

**THE EXPERIENCES OF PEOPLE WITH LEPROSY (PWL) LIVING OUTSIDE
INSTITUTIONAL CARE FACILITIES. A CASE STUDY OF MUTOKO CENTER**



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**A dissertation submitted to the Department of Social Work, Faculty of Social Sciences
and Humanities at Bindura University of Science Education in partial fulfilment of
the requirements for the Bachelor of Science Honors Degree in Social Work.**

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APPROVAL FORM

To be completed by the Supervisor

I certify that I have supervised **ANNAH DZIMUNWE (B190681B)** for this research titled: **“THE EXPERIENCES OF PEOPLE WITH LEPROSY (PWL) LIVING OUTSIDE INSTITUTIONAL CARE FACILITIES. A CASE STUDY OF MUTOKO CENTRE”** in partial fulfilment of the requirements for the Bachelor of Science Honors Degree in Social Work, and I recommend that it proceeds for examination.

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Chairperson of the Department Board of Examiners

The Departmental Board of Examiners is satisfied that this dissertation report meets the examination requirements and I therefore recommend to the Bindura University to accept a research project by ANNAH DZIMUNWE titled **“THE EXPERIENCES OF PEOPLE WITH LEPROSYU (PWL) LIVING OUTSIDE INSTITUTIONAL CARE FACILITIES. A CASE STUDY OF MUTOKO CENTRE”**, in partial fulfilment of the requirements for the Bachelor of Social Work Honors Degree.

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DEDICATION

I dedicate this dissertation to my loving family, Mr and Mrs Dzimunwe, my sisters, my brothers and my friend Takunda for their unconditional love and support they gave me throughout my educational journey.

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Firstly, I am sincerely grateful to God for his glory and authority that empowered and gave me the strength to accomplish my goals. I would also like to thank my family and friends for their unconditional love and support, and the encouragement they gave me to work extra hard in my studies.

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ABSTRACT

The goal of the research was to explore the experiences of people with leprosy living outside institutional care facilities: a case study of Mutoko Centre. It was guided also by three objectives which were: to explore the experiences of people with leprosy living outside institutional care; to find the coping strategies adopted by leprosy patients after leaving care and; to provide strategies to address the challenges mentioned by leprosy patients. Underpinned by Maslow's hierarchy of needs, the research used qualitative research approach was utilized to collect, analyze and present data. 16 participants were ultimately drawn from the targeted population using purposive sampling and snowball sampling. The findings of the research found out that disability, drug shortages, homelessness, isolation, lack of education, social acceptance, mental health and unemployment are the experiences that are being faced by people with leprosy living outside institutional care facilities. The research also found out that begging and stealing were the coping strategies that were adopted by leprosy patients in order to sustain themselves. The research recommends that healthcare professionals at the lowest levels of care should be trained in the care of patients with leprosy in order to avoid lepers from travelling long distances and also leprosy people should receive counselling in order to deal with stigma and discrimination. The study suggests adopting socio-economic policies and educating leprosy sufferers and the communities in which they live hence increasing awareness of the disease.

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CHAPTER 1

INTRODUCTION AND BACKGROUND OF THE STUDY

1.1 Introduction

The Bible states that leprosy is a sign of punishment from God or divine interference (Numbers 12:10; Deuteronomy 24:8; Luke 5:12-13). This chapter provides the introduction and background to the study in light of the experiences of people with leprosy living outside institutional care facilities. The chapter is arranged as follows: the background to the study, statement of the problem, aim of the study, research objectives and questions, significance of the study, assumptions, definition of terms and chapter summary.

1.2 Background of the study

One of the earliest known diseases in the globe is leprosy. *Mycobacterium leprae* typically causes it (Bhat and Prakash, 2012) and targeted nerves which includes those in the body's colder parts as well as the nervous system as a whole. For instance, the patient's hands, eyes, feet and face lead to abnormalities, which affect their daily activities and eventually cause them to become permanently disabled. To achieve the Sustainable Development Goals of eradicating leprosy, the Global Leprosy Strategy 2021-2030 directs the nation to speed up development in that direction. Despite the COVID-19 pandemic disrupting health services generally, an opportunity to strengthen digital health initiatives for staff training, monitoring, referral and diagnosis have been made available in a number of nations. Although there was interruption of health services in general due to COVID-19 pandemic, a window to reinforce digital health initiatives for diagnosis, referral, monitoring and training staff in several countries were provided. Prince (2017) asserts that leprosy

control efforts over the last decades have concentrated on disease remission, infection management, disability prevention and leprosy cases are declining, which has improved the reported report on worldwide eradication. Leprosy can spread to humans in variety of ways but contact with those who have untreated or medication-resistant leprosy seems to be the predominant way. Leprosy infection transmission is likely thought to occur by mouth and nasal secretions when close and frequent contact is made (Elamin, Stehr and Singh, 2012; MA et al, 2012). Since leprosy has no primary preventive, there is no specialised vaccine to protect against it. It is thought that neighbouring nations are where leprosy first arrived (Desalegn, 2014).

In Africