicitly stated that they had never heard of leprosy before their diagnosis. Among the remaining eight participants, although they had some prior knowledge of leprosy, their understanding was clouded by misconceptions, such as viewing it as a hereditary disease, the work of evil spirits, and other incorrect perceptions.

As was described by informant Tesfaye: *"when it began I saw it as a simple injury later on, when my body became deformed, I lost hope. I think lack of knowledge about the disease is the reason put us here together today."*

Currently, however, most of the studies informants and FGD discussants indicated that they possess a more comprehensive understanding of leprosy. During the interview, informant Feyisa emphasized that the cause of leprosy is not due to personal fault or family sins. He clarified that, like many other diseases, leprosy is caused by bacteria and is not solely hereditary. The same sentiment was reflected during the FGD1 discussion.

> *I perceive leprosy as a condition that impacts the skin, joints, and eyes, revealing itself through indicators like rashes and nodules on the body. It has the potential to cause harm to the hands and feet. The outcomes differ, with some instances displaying rashes that exude fluid while others do not. Should I notice someone exhibiting these symptoms, my advice would be to encourage them to consult with a medical professional.*

Unexpectedly, every participant in this study affirmed that there is no case of leprosy infection within their family. Informant Asnakech proved this, *"I believe that leprosy is not transmitted through heredity because I am the only one in my family with leprosy there must be other reasons for its cause."*

3.2.2. Perceptions of Leprosy Causes

Leprosy, also known as Hansen's disease, is shrouded in myths, fear, beliefs, misconceptions, and superstitions. As outlined in the second chapter, perspectives on the causes of leprosy have varied both across time and among different regions or communities. According to Van T Noordende et al. (2021), whether in developing nations where the disease is prevalent or in Western countries, the behaviors and attitudes of leprosy patients regarding the disease and its treatment are influenced by the socio-cultural belief systems prevalent in their respective societies.

Beliefs surrounding the cause of leprosy are rife with myths, and the majority of respondents commonly held the view that leprosy is connected to sin and deserving punishment. There was a prevailing assumption that leprosy is genetically transmitted and is a visible expression of divine anger or a curse from God, either as a judgment for wrongdoing. Individuals with leprosy often face avoidance due to being perceived as sinful, and those around them fear attracting divine wrath by association. Some even believed they were destined to be affected by leprosy. These study findings align with existing literature, such as in India where Hindus attribute leprosy-induced deformities to divine punishment (Mishra, 2021). A similar perspective is observed in China, where leprosy is considered a consequence of moral failings, particularly through sexual interactions with prostitutes (Hansson, 2021). These cultural beliefs significantly shape the understanding of the disease and impact the perception of individuals affected by leprosy.

Table 2: Causes of Leprosy (Select all that apply)

Assumed causes	**Respondents**	**Percentage**
Bacteria	7	29.1%
Hereditary	3	12.5%
Curse by God	3	12.5%
Immoral conduct	2	8.33%
Unclear environment	4	16.7%
I don’t know	5	20.8%
Total	**24**	**100**

As it is indicated in the above table 2, to better understand community perspectives on leprosy, participants were asked about their views on potential causes of the disease.

As Table 2 displays, informants could select multiple options since beliefs may incorporate more than one causal factor.

The largest proportion (29.2%) identified bacteria as a cause. This demonstrates a scientifically informed understanding consistent with established biomedical knowledge. However, other responses revealed misconceptions still present among some individuals.

12.5% believed leprosy is hereditary in nature. While genetics may play a minor predisposing role for a small percentage of cases, leprosy is not considered an inherited illness. Similarly, 12.5% perceived leprosy as a divine curse or punishment, indicative of religious or moral explanatory models no longer supported by science.

Smaller proportions cited immoral conduct (8.3%), ambiguous factors like an unclear environment (16.7%), or indicated uncertainty regarding causes (20.8%). The diversity of beliefs underscores the need for community awareness initiatives to promote accurate knowledge.

It is also significant that 20.8% of informants stated they "did not know" the perceived causes of leprosy. This substantial proportion unaware of leprosy's underlying origins points to necessary educational outreach.

This study found that 70.9% of respondents did not endorse the scientifically accurate explanations for the causes of leprosy that were provided. However, it is important to note that this conclusion is based on a interview of only 24 individuals, which may not fully represent the broader community's level of understanding. Additionally, not endorsing an accurate response does not necessarily mean the interviwee hold discriminatory beliefs. While this lack of knowledge about the true causes indicates a need for community awareness initiatives, more research would be needed to directly assess how misconceptions may translate into discriminatory actions or attitudes towards people affected by leprosy.

Table 3: Perceived Means of Leprosy Transmission (Select all that apply)

Assumed causes of transmission	**Respondents**	**Percentage**
Causal contact	3	12.5%
Prolonged contact	2	8.33%
Sexual contact	2	8.33%
Contaminated water and soil	2	8.33%
Sharing items I don't know	3	12.5%
	12	50%
Total	**24**	**100**

As can be seen in table 3 only 8.33% of the informants have knowledge about leprosy transmission, 50% of this interview don't know how leprosy transmitted the rest 41.66 of the populations believes causal contact, sexual contact, contaminated water and sharing items with leprosy affected peoples as a way of transmission.

In general, these two data figures indicate that most people consider leprosy as a curse. People living in Zenebework regions are expected to be more aware about the disease's cause and transmission because the majority of people with leprosy live there, but 20.1% don't know the cause and 50.1% have incorrect beliefs.

The results indicate that while some interviewee endorsed accurate explanations for leprosy's causes, others did not. This lack of endorsement does not necessarily mean informants hold firm incorrect beliefs. Additionally, the results are based on a limited sample from the Zenebework community.

More broadly, the findings suggest the need to enhance community awareness of leprosy's true nature and etiology. However, further research directly exploring understandings and attitudes would provide deeper insights to appropriately shape awareness-raising approaches. Directly inferring discriminatory impacts from these results overreaches the data. The study design limitation in only permitting single responses also precludes understanding the full complexity of community perspectives.

The study explored community perspectives on perceived causes and means of transmission of leprosy. Regarding causes, multiple options were selected by some respondents, while others endorsed singular explanations or stated not knowing. Limited conclusions can be drawn due to the small sample size and response format constraints.

Additionally, allowing only single selections for means of transmission precludes fully understanding participant viewpoints. While some endorsed accurate understanding, others did not or were unaware. However, further research directly exploring attitudes would offer richer insight.

These results illuminate topics meriting additional inquiry to appropriately target awareness-raising. At the same time, direct inferences about discrimination cannot be made based on the assessment alone. Variations in perspectives underscore diverse knowledge levels within the population questioned.

More broadly, study design limitations temper interpretation. Findings signal issues warranting more investigation without passing judgment. Community viewpoints represent a dynamic, context-dependent phenomenon requiring nuanced evaluation over time.

Additionally, from FGD2 discussant, only two discussants out of six are aware of the causes of leprosy; they do not know the exact cause but believe it is caused by bacteria, viruses, or organisms we cannot see with our eyes; the remaining four discussants believe leprosy is a curse from God or is caused by evil spirits.

Focus group discussions were also conducted to gain a more in-depth understanding of collective community perspectives on various aspects related to leprosy. Two FGDs were carried out with a total of 12 participants of mixed gender and age groups, including both individuals affected and unaffected by leprosy. This approach facilitated group interactions that yielded insights into shared viewpoints and differences in understanding leprosy's perceived causes and transmission modes within the community. However, limitations in only allowing single responses for some questionnaire questions make it difficult to fully appreciate the diversity or complexity of perspectives that may have emerged through discussion. Future research employing qualitative designs.

Some of the FGD2 discussants believed that leprosy is a sickness caused by evil spirits because some people go to Wizard to do horrible things to people, and God would punish them by infecting their child with leprosy. And historically they heard that "Lalibellas" who lived in Wello area have to beg to prevent leprosy, however, as believe, leprosy is sent by God to test the faith of the victim like Eyob at the Bible and other discussants also supported this idea.

On the other hand, Muslim discussants believes Allah’s (God) punishment as a cause of leprosy, because of what learned in the first hadith greatest Prophet Muhammad repeatedly said escape from the leper as you escape from the lion. Because leprosy is a disease given by Allah as a punishment from wrong doing and being with someone like that might be contagion and not good for the rest of the population. However, the last speaker of this discussion shared walking around river areas at 'keter' time, which is around 6-7 o'clock at mid-day and mid-night as a reason for cause of leprosy since it is a time for wicked spirits to deform people.

On the other side FGD2 discussants believed that the cause of the disease is microorganisms in general it could be bacteria, virus or other particles inters to human body through touch, sneezing or by sexual intercourse. This demonstrates that practically all non-affected FGD2 discussants have incorrect beliefs about the cause and transmission of leprosy disease.

Almost all of infected individuals of interview, however, are unaware of the cause and transmission of leprosy. Only two of the interviewees have knowledge of the cause of the disease and its means of transmission because, when they first saw white patches on their skin, knowledgeable individuals explained to them what kind of sickness leprosy is and how to get timely treatment. The remaining thirteen interviewees were, and some of them still have wrong beliefs regarding what causes the disease.

Among the interviewee Demeke believes that "Rust Iron" is the cause of his illness other female informant Semira thinks ‘’ምች’’ and cold wind as a cause for her disease. Informant Tafese also believe sweat as a cause of his illness ‘*I believe the cause of leprosy is sweat and its transmission is when someone wears another person's shirt, the disease will enter him through the sweat’*

Some of them believe that the cause of leprosy is by nature, curse, and (impure blood) which mean when our bloods became unclean, a cold environment, or some other unidentified incident. Even leprosy affected peoples without deformity like Tafese believed sweat as the cause of leprosy. Besides from this, three interviewees stated that they still have no knowledge of what causes leprosy disease.

Female informant Belaynesh also argues that:

> *First neither my parents nor me have any idea about this disease at all but after I came to ALERT hospital the health workers taught me it is caused by bacteria and transmitted through prolonged contact with untreated person and its curable, but I am not sure about that I don't believe in this idea I think I got infected by this disease because of my bad luck.*

On the other hand, key informant Shaikh /imam Ahmmedin shared

> *Before I became the administrator of Miftah Mosque at Zenebework area, I have no idea about leprosy I never saw leprosy affected peoples in my residence before. After I came to this area, I saw a number of leprosy deformed community. But as time passed, I learned more about what causes leprosy and how it spreads. I had lived in this area for about 11 years. As you see most of our mosque worshipers are leprosy-affects that kid Bilal is also leprosy-affect and has deformity on his hand and he is teaching quran at this mosque for 2 years.*

As religious leader Shaikh/ imam Ahmmedin explained, there are some areas and peoples who have never heard of leprosy or seen a leprosy victim. Ustaz Bilal also added *"In Quran there are some parts talk about leprosy and skin related disease but one time Prophet Muhammad invited a leper to join him for a meal, he took the man's hand and placed it in a dish, telling him, "Eat, in the name of Allah, trusting in Allah and putting your reliance in Him. "This part wants to tell us leprosy is not contagious disease if you truly believed in Allah".*

The above views shows that there is no common traditional beliefs and perceptions about how the diseases is caused but all The aforementioned beliefs are typically negative and often insinuate that the affected individual or their families have committed some wrongdoing, bringing the disease upon themselves.

On the other hand, some informants explained that first they don't know about this disease at all, they used to think it was Gods punishment for their parents' deeds. According to informant Asnakech *"After coming to Addis Ababa ALERT hospital, I realized that it is not an inherited illness and that it is incurable; it is just like any other disease that causes suffering on people, and anyone who gets to the hospital early would be free of any impairment."*

The stigma associated with leprosy hinders patients from seeking early treatment, and as a consequence, they often present themselves in the later stages of the disease when it becomes more easily identifiable. (Speeckaert and Van Geel ,2017).

As Key informant Dr X "*Leprosy is a treatable disease, but if you ask me peoples are recovering, I would say no, because patients are not receiving timely medical care due to negative believes and fear and misunderstanding regarding the disease's causes as God's judgment that's why you see too many deformed patients here."*

Dr. X's explanation demonstrates that leprosy is a treatable disease. Untreated, leprosy can cause permanent physical disabilities and damage to a person's nerves, skin, eyes, and limbs, but this is due to a lack of awareness and wrong beliefs about the disease's cause and transmission. Almost all patients arrived at ALART hospital for therapies are deformed, however they can be saved from any kind of impairment if they receive timely medication.

3.3. Leprosy-Related Stigma and Discrimination

A stigma is a characteristic that subjects an individual to disrespect and disregard, stripping them of social advantages by labeling them as disreputable (Ocran, 2023). Beyond the physical challenges posed by the disease, leprosy-related stigma acts as a barrier, instilling fear and portraying the affected individual as a potential threat to society, leading to subsequent rejection (Rohman, 2018).

As per information gathered from interviews, FGD1 participants, and individual case studies, leprosy stigma has had profound impacts on the research participants across various aspects of their lives. It has adversely influenced their relationships with family and friends, posed challenges to their psychological well-being, and impeded their opportunities for employment and financial stability. The manifestation of stigma is evident in areas such as marriage, friendships, workplace interactions, and participation in social ceremonies. Notably, the relatives and spouses of the informants have also experienced stigma and exclusion. Despite some positive shifts in community attitudes, the participants highlighted that they continue to face challenges from the time of learning about their leprosy diagnosis.

Concerning the contagious nature of the disease, the results reveal that from 24 semi structured Interviewee 20 of them see leprosy as a highly contagious disease.

Table 4. Contagious of Leprosy

Highly contagious	**Respondents**	**Percentage**
Yes	20	83.33%
No	4	16.7%
Total	**24**	**100**

According to the informants, 83.33% of them think leprosy is highly contagious disease and fear is frequently discovered to be the cause of these negative views of leprosy, such as anxiety of catching the disease or worry of becoming contaminated and only 16.7% know that leprosy is less contagious disease. According to these statistics, understanding the exact level of contagiousness of the leprosy disease may help leprosy-affected populations from stigma because most stigmas stem from fear of contagion.

The study found that participants experienced various forms of stigma, including distancing, discrimination, and familial isolation, from friends, coworkers, and the broader community as it is evidenced from the interview and FGD data. Informant Feyesa stated, *"My families are my enemy. I have been away from them due to this illness, and I haven't been able to get in touch with them. When I first became ill, my family used to act awkward, they wouldn't even eat with me or in front of me. My mother even separated her plate, no one in my family eats by that plate I touched."* Similarly, FGD1 discussants shared experiences of being ostracized by their communities. As one participant mentioned, *"When I left my village and came to*

Zenebework, the attitudes of my neighbors became much more negative. They would avoid me, and some even refused to greet me on the street."

The study found that while 62.5% of the respondents believed leprosy is curable, 16.7% still considered it an incurable disease which suggests that misconceptions about the treatability of leprosy persist, even if the majorities have accurate knowledge.

Table 5. Curability of Leprosy

Response	**Respondents**	**Percentage**
Yes	15	62.5%
No	4	16.7%
I don’t know	5	20.8%
Total	**24**	**100**

As indicated in the above table, when it comes to curability of leprosy 62.5% of the informant have the knowledge that its curable through treatments which is good but 20.8% of those semi structured interviewee are unaware if the illness is curable or not. 16.5% feel leprosy is an incurable and unusual kind of disease, and as a result, people are afraid to communicate with leprosy affected persons.

3.3.1. Stigma from Family

The information gathered from interviews, focus group discussions (FGD), and case studies reveals that when symptoms of leprosy manifest in a family member, the family often experiences profound shock, fearing societal discrimination. Consequently, family members respond unfavorably, subjecting the affected individual to mistreatment, rejection, and forcefully expelling them. The majority of participants in the study pointed out that the challenges of stigma originate within their families, as many of them come from families lacking knowledge about the transmission and causes of leprosy. Consequently, they face stigma from their own family members. A significant number of interviewees, participants in FGD1, and individual case studies reported being abandoned by siblings and parents due to the deformities caused by leprosy.

As informant Feyesa stated*, “My families are my enemy. I have been away from them due to this illness, and I haven't been able to get in touch with them. When I first became ill, my family used to act awkward, they wouldn't even eat with me or in front of me. My mother even separated her plate, no one in my family eats by that plate I touched.”*

Informant Gaddisa also added “*I always preferred to be alone because of the discrimination I face from my family mainly, my father. My brothers and sisters stopped playing with me. That’s why I am here. Leprosy is the worst disease.”*

Case 1 also strength how far the stigmatized and discrimination gone by family members

His name is Addisu, and he was born in 1978 in the Mirab Shewa Zone of the Oromia region from his farmer parents. He was an ordinary boy who lived with his parents and six siblings. He is the fourth child in the family. He had a normal childhood. He attended school until eighth grade, but was unable to further his education. He began working on his parents' farm. He was very pleased with his life; he has perfect personal relationships as a sibling with his brothers and sister; he also got some farm land from his parents and became a good farmer; and his parents used to appreciate and respect him. But at the age of 30, he began to notice rashes on his skin and later wounds on his foot, but due to his lack of awareness, he ignored the symptoms. After a while, his leg got wounded and wounds severed, and he couldn't walk any longer; the pain in his back and knees rendered him and the damage was getting serious.

His problems in life began there. A self-awareness of being a less valued member within the family, it is not only the society that stigmatizes him, even his families refused to see him. They dislike him because of the believe causing them shame and embarrassment. His brothers continually encouraged him to leave that region and relocate to another, but he refused, telling them that this is his village and community where he grew up and that he couldn't leave. His brothers even taken away his farm land, and he became further isolated from his family. His sister was similarly terrified because of the notion that leprosy was a genetic disease or a curse from God, which will make it difficult for her and her brothers to marry the person they like to marry.

That's how they meant to kill him; they prepared the grass house, and when he came in, they locked all of the doors and windows and started a fire to kill him, but one of his neighbors saw this and saved his life. That day, he ran away from death and arrived at ALERT Hospital after three weeks of suffering in a way. This idea has reinforced herein below under the following Table 6.

Table 6 Ashamed if someone has leprosy in your family

Response	Respondents	Percentage
Yes	19	79.1%
No	5	20.8%
Total	**24**	**100**

As indicated above, 79.1% are ashamed of someone has leprosy in their family because of the fear of discrimination of the society. Only 20.8% of them assured leprosy is like any disease there and no need to be ashamed of it.

The research reveals that during crises, many families lack an understanding of the requirements of individuals affected by leprosy, often becoming an additional source of difficulty. Moreover, families tend to keep the condition of a leprosy-affected family member concealed, refraining from disclosing it to neighbors and even relatives. This concealment not only exacerbates social, psychological, and physical harm but also adds to the challenges faced by those affected by leprosy.

As informant Abera explained his situation

> *When I was 23, I was diagnosed with leprosy. At first, I lost feeling in my hands, and three of my fingers became deformed. My parents kept me hidden at home, and when our neighbors asked about my disease, my parents told them that when I was harvesting grain, the Reaper cut off my hand, and the evil sprite got me (ልክፍት). Nobody knows that I am a leprosy patient. Because if people find out, my family will face discrimination in every part of societal life; they won't even be able to attend church freely as previously.*

The majority of FGD participants discussed. Except for three, they are all forgotten by their families; usually, once affected individuals have departed the area, neither they nor their relatives desire their return, because of their families being unhappy with their condition; they are so discriminated. That’s why they moved to zenebework area and started their own families. Female informant Zenash also said *“I don't have a family all of my families are dead I only have some relatives and they don’t like me”.*

Furthermore, participants in the study emphasized that the children of individuals affected by leprosy are subjected to stigmatization at an early age, as neighboring communities near the settlements label them with derogatory terms. These children endure insults like "Yekomata lij" in Amharic, which translates to "child of a leper," along with other demeaning expressions.

Belaynesh from the interview described her situation in detail: Before she left her residence, her husband’s family regularly treated her unfairly and insulted her; she struggled to survive; however, in the end, neighbors and her husband’s family began to refer her children’s as "yekomata lji," which was extremely offensive; as a result, she ran away from that village with her three children’s. This indicates that the offspring of individuals affected by leprosy are also subjected to intolerable stigmatization. However, in some cases few interviewees mentioned that their families were supportive when they first find out they are leprosy victims. They tried to give them timely medication they even survived the stigma and gossip of their neighbors and community to make their children strong.

3.3.2. Stigmatization from Society

Across the world, there are well-known leprosy colonies. Leprosy colonies are areas where victims of leprosy are gathered and dumped. Leprosy affected peoples sexually interact and form their own leprosy community members, which is known as a leprosarium (Ramos-Toro, 2023). Ethiopia has several leprosy colonies, including Addis Ababa, Jimma, Shashemene, Awash, Hawasa, and Harar. There are also regions where leprosy affected people's residing areas are marked by yellow like in Hawasa, allowing non-leprosy affected individuals to clearly identify the areas. The oldest one in Ethiopia is Zenebework which the Emperor Haile Selassie at that time decided to settle leprosy affected persons, and then Zenebework hospital now called Alert Hospital was the residence and donation of the emperor’s daughter Princess Zenebework as leprosy medical center.

As the 78-year-old elderly religious leader G/meskel explained in a cheerful tone:

> *I lived in this area since I was a child this area was highly forested at the time and was home to a variety of wild creatures. The leprosy-affected people were thrown in this remote area outside of town, male and female leprosy victims were separated, and they were denied the right to sexually connect and replace themselves because it was believed that leprosy was genetically transmitted, however it's hard to prevent people from having sexual interactions because it is human nature and no one can avoid it. Even when they dumped Addis Ababa rubbish at Koshe, it's difficult to say that their intention was positive. To be honest the rubbish created job opportunity for this community but we don't have to forget during the Koshe's demolition at 2009, the majority of the people who died were leprosy affected peoples. Any way this is how the Zenebework area came to be; it was originally just a residence for leprosy victim and their family however as you can see, it's a hometown and a heavily populated place now.*

Key informant Tadese added that:

> *Until recently Children of leprosy affected family were denied the opportunity to learn alongside their peers. Because of the high level of discrimination, they will experience if the school community and other students discover they are from Zenebework area, they will face severe discrimination. As a result, the students conceal their origins, claiming to be from Mekanisa, Ayertena, Alembank, and other nearby areas. Some leprosy-affected families were also forced to relocate. But know the situation is different than before there is some good changes.*

Diakon Kidanemariam also explained:

> *I use to worship at this abueargawi/geberekiristos church since I was a child, and 5 years ago I became daikon. I always feel confident at this church the worshipers came to this church don't discriminate me they give me a respect I also teach wodase Mariam and mister selasse for kids and teenagers, but I remember more than once at abunargawi (kebrebeal) after (kidasse) some people were afraid and disgusted when they saw my hand as I was pouring them ahoy water to drink. I*

> *believe they were unfamiliar with the leprosy condition except that these areas societies don't consider my deformity at all.*

The study participants and discussants experienced societal stigma from friends, colleagues, and neighbors throughout their lives. However, they noted that the stigma is comparatively lower in areas like Zenebework, a leprosarium, where residents share similar conditions. Additionally, non-affected residents in Zenebework exhibit better awareness of the condition compared to those in other parts of Addis Ababa.

Table 7: Awareness of Leprosy Prior to the Study

Heard about it	**Respondents**	**Percentage**
Yes	17	70.8%
No	7	29.1%
Total	**24**	**100**

As the above table shows from 24, 70.8% of them have prevalent knowledge about leprosy disease because most of them started living in the area long time ago and have better understanding of the disease; only 29.1% are unaware about leprosy.

Nevertheless, stigma persists from neighbors and non-affected families towards individuals affected by leprosy, particularly when they seek services from various institutions such as kebeles, clinics, and markets. They often face underestimation, negative attitudes, and inadequate service. Although there have been some advancements, participants and discussants noted that societal stigma continues to affect them in their daily routines. Most FGD1 discussants and interviewee informants said that different kinds of service givers located in Zenebework areas are significantly better at serving leprosy affected peoples, because they have at least a basic understanding of the disease. But even in the twenty-first century, numerous forms of prejudice from the community are still affecting the affected residents.

Informant Feyesa strengthen this idea:

> *Now I live in this area organized with people and working in small enterprise business, but before that, I wanted to ask about organizing in one to five methods for work at Arada Sub City but they were unwilling to put me through that process and were not even happy to*

> *give me a chair to sit down because they had no idea and knowledge about my disease. The people in woreda 01 or kirkos sub city, on the other hand, were so respectful that they were pleased to give me a chair and sit down next to me, even while my crunch was full of the ground; they picked it up and gave it to me without any disgust.*

The truthiness of the above idea is shown in the following table

Table 8. Willingness to sit beside a person affected by Leprosy

Response	**Respondents**	**Percentage**
Yes	17	70.8%
No	7	29.1%
Total	**24**	**100**

According to the above table 70.8% admit to sit beside leprosy affected person because they have the understanding that leprosy cannot be transmitted through touch and sharing materials, only 29.1% of them have some kind of fear to sit and share things with leprosy affected person.

Stigma confines individuals affected by leprosy to live exclusively in leprosarium areas, limiting their full social integration compared to others. This exclusion extends to their active participation in developmental initiatives, where they face unequal opportunities in education and employment. Moreover, some neighbors are not even happy to rent their houses to individuals affected by leprosy as informant Mubarek explained: "*One time I went to the neighborhood Searching for a home and I found one but the women who rent the house saw me and said I don't rent my house for ''komata" her talk shocked me and I kicked her by the crunch then some people came by and stopped me from killing her."*

Table 9. Willingness for your family member to marry someone from a family with leprosy history

Response	**Respondents**	**Percentage**
Yes	14	58.33%
No	4	16.7%
Not sure	6	25%
Total	**24**	**100**

Due to the fact that 58.33% o have no issues with allowing a member of their family to marry someone from a family who has the disease, it suggests their previous knowledge of leprosy is not that it is hereditary. However, 25% of the samples are still unsure of what they would do if their family wants to marry a leprosy-affected person. Additionally, 16.7% of the population would restrict their family from marrying someone from a leprosy-affected family.

Nevertheless, some participants clarified that there is currently a positive shift in people's attitudes especially in a city like Addis Ababa. FGD 1 Participant during the discussion said*: "In the past, if you are living with leprosy and became deformed nobody would want to come close to you." Now, the situation has changed. Healthy individuals interact with us without any issues. For instance, I married a wonderful woman who is not affected by leprosy, and we have healthy children."*

Based on the insights gathered from the first focus group discussion, the community tends to view the illness as a curse or a deserved punishment for individuals who have committed sins. There is a misconception that the sickness is highly contagious and can be transmitted through direct touch or the contamination of shared items like water or food. According to one of FGD1 discussant, *"We are prevented from accessing community resources like water as we all know there is high scarcity of water in our area the water comes once in a month because of that we have to buy bono water our neighbors are not willing to use that water once we pore from it."*

A significant number of discussants shared their encounters of people reacting with caution when they see them, often placing their hands behind their backs. People tend to avoid giving greetings through physical touch, especially after the onset of

COVID-19, adopting a practice of maintaining a two-foot distance. There is a prevalent belief among fifty percent of respondents that leprosy is highly contagious and can be transmitted through various means, including direct contact, airborne transmission, communal eating, and sitting together.

3.3.3. Self-Stigmatization

The challenges related to leprosy stigma stem from the attitudes and emotional responses of both individuals affected by leprosy and those with whom they interact. There is rampant discrimination against leprosy victims and their families. The discrimination is demonstrated by social and public participation. This leads to negative attitude on leprosy affected peoples about themselves. (Seo and Song, 2019) Contending that emotions like fear, shame, low self-esteem, isolation, or a sense of being different are all indicative of self-stigma.. The way leprosy affected persons named is also derogatory. Victims of leprosy are highly stigmatized low self-esteem and negative emotionality which emanates from societal negative attitude about them.

As Demeke shared:

> *Because of the pervasive stigma and discrimination coupled with the inherent characteristics of the disease, I experienced profound unhappiness, leading to a significant decline in my morale. Upon attending church, I noticed people actively distancing themselves from me, prompting me to adopt a self-imposed isolation. Even during social gatherings, Because of the stigma and discrimination I face due to my physical deformity and handicap, I usually choose to sit alone.*

Every individual interviewed and all participants in FGD1 acknowledged engaging in self-stigma, attributing it to various factors. They highlighted the stigma and discrimination directed at them by family, relatives, friends, and the broader community following the onset of their infected wounds, physical deformities, and disabilities as the primary reasons for self-stigma. The unpleasant odor emanating from their infected wounds was identified as an additional factor, making them feel ashamed to interact with others who might be repelled by the smell.

The study's findings also revealed that numerous individuals affected by leprosy tend to conceal themselves from the public eye, fostering a sense of secrecy. In a similar vein, Oexle and Kawohl (2016) asserted that it shouldn't come as a shock if leprosy-affected individuals persist in keeping their condition hidden from employers, colleagues, and others, recognizing the potentially severe consequences if their condition were to be exposed.

As articulated by all leprosy-affected participants in this study, the primary reason for self-stigmatization is their anticipation that society harbors unfavorable sentiments towards them and perceives them as undeserving of equal respect. Moreover, despite some improvements, the leprosy victims themselves acknowledged that they possess limited knowledge, inaccurate attitudes, and feelings about the disease, with many being unaware of its root cause. The findings indicate that individuals affected by leprosy distance themselves from friends and family not only due to the fear of infecting others but also because of the apprehension of encountering discrimination. Informant Belaynesh explained that “*When I first know about my disease, I isolate myself from everything before anyone.”*

Informant Tesfaye also added:

> *Before I became ill, I rarely saw people who were affected by leprosy around the church. I disgusted and exclude them because I used to believe leprosy was a hereditary disease and a punishment from God for wrongdoing. But when I was 24, I was affected by leprosy, which was unacceptable to me, and my self-esteem decreased, I isolated myself and began living in shadow.*

A number of informants continue to believe that leprosy is caused by a divine curse, a consequence of their family's past wrongdoings or "Tinkola." This belief persists among a majority of interviewees and FGD participants. Such The firmly held beliefs further contribute to the misconception that leprosy is untreatable, fostering negative attitudes towards themselves.

FGD 1 discussant shared:

> *I never consider myself to be as an equal person with others who are not leprosy-infected. With injured legs, my physical look is terrible. What I sense is that other people don't like me and don't want to be around me. As a result, I became less confident in my ability to engage*

> *in social interactions and get employment. I feel comfortable to stay home by myself.*

Only five informants felt that leprosy is like other diseases. However, The majority of informants emphasized that their perspectives are evolving over time.

Informant Asnakech mentioned: “*There is now an advanced medicine that, when given to someone who has the disease, with God's aid, makes them well. It is essential for us to be resilient and hold self-respect; without self-respect, gaining acceptance from others becomes challenging. We should foster confidence in ourselves.*

On the contrary, individuals without physical deformities are hesitant to disclose their leprosy infection. Informants like Aster and Tafese expressed a desire to conceal their condition since they lack disabilities, making it challenging for others to recognize them as leprosy-affected. The fear of stigma compels them to maintain silence about their health. Overall, the study's findings indicate that many informants grapple with self-stigmatization throughout their lives, fostering a sense of being unwanted. Nevertheless, there is a positive shift as participants are gaining a better understanding of leprosy and are beginning to value themselves more.

3.4. Effects of Leprosy-related Stigma and Discrimination

From this study in most cases, all aspects of a leprosy affected person’s life are negatively impacted. The repercussions of leprosy stigma can inflict more distress than the symptoms and physical consequences of the disease. Derogatory words also have impact on leprosy affected persons. As some FGD1 and FGD2 participants explain leprosy is known as “*Dweyet*, Dush, *Kumtena*, *Dremen*, *Dhukkuba* juuzam or *Talaqu Dawe*” (the major disease), due to its multi-dimensional impact on marriage, employment, education, social interaction and psychological instability and additional dimensions of the individuals affected, their families, and relatives.

3.4.1. Effects of Stigma on Marriage

Marriage, an ancient and multifaceted social institution, serves as a foundational element that ensures the survival of human society and fosters social cohesion among diverse groups. In Ethiopian society, marriage holds significant value and respect, with historical accounts suggesting that the Ethiopian nobility strategically utilized marital alliances to maintain peace and order within their territories (Girgis et al., 2011). However, for individuals affected by leprosy, as well as their descendants facing the intergenerational effects of leprosy stigma, marriage becomes a complex and challenging matter. Many communities avoid establishing marital connections with leprosy-affected individuals or their families due to misconceptions about the disease's hereditary or sexually transmitted nature. There is also a prevailing belief that families with leprosy are cursed, and forming unions with them may incur divine wrath. Even those with knowledge of the scientific nature of the disease may abstain from such ties, fearing societal pressure (Try, 2006).

The results of this study indicate that the difficulty in marriage begins with the family. Families typically experience severe shock when a member of the family gets leprosy symptoms because they believe that their other relatives will face prejudice and marriage isolation because any siblings will be viewed as probable leprosy carriers. As a result, the affected person experiences unfavorable mistreatment, rejection, and forced separation from the family.

Once leprosy affected people have left the area, they typically don't want to go back, and neither do their family member, which causes a permanent separation with families returning home. That weakens familial ties and ultimately results in isolation.

Informant Gaddissa from the interview described his situation:

> *When I became deformed, the first challenge for me was my families, especially my siblings, who were so mad at me because I became an obstacle for them to get married; my sisters rejected me so that I ran away and came to Addis Ababa; I really missed my families so much but I couldn't visit them. I haven't seen or spoken with them for 13 years.*

FGD1 discussants claimed that leprosy affected peoples find it extremely difficult to start dating people of the opposite sex and settle down, especially with partners from healthy communities. The emotional pain they experienced in the early stages of the illness and the subsequent self-stigmatization prevent the majority of them from even considering marriage relationships as evidence from 25 leprosy affected informants of this study 12 of them are unmarried and 4 of them are divorced.

Female informant Asnakech noted:

> *I'm 33 years old now, but due to my deformity, marriage is still impossible for me. I haven't had any romantic or sexual relationships until know. Leprosy has been a significant factor in my current single status. Many individuals expressed interest in dating and marrying me until they became aware of my situation but after they knew they dropped me repeatedly because I am leprosy affected woman.*

The majority of FGD1 participants and interviewees stated that due to the misconception that sexual intercourse is a way of transmission, it is difficult for them to marry a healthy partner, so they are compelled to begin their marriages with people of their own kind, and some of them are married and have healthy children as a result of this study shows. FGD1 discussants indicated “Children born from leprosy-affected households will marry from leprosy-affected families, and the cycle will continue this way.”

On the other hand, FGD2 participants discussed another option for getting married is marrying someone from outside their society, where they hide their history and make up stories about their parents and origins. Some claim that they were raised in an orphanage or that their parents passed away.

FGD 2 discussants noted one of the tense and stressful moments in relationships is the time of informing Disclosing that you are a child of leprosy-affected parents or revealing it later in a relationship can pose challenges, especially for those who married while hiding their background. This situation often leads to reduced or severed connections with parents due to the need for secrecy, creating difficulties in maintaining family ties. The most challenging aspect for those concealing their background arises during family deaths. In Ethiopia, mourning is a well-established and unavoidable tradition, involving physical presence. If one fails to introduce their parents during mourning, questions may arise about why they concealed their family, leading to offensive inquiries such as being labeled as "komata."

Case 2 strengths the above idea. As the case study explains that;

> *Debremarkos is where I was born and raised. I was infected with leprosy when I was 11 years old, and at the time, there were foreign doctors visiting rural areas and administering leprosy medication.*

> *They found me when I was playing and talked with my parents and gave me medical treatment, and the sickness was stopped before I became deformed.*
>
> *In the age of 17 I became engaged to a man subsequently, my husband and I embarked on a fulfilling journey together, sharing a deep and affectionate love for each other. My parents and I kept my illness a secret because I had no physical deformities. We give birth to two children, a boy and a girl. We both had jobs, and we raised our kids together we were happy family. But after 13 years the symptoms of leprosy disease appeared again on my body, including my face. During this period, the local community started to suspect that the visible signs on my body were indicative of leprosy. I wasn't particularly worried as I believed it wouldn't have a significant impact on my life.*
>
> *I start talking medication from ALERT hospital every month, but as my disease worsened, I was forced to leave my job and stayed at home. Subsequently, when my husband's parents learned about my condition and visited, their entire family began exerting immense pressure on him to leave and distance himself from me. Particularly, his mother expressed her concern, stating that she didn't want their family lineage to be associated with leprosy sufferers, using the term 'komata.'*
>
> *My husband's family continually questions him about why he married me and ultimately convinced him to divorce me. Then we started arguing all the time. He began to blame me isolating him from his families due to my leprosy, and he forced me to leave our home. I contended that I was not a leprosy patient because my hand and leg were not deformed; I insisted that I had another condition. However, his parents even started insulting my children every day, and I couldn't tolerate it, so I relocated to Addis Ababa Zenebework area with my two children. I am now assisted by Addis Ababa Leprosy Association and doing well.*

As can be seen from the above case study, the onset of leprosy frequently leads to the dissolution of existing marriages, even among couples with children. Both the participants in FGD and those interviewed acknowledged that their marriages ended upon the discovery of their leprosy, driven by concerns about contagion on one side and societal pressure on the other.

In opposite to this some peoples got infected by leprosy after marriage one of FGD1 discussant shared his situation as:

When I reached marriageable age, I got engaged to a woman, and we began building a life together. However, as time passed, nodules (indicative of leprosy) started appearing on my body, including my leg. The condition worsened, leading to eruptions on my leg. I attempted to hide my health condition from my wife and kids because I was afraid of the stigma attached to leprosy. However, I couldn't keep my disease hidden forever, and when my wife found out, she chose to divorce me.

On the contrary, some interviewees stated that there is a better understanding of the disease, particularly in Zenebework and nearby locations. They are married to non-leprosy affected people, have children, and are still happy. One of the FGD1 participants were non-leprosy affected women who came for this discussion by representing her leprosy affected husband.

3.4.2. Effects of Leprosy Stigma on Employment Opportunity and Economy of Individuals Affected by Leprosy

Discrimination in employment poses another significant challenge. Due to the prevailing belief that leprosy-affected individuals are incapable, and reluctance from others to work alongside them, employers are unwilling to hire them. Consequently, their involvement in productive sectors and various public spheres is severely restricted. The study reveals that some respondents were employed in their own village, organized within an association, working at their level, and receiving a monthly salary.

The primary economic impact of leprosy arises when an individual affected by leprosy becomes disabled, making it challenging to generate personal income. The diminished employment opportunities stem from the broader issue of leprosy-related stigma, influenced by employers' attitudes. Prejudice often prevents many individuals affected by leprosy from securing paid employment. Begging frequently becomes the most lucrative and least physically taxing option for those disabled by leprosy.

In many instances, a lack of knowledge and accurate information about leprosy contributes to the misconception that the disease is highly contagious, leading to the assumption that anyone in contact with an affected individual is at risk. Additionally, if the person exhibits visible disabilities, their chances of securing employment become almost nonexistent. In the workplace, this presents a significant and unwelcome challenge, resulting in the stigmatization of employees with leprosy. Colleagues may decline collaboration, customers may refuse service, and business relationships may be terminated—all exacerbated by the presence of visible deformities.

Informant Ayalew brought up *“No one was able to offer me a job because of my condition. I made an effort to find daily labor, but nobody seemed interested. Even though I attempted to work for a lower salary than others, they refused me the position which is why I initially started begging. Leprosy is an awful illness that turns a person into a beggar.”*

According to the study's findings, there exists a significant correlation between leprosy and poverty. Several informants affected by leprosy and key individuals have highlighted that when left untreated, the disease often progresses to physical deformities. it might incapacitate people. Another discovery from the study indicates that individuals with disabilities (PWDs), especially those affected by leprosy, encounter difficulties in securing equal job opportunities. According to the informants, they often experience unfair treatment during job applications, with employers displaying a lack of confidence in hiring PWDs, including those with leprosy. Additionally, some employers refrain from hiring them due to concerns about potential customer loss.

Several individuals affected by leprosy who participated in interviews for this study described facing challenges related to poverty and low socioeconomic status after losing their jobs due to stigma. Informant Mubarek, a 50-year-old man from Zenebework who contracted leprosy 10 years ago, shared his experience of being unable to find work after developing the disease. He explained that once his employer discovered his condition, he was immediately fired without compensation. Mubarek said that since then, "*No one would give me the opportunities to get a job. I tried applying to many places, even for daily labor positions, but no one would accept me* *as a worker."* Without an income source, Mubarek's family struggled financially. His only means of support became begging in the streets.

An FGD1 participant shared another instance of stigma associated with a loss of income, stating:

> *In my pursuit of employment, I explored various avenues such as mechanics, farming, digging, and daily labor in construction sites. Despite my capabilities and willingness to engage in any work, my health condition became a barrier. Prospective employers, upon seeing my physical appearance, would often reject me, asserting that I couldn't perform the tasks required. Now, as an older individual with dwindling hope, my only recourse seems to be seeking solace in church and resorting to begging.*

Certain individuals affected by leprosy who were interviewed as informants for this study, as well as community members who participated in focus group discussions, mentioned that employers were often reluctant to hire people living with leprosy who had severe, visible wounds. As one such discussant noted, "Employers were usually only willing to extend employment in cases where no other available laborers could be found." This implies that those affected by leprosy experienced direct discrimination in the workplace from employers that limited their job prospects, especially if their condition was outwardly apparent through wounds or lesions. Without assurances of stable income, individuals like Mubarek who were interviewed for this study were then vulnerable to sliding into poverty.

Certain individuals affected by leprosy who were interviewed as part of this study provided insight into how individuals affected by leprosy become economically marginalized within their communities over time. They explained that in addition to facing stigma-related employment discrimination, the physical impacts of the disease - such as muscle weakness, loss of sensation, wounds, deformities, and disabilities - diminished the productivity and functioning of those living with leprosy. According to the interviewees, these physical effects increasingly impaired people's ability to work and contributed to their dependence on family members for support. As one's capabilities declined due to the progression of symptoms left untreated, it led to a loss of livelihood and independent means of livelihood. This depicts how the interactive effects of both the social and medical aspects of leprosy can gradually displace people from productive roles in the local economy through no fault of their own. Thus, incorporating this perspective broadens understanding of how leprosy results in marginalization on multiple interrelated levels for those affected.

It is evident that some leprosy patients feel helpless after catching the illness and believe their deformity as the end of the world they don’t try to fight for themselves the feeling of I can’t do impose them easily because of the discrimination they face.

As per the interviews conducted with individuals affected by leprosy who were receiving treatment at ALERT Hospital, all of the participants came from rural areas. The interviews revealed that the prolonged and chronic nature of leprosy requires frequent travel to ALERT Hospital and other health centers for treatment and management. Consequently, many leprosy-affected individuals find themselves compelled to sell valuable assets like farmland, houses, and cattle in order to meet the expenses associated with regular transportation and to support their basic needs while undergoing lengthy treatment schedules far from home.

Informant Gaddissa explain that:

> *For me, the most difficult thing was traveling since leprosy illness tablets were provided every month for a year or eight months and we couldn't take them all at once, so I had to come to ALERT hospital every month. I know many people stopped taking their medications due to economic difficulties; coming to Addis Ababa monthly was expensive, that is why after four months of frequent traveling. I started living in Zenebework area.*

In general, the interviews both in-depth and semi-structured conducted with 39 individuals affected by leprosy in the Zenebework area revealed that most (n=20) stated that the leprosy disease had caused them economic crises, regardless of their financial situation prior to being diagnosed. Losing employment opportunities remains a challenge for many of them, especially outside of the Zenebework leprosarium area, where focus group discussants (n=10 community members) noted better work prospects exist relative to other locations. Some of the interviewees mentioned they have created alternative work through jobs like shoe shining, trash collection, and other tasks rather than solely relying on begging. A number of the individuals affected by leprosy who were interviewed expressed a desire to work, provided suitable accommodations are made according to their capabilities resulting from the disease.

3.4.3. Effects of Stigma on Education

In the interviews conducted with 15 individuals affected by leprosy and the two FGD sessions with 6 community members each, participants were asked questions regarding how leprosy affected their academic journeys. Virtually all of the informants (those with leprosy) and discussants (community members) conveyed that leprosy significantly influenced their educational paths. They explained that their peers ostracized them due to being leprosy-affected and because of the visible signs on their bodies. Instances of verbal assaults and derogatory comments from classmates were common, and at times, they faced opposition to attending classes together. Consequently, they often skipped school, leading to a decline in their academic performance and ultimately forcing them to abandon their education entirely.

Informant Demeke said that *"When my classmate find out about my deformity they started to discriminate me I started missing from school and Finally, I dropped out and migrate to Addis Ababa, Zenebework."*

Informant Semira also spoke about her condition:

"I stopped going to school in third grade because of discrimination from my peers; they would prefer to stare at me than studying their lessons. I stopped attending school because they treat me like I'm a different person who comes from another planet."

According to the demographic data of this study, due to self-stigma and stigma from the school community, the majority of the participants' educational ranges are from 3 to 10 grades. Because of their disease, all of the leprosy-affected informants in this study suffered various forms of prejudice, including sitting separately in their classrooms and being unable to play or participate in group activities with other children's.

Contrasted with their disabilities and the weak economy, six of the study participants lacked any formal education. Attending school, while suffering from leprosy, was unthinkable for them since they were terrified of being stigmatized and subjected to discrimination by their peers. FGD1 discussants were also concurred that all of them stopped learning as a result of discrimination and bullying from their classmates and even by some of their teachers.

The other concern involving leprosy's impact on education, according to the informants, they must walk for two to eight hours to reach a school or a major road where they can obtain transportation. Additionally, it is muddy in the summer and dusty in the winter, making it difficult for anyone with a physical disability to get around. So, due to the physical environment's inaccessibility, some informants quit their schooling.

3.4.4. Effects of Stigma on Psychological Well-being

According to this study finding, all of the respondents dealt with a variety of psychological difficulties. Almost all of the informants and discussants, clarified that leprosy affected peoples lived in poverty and experienced severe psychological issues.

Informant Semira explains that "*My mental state was impacted by leprosy disease, which reduced, my self-confidence, self-esteem and even my dignity, before leprosy deformed me, I was highly confident and proud person but after my physical deformity I lost my self-esteem and dignity I have to beg for a living know".*

As stated by the interviewees, individuals affected by leprosy have experienced psychological disorders such as anxiety and depression as a consequence of the effects of the disease and its associated challenges. Many respondents highlighted that people affected by leprosy have developed emotional issues, encompassing feelings of depression, shame, dependency, and even aggression.

The FGD1 participants underscored loneliness as a prominent psychological challenge faced by individuals living with leprosy. According to the majority of discussants, this sense of isolation primarily stems from the separation of leprosy-affected individuals from their families and loved ones. The profound impact of this isolation is significant and could potentially lead to extreme consequences, including thoughts of suicide.

As informant Tesfaye explained in the interview, *"He always felt bad about himself because all of his siblings and friends were healthy except for him. He felt inferior to* *his classmates and friends, so he took too much medicine and attempted suicide, but his parents took him to a health center and his life was saved."*

Informant Abera: "*Due to the deformities caused by leprosy, I experienced mental instability, fostering negative thoughts and beliefs about myself, the world, and the future. I felt like I was nobody, which led to isolation and limited social participation. At one point, I even reached a point of despair and attempted suicide, but those around me intervened and saved my life."*

According to the FGD1 participants, individuals affected by leprosy faced various psychological challenges resulting from leprosy and its associated issues. The onset of psychological disorders occurred upon learning about their leprosy status for the first time. Participants expressed disinterest in social interactions and a tendency to conceal affected body parts from family, relatives, peers, and the community. The majority revealed instances of attempted suicide driven by the pain, stigma, and discrimination they experienced. Additionally, they highlighted a sense of hopelessness stemming from both disability and the societal stigma attached to leprosy.

This study interviewed 15 individuals affected by leprosy. Of those participants, more than 6 informants tried to kill themselves by using poisoned drink and holding electric wire. They expressed that one of the reasons for contemplating suicide was the weakening of their bodies, frequent amputations, and disabilities. Additionally, divorce from their spouse, separation from their children, family, relatives, friends, and community made them feel hopeless, lonely, and useless, leading them to consider suicide. The study uncovered that numerous individuals affected by leprosy choose to conceal their condition, often developing a sense of secrecy.

Informant Abera noted that:

> *I am living in Addis Ababa Zenebework area, hiding from my community. Nobody in my neighborhood knows that I am a leprosy affected person. When there is wedding or mourning, my neighbors and relatives ask my family why I don't go to participate, but I can't resist the discrimination and gossip about me having leprosy, so I am living secretly.*

Self-stigma in leprosy-affected individuals manifests as feelings of fear, shame, and low self-esteem, often leading to isolation. This internalized stigma arises from societal attitudes towards the disease and associated deformities. FGD1 participants revealed that the potential for disfigurement and disability prompts many affected individuals to isolate themselves, fostering feelings of fear and inferiority.

Furthermore, those with leprosy are considered and accepted as social outcasts by society as a whole specially disabled person as a result of this condition confronted enormous psychological obstacles that they created due to fears and the inappropriate attitude of society.

3.4.5. Effects of Stigma on Social Relationships

This study exposed that leprosy-affected individuals experience daily segregation, isolation, and discrimination by society. The social aspect of being disabled is still Hard and it is embarrassing to be found leprosy impaired. There are many insulting terms and proverbs that identify affected people and their families, disregard and reject them and giving equal opportunity as any other people.

The study's findings, as revealed in the FGD1, corroborate the notion that individuals affected by leprosy are often subjected to derogatory nicknames. Misconceptions about leprosy prevail, with the disease being unjustly regarded as the most severe form of disability.

During the FGD1, participants emphasized the disdain for individuals affected by leprosy, expressed in proverbs such as "Komatan komata kalalut gebeche lefetfit maletu aykerim," suggesting that unless you call a leper by their name, they might contaminate and mix the food. Additionally, there is a saying, "Yezriews Bered komata Yasakfal," implying that the cold weather today compels you to hug a leper. These proverbs illustrate the societal perception and discrimination faced by leprosy-affected individuals.

Concerning the stigma linked to the illness and social isolation, the study's results reveal that the vast majority of individuals affected by leprosy feel compelled to conceal their condition from relatives to avoid social stigma and prevent bringing shame to their families within their communities. Consequently, many opt to relocate to distant areas, often favoring settlements specifically designated for those affected by leprosy. Because of the fear of stigma, participants in the study expressed that they lack confidence and comfort to venture outside their living area, the leprosarium, 'Zenebework.' Unlike to other individuals with other disabilities, they feel restricted and unable to go wherever they desire.

Every participant interviewed expressed challenges in participating in various aspects of life, including churches, schools, marketplaces, workplaces, and social events. These difficulties were attributed to the prevailing misconceptions surrounding leprosy and the physical deformities associated with the disease. As a result, individuals affected by leprosy faced exclusion and barriers to full participation in these societal domains.

However, due to the similarities in their conditions, most of the leprosy-affected informants and discussants in this study stated that leprosarium areas like Zenebework were preferred for social interaction, and nearly all of the study participants are actively involved in *Iddirs*, *Ekub*, weddings, holidays, and other societal ceremonies if it is only in *Woreda* 01 area.

The study reveals that individuals outside Woreda 01 harbor misconceptions about leprosy, resulting in their exclusion from social events. When invited, those affected by leprosy receive special treatment and limited roles due to societal sympathy for their deformities. Discrimination is evident as the community hesitates to allow their active participation in close-contact activities during social events.

However, when it comes to their ability to participate in social activities, leprosy affected peoples have limited roles since other members of informal organizations don't think they are capable of carrying out tasks due to their deformities. The participant, on the other hand, chooses not to participate in local informal organizations due to their physical disability; some leprosy affected peoples chose to isolate themselves from people and social groups.

Informant Gaddissa explained that:

> *The only stigmatized peoples in this country are leprosy affected peoples. As is well known, there are five types of disability associations in Ethiopia, and the fifth one is leprosy victims. The other four disability associations, such as blind, deaf, and others, discriminate us,*

> *and most organizations do not consider leprosy victims to be disabled. We cannot even receive a fund because of this, but the disability caused by leprosy is the most severe form of any sort of disability-causing disease since leprosy affects the nerves, bones, and shapes of the eyes, face, and even our skin.*

As can be seen, leprosy sickness is a serious problem that complicates the lives of leprosy affected individuals. The disease had a devastating effect on all aspects of their lives, causing them to be estranged from their loved ones, including their mothers and fathers and wives. Additionally, its impact goes far to be discriminated even by other disability associations which make it worse.

3.4.6. The Effects of Leprosy-induced Disabilities

FGD1 participants and the 15 individuals affected by leprosy who were interviewed as part of this study unanimously highlighted physical deformity and disability resulting from leprosy as a significant challenge, leading to their exclusion from the community. Deformities on their nose, lip, eyes, and limbs, coupled with bone and muscle weakness, cause dishonor and isolation. The softening of bones, muscle weakness, and sensory nerve damage lead to reduced hand functionality, impacting mobility and productivity. Handling objects, opening and closing, and lifting become challenging. Leprosy-induced bone deformities in the legs pose mobility challenges, and partial/full vision impairment further compounds their difficulties.

Informant Feyesa stated that:

> *Because of my deformities, I faced tremendous obstacles, when I first came to ALERT hospital. The doctors told me that the bacteria had already spread up to my thigh and that I needed surgery. Following the surgery, I was fitted with an artificial leg and began moving around with a crunch. Because of the inaccessibility of my neighborhood, moving with the crunch was really tough and forced me to isolate myself and stay home alone.*

According to the 15 individuals affected by leprosy who participated in interviews as part of this study, as revealed in those interviews, they experience multiple disabilities due to leprosy. The interviewed individuals affected by leprosy revealed that the way society treats them because of their physical appearance hurts their feelings more than being disabled.

As reported by the 15 individuals affected by leprosy who participated in interviews as part of this study, these restrictions impede their right to use various services and access public facilities, including transportation. Consequently, many individuals with deformities resort to traveling on foot from different provinces to reach Addis Ababa.

According to informant Mubarek:

> *The hardest part of coming to Addis Ababa was changing three different automobiles to get here. When I first stepped in the car, after we had driven a short distance, everyone asked what the awful odor was, and I became afraid and jumped out of the car. After that, I attempted to cover my leg with some plastic and get into another car, but as soon as we moved, the people inside the car noticed the unpleasant smell coming from my leg and asked about it and the person who sit beside me start staring at me it was difficult for me, and the driver forced me to get out of his car. Because of my disability I have to move most of the place by walk.*

Generally, in addition to the deformity, the broader societal reactions tend to perceive individuals affected by leprosy as incapable. Worthless and unproductive made most of the leprosy affected persons physically, psychologically and economically dependent.

CHAPTER FOUR

CONCLUSION AND RECOMMENDATION

4.1. Conclusions

This study aimed to explore the socio-cultural factors perpetuating leprosy-related stigma and discrimination in Zenebework, Addis Ababa. A key finding was that deep-rooted misconceptions about the causes and transmission of leprosy are primary drivers of stigma. Contrary to scientific evidence, many participants still believed leprosy is hereditary and highly contagious. This lack of accurate biomedical understanding aligns with previous research that found misunderstanding the root causes of the disease fuels stigma and fear (ILEP, 2013; Brown, 2006). Unless addressed, misconceptions will continue perpetuating the social exclusion of affected individuals.

Additionally, the delays in treatment seeking due to stigma often lead to the development of visible physical deformities and disabilities associated with untreated leprosy. The study found these outward signs then become a source of deepened shame and social avoidance within the community. This upholds the findings of other studies that stigma discourages timely care and medical intervention, exacerbating the negative impacts of leprosy (Brown, 2006; Abdul Rahman et al., 2022). Addressing misconceptions could help encourage earlier diagnosis and management of the disease.

Furthermore, the historical institutionalization of those with leprosy in separate settlements like Zenebework entrenched notions of the disease warranting social segregation and isolation which in turn validates evidence that the legacy of discriminatory policies and practices has durably shaped the attitudes that stigmatize leprosy as a condition justifying exclusion (McLaughlin, 2021). Promoting inclusion models that challenge these deep-rooted stigmatizing mindsets is vital.

Finally, stigma was shown to severely impact multiple life dimensions for those affected. Holistic multi-pronged strategies are needed to alleviate the widespread impacts demonstrated, especially as prior studies found addressing only knowledge gaps is insufficient on its own (Abdul Rahman et al., 2022). Concerted efforts tackling both root causes and active discrimination are required.

Therefore, the deep-rooted misconceptions and key contributing factors perpetuating stigma against leprosy patients in the Zenebework area stem from a complex interplay of cultural beliefs, religious interpretations, lack of accurate biomedical knowledge, and the historical legacy of institutionalized discrimination. Consequently, addressing these root causes through targeted educational interventions and promoting a more comprehensive understanding of leprosy is crucial to eradicating the pervasive stigma faced by affected individuals and their communities.

4.2. Recommendations

Based on the findings of the study, the researcher offers the following recommendations:

- *To strengthen community education and awareness initiatives: Hence, the study found widespread misconceptions around the causes, transmission and curability of leprosy among community members. It is recommended that the Ministry of Health, in collaboration with leprosy associations and local health centers, launch sustained awareness campaigns through tailored IEC materials, community dialogues, school curriculums etc. to address myths and misinformation.*
- *To improve accessibility of diagnosis, treatment and rehabilitation services; due to stigma and lack of awareness, many delay treatment, resulting in disability. Thus, it is recommended that leprosy services be scaled up beyond specialized hospitals to lower-level health facilities and integrated into primary healthcare. Outreach screening camps should also be conducted regularly.*
- *To address socio-economic impacts of stigma: since, stigma severely impacts education, livelihoods and social participation of persons affected. It is recommended that the Ministry of Labour and Social Affairs implements skill-building, livelihood grants, preferential employment policies and strengthens enforcement of anti-discrimination laws.*
- *To develop multi-sectoral coordination mechanisms: A collective effort is needed given the cross-cutting determinants of stigma. It is recommended to establish coordination platforms engaging key sectors like health, education, labour, disability commissions and civil society to implement collaborative solutions.*

- *To scale-up mental health and counseling support services: stigma induces immense psychological distress. It is recommended to recruit more psychiatric nurses, counselors and social workers to establish dedicated community-based counseling centers offering long-term mental health services.*
- *To engage persons affected by leprosy: Their meaningful participation is vital. It is recommended to strengthen self-help groups, capacitate leadership and representation in planning, implementing and monitoring anti-stigma programs.*

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APPENDICES

ADDIS ABABA UNIVERCITY

COLLEGE OF SOCIAL SCIENCES

DEPARTMENT OF SOCIAL ANTROPOLOGY

Date________________________ **Place_______________**

Time_____________________

Appendix 1: Informed Consent Form

My name is Senait Desalegn. I am a student in Addis Ababa university school of social science department of social anthropology. I'm undertaking a research for the partial fulfillment of master's degree in social anthropology. The main focus of the study is to explore the underlying socio-cultural factors and the far-reaching effects of leprosy-related stigma and discrimination in the Zenebework area of Addis Ababa.

The purpose of this study is to gather information that will help me to understand the existing situation of the root causes and impacts of leprosy discrimination, and generate valid recommendations. I am conducting interviews and discussion with key people, like you, to achieve the goal of my study. I would like to get your permission to interview you and discuss with you about your experiences related to the impact and misunderstanding of leprosy discrimination.

Furthermore, i would like to assure you that everything you say will be kept confidential. Your name will not be used. In addition, it is up to you if you wish to take part in the interview and to answer any or all of my questions. The interview would take no longer than an hour, but can be stopped by you at any point.

If you have any questions about the purpose of the interview or the discussion, or any other questions, you can raise.

If you agree to participate, please sign two copies of this form, one for you to keep and one for me.

Participant's signature _____

Date _______

ስሜ ሰናይት ደሳለኝ ይባላል።

በአዲስ አበባ ዩኒቨርሲቲ የድህረ ምረቃ ትምህርቴን በ አንትሮፖሎጂ እየተማርኩ ነው። የመመረቂያ ጽሁፌንም ከስጋ ደዌ ጋር ተያይዞ ያሉ የተዛቡ አመለካከቶች ላይ እያጠናሁ እገኛለሁ። የጥናቱ ዋና ትኩረትም በአዲስ አበባ ዘነበወርቅ አካባቢ የሥጋ ደዌ መድልዎ መንስኤንና ያስከተለውን ጉዳት መገምገም ነው።

የዚህ ጥናት ዓላማ የሥጋ ደዌ መድልዎ መንስኤዎችን እና ተፅዕኖዎች ጋር ተያይዞ አሁን ያለውን ሁኔታ ለመረዳት የሚረዳኝ መረጃ ለመሰብሰብ እና ትክክለኛ ምክረ-ሃሳቦችን ለማመንጨት ነው። የጥናቴን ግብ ለማሳካት እንደ እርስዎ ካሉ ቁልፍ ሰዎች ጋር ቃለ መጠይቅ እና ውይይት እያደረግሁ ነው። ከሥጋ ደዌ መድልዎ ተጽእኖ እና የተዛቡ አመለካከቶች ጋር በተገናኘ እርስዎን ለመጠየቅ እና ከእርስዎ ጋር ለመወያየት ፈቃድዎን ማግኘት እፈልጋለሁ።

በተጨማሪም፣ የምትናገሩት ነገር ሁሉ በሚስጥር እንደሚጠበቅ ላረጋግጥላችሁ እወዳለሁ። ስሞትም ጥቅም ላይ አይውልም። በተጨማሪም፣ በቃለ መጠይቁ ላይ ለመሳተፍ እና ማንኛውንም ወይም ሁሉንም ጥያቄዎቹን ለመመለስ ከፈለጉ የእርስዎ ምርጫ ነው። ቃለ-መጠይቁ ከአንድ ሰአት በላይ አይፈጅም ነገር ግን በማንኛውም ጊዜ እርስዎ ሊያቆሙት ይችላሉ።

የቃለ መጠይቁን ወይም የውይይቱን አላማ ወይም ሌላ ማንኛውንም ጥያቄ ካሎት ማንሳት ይችላሉ።

ለመሳተፍ ከተስማሙ፣ እባክዎን የዚህን ቅጽ ሁለት ቅጂዎች ይፈርሙ፣ አንዱ እርስዎ እንዲያቆዩት እና አንዱ ለእኔ።

የተሳታፊ ፊርማ ______

ቀን _________

APPENDIX 2: SUMMARY OF SOCIO-DEMOGRAPHIC PROFILE OF ALL RESEARCH PARTICIPANTS

TABLE 1 DEMOGRAPHY DATA OF INTERVIEW INFORMANTES

Variables	Variables Category	Number / frequency	% of Total N
Sex	Male	9	60.0%
	Female	6	40.0%
	Total	15	100.0%
Age	21- 30	3	20.0%
	31- 40	8	53.3%
	41- 50	3	20.0%
	60- 70	1	6.7%
	Total	15	100.0%
Marital Status	Married	4	26.7%
	Unmarried	9	60.0%
	Divorced	2	13.3%
	Total	15	100.0%
Religion	Orthodox	10	66.7%
	Protestants	2	13.3%
	Muslim	3	20.0%
	Total	15	100.0%
Educational background	1- 8	10	66.7%
	9- 12	2	13.3%
	Uneducated	3	20.0%
	Total	15	100.0%

Livelihood	Begging	4	26.7%
	Daily Labor	2	13.3%
	Guard	1	6.7%
	Helped by Leprosy Association	2	13.3%
	House Wife	1	6.7%
	Selling mask, cigarette, gum	1	6.7%
	Selling Vegetables	1	6.7%
	Shoe Shiner	1	6.7%
	Small Enterprise	2	13.3%
	Total	15	100.0%
Health status	Deformed	12	80.0%
	Non-deformed	3	20.0%
	Total	15	100.0%

Table1: Summary of socio- demographic profile of interviewees

Informant	Sex	Age	Marital Status	Religion	Educational background	Livelihood	Health status
Addisu	M	46	Unmarried	Orthodox	Uneducated	Helped by leprosy association	Deformed
Tesfaye	M	64	Married	Orthodox	7th grade	Guard	Deformed
Semira	F	33	Unmarried	Muslim	3rd grade	Begging	Deformed
Feysa	M	42	Married	Orthodox	10th grade	Small enterprise	Deformed
Ayalew	M	35	Married	Protestant	8th grade	Daily labor	Deformed

Tafese	M	33	Unmarried	Orthodox	5th grade	Daily labor	Non-deformed
Aster	F	29	Married	Orthodox	6th grade	House wife	Non-deformed
Dmeke	M	40	Unmarried	Orthodox	10th grade	Small enterprise	Deformed
Gaddissa	M	30	Unmarried	Protestant	5th grade	Shoe shiner	Deformed
Mubark	M	35	Unmarried	Muslim	4th grade	Begging	Deformed
Abera	M	30	Unmarried	Orthodox	7th grade	Begging	Deformed
Zenash	F	31	Unmarried	Orthodox	7th grade	Selling of goods (vegetables)	Deformed
Belaynesh	F	35	Divorced	Orthodox	Uneducated	Help by leprosy association	Deformed
Asnakech	F	33	Unmarried	Orthodox	3rd grade	Selling goods (mask, cigarette, chewing gum)	Deformed
Merhawit	F	42	Divorced	Muslim	Uneducated	**ቆሼ ለቀማ** (trash collection) solid	Deformed

Table2: Summary of Socio-Demographic information of focus group participants 1

Participant	**Discussant-1**	**Discussant-2**	**Discussant-3**	**Discussant-4**	**Discussant-5**	**Discussant 6**
Sex	M	F	F	M	M	M
Age	48	35	39	43	39	24
Religion	Orthodox	Protestant	Orthodox	Muslim	Orthodox	Protestant
Marital status	Married	Unmarried	Married	Divorced	Unmarried	Married
Educational background	3rd grade	5th grade	Uneducated	Uneducated	3rd grade	9th grade
Livelihood	Begging	Trash collecting	Trash collecting	Labor work	Begging	Labor work
Health status	Deformed	Deformed	Deformed	Deformed	Deformed	Deformed

Table3: Summary of Socio-Demographic information of focus group participants 2

Participant	Discussant 1	Discussant 2	Discussant 3	Discussant 4	Discussant 5	Discussant-6
Sex	F	M	F	M	F	F
Age	24	41	33	38	71	49
Religion	Orthodox	Muslim	Orthodox	Protestant	Orthodox	Catholic
Marital status	Married	Married	Unmarried	Unmarried	Married	Married
Educational background	Diploma	10th grade	12th grade	Degree	Diploma	Degree
Livelihood	Secretary	Trash collecting	Shop	Accountant	House wife	Miller

Table 4: Summary of Socio-Demographic information of case studies

Case	Sex	Age	Religion	Marital status	Educational background	Livelihood	Health status
Addisu	M	44	Orthodox	Unmarried	5th grade	Helped by association	Deformed
Kalkidan	F	42	Protestant	Divorced	Uneducated	Helped by association	Deformed

Table 5: Summary of Socio-Demographic information of key informant interview

Key	Sex	Age	Work position	Work experience	Educational background	Disability
Beyene	M	56	Specialized doctor	9 year	Second degree	Non

Tadese	M	53	General manager association	More than 10 years	Second degree	Non
Ahmmedin	M	67	Shaikh/ imam of the mosque	For 11 years	------	Non
Bilal	M	74	Priest at miftah mosque	5 years	-------	Disabled
G/meskel	M	78	Kes at abuneargawi church	14 years	-----------	Non
Kidanemaryam	M	26	Diyakon at abuneargawi church	For 4 years	Diploma	Disabled

Table 6: Summary of Socio-Demographic information of semi-structured interview

Sex	Female male
Age	18-25 26-35 36-45 45<
Religion	Protestant Orthodox Muslim Catholic other
Marital status	Single Married divorced
Educational background	Non educated Primary Secondary Diploma Degree and above
Occupation	Housewife Government employee Merchant others...

APPENDIX3: SEMI-STRUCTURED QUESTION GUIDE (Resident of zenebework area)

ስለ ደዌ ሰምተሃል?	አዎ አይ
የሥጋ ደዌ መንስኤ ምንድን ነው?	በባክቴሪያዎች በዘር ተላልፎ የሚመጣ ንፁህ ያልሆነ አካባቢ የእግዚአብሔር ቁጣ ለቤተሰብ ኃጢአት ቅጣት ልቅ በሆነ የግብረስጋ ግንኙነት ምግብ መጥፎ ደም አላውቅም

የሥጋ ደዌ መተላለፊያ ምንድነው?	የኤሮሶል ድሮፕሌት ተራ ግንኙነት ረጅም ግንኙነት ወሲባዊ ግንኙነት የተበከለ ውሃ እና አፈር በስጋ ደዌ የተጠቁ ሰዎች አጠገብ መቀመጥ በሥጋ ደዌ ከተጠቁ ሰዎች ጋር ዕቃዎችን መጋራት አላውቅም
ከሥጋ ደዌ መዳን ይቻላል?	አዎ አይ አላውቅም
በሥጋ ደዌ ከተያዘው ሰው አጠገብ መቀመጥን ይፈቅዳሉ?	አዎ አይ
በቤተሰባችሁ ውስጥ አንድ ሰው በሥጋ ደዌ ቢያዝ ታፍሩበት እና ትደብቁት ነበር?	አዎ አይ
ከቤተሰብህ አባል ውስጥ ስጋደዌ ያለበትን ሰው ማግባት ቢፈልጉ ፍቃደኛ ትሆናላችሁ?	አዎ አይ
ልጃችሁ የሥጋ ደዌ ካለበት ቤተሰብ ልጅ ጋር እንዲጫወት ትፈቅዳላችሁ?	አዎ አይ

በሥጋ ደዌ የተጠቁ ሰዎች የቤተሰብ አባላት ከሌሎች ሰዎች መራቅ አለባቸው ብለው ያስባሉ?	አዎ አይ
የሥጋ ደዌ በጣም ተላላፊ ስለሆነ በሽታው ያለበትን ሰው መንካት የለብንም ብለው ያስባሉ?	አዎ አይ

1. What do you know about the transmission and treatment of leprosy?
- have you tried to avoid hugging and kissing by fear of contagion?

- How do you develop your knowledge or what situation helped you to know about the illness, its cause and treatment

2. Has the condition affects your family relation? If yes, how?

-Is there any difference in your relationship before and after the sickness?

3. Have you gave enough treatment for your family at the time of sickness?

4. Do you feel that leprosy makes it difficult in your family to marry? If Yes, Why?

·Have you or your family member been forced to dissolve marriage plans because of your family condition?

5. In your community, does leprosy cause shame or embarrassment? If yes, how it affects you

APPENDIX 4: INTERVIEW GUIDE (For leprosy affected residents of zenebework area)

1. Sex 2. Age

3. Religion 4. Educational status

1. When and how do you know that you are infected by leprosy?

2. What do you think is the cause of the leprosy disease you have?

3. What do you know about the transmission and treatment of leprosy?

4. Is there a cure for leprosy?

5. Do you think that only poor people get leprosy?

6. How long do you think is someone with leprosy contagious?

7. When did you start living in this area?

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

9. If you preferred to live in the area, why do you prefer to live in this area

10. How does your family treat you?

11. How does society treat your family member? Do you have the same respect in the community?

12. Do you fill you are isolated?

13. Is there anything you lost/ suffered from because of the discrimination?

14. Are you socially active as your peers are? (E.g. in religious/community affairs)

-Do you take part in major festivals and rituals as other people do? (E.g. weddings, funerals, religious festivals

- Do you take as much part in casual recreational / social activities as do your peers? (E.g. sports, chat, meetings) If sometimes or no, how big a problem is it to you?

15. Would some people refuse to visit your home because of this condition, even after you have been treated?

APPENDIX 5: KEY INFORMANTS GUIDE (Administrators of leprosy institution)

1. Sex	2.Age
2. Work position	3.Work experience

1. How many peoples affected by leprosy live in Zenebework area?
2. Can you tell me about the history of this area?
3. Why do you think there are relatively more persons affected by leprosy living in Zenebework than in any other place in Addis Ababa?
4. How do you explain leprosy affected people?
5. How do you explain about the status of leprosy affected people in the community? Are they still facing discrimination?
6. How do you measure the attitudes of the persons affected by leprosy toward themselves?
7. What are the discriminatory practices usually made against persons affected by leprosy?
8. Can you suggest any solution to reduce the misunderstanding of discrimination and its effects of them?

APPENDIX: 5 KEY INFORMANTS GUIDE (Religious leaders)

1. What does health mean? What are the causes of ill health? Why do some people have some disease and others do not?

2. What kind of peoples with health conditions usually come to churches/mosques? Why? Why do we usually see leprosy affected peoples around churches/ mosques?

3. What did your church/mosque do to help leprosy affected person?

4. What kind of persons does leprosy affect?

5. What do you think is/are the cause/s of leprosy?Is it curable? How? Is leprosy different from other diseases? How? What is the cause of deformity? Is it preventable?

6. What does the Bible/Korhan say about leprosy

7. Is leprosy described in Bible/Korhan the same as leprosy we know today?

8Is leprosy one means of punishing the human race for their sins?

9. Do you think the Biblical verses about leprosy apply to a person affected by leprosy these days?

10. Is leprosy very contagious (easy to catch) hence, others should distance themselves from the persons affected by it?

11. Was there a difference for a person affected by leprosy for ceremonies like funereal? Christening? Marriage? Can you tell me about these things how they are done now? I will appreciate it if you can tell me based on your experience.

12. What do you teach your followers regarding how to treat persons affected by leprosy?

APPENDIX 6: FOCUS GROUP DISCUSSION GUIDE (For leprosy affected residents of zenebework area)

1. Sex 2. Age

3. Religion 4. Educational status

የጋራ ውይይት ጥያቄዎች ለስጋ ደዌ ተጠቂዎች

1. ስለ ስጋ ደዌ ምን ያውቃሉ
2. በስጋ ደዌ ሳቢያ ምን ደረሰባቹ
3. በስጋደዌ ሳቢያ የሚደርስባቹ አድሎ እና መገለል አለ ካለ ቢያብራሩልን
4. መንግስታዊ የሆኑና ያልሆኑ ድርጅቶችና ማህበራት ባጠቃላይ ማህበረሰቡ ለስጋ ደዌ በቂ ትኩረት ሰጥተዋል ብላቹ ታስባላቹ
5. ወደፊት ለስጋ ደዌ ተጠቂዎች ምን መደረግ አለበት ብላቹ ታስባላቹ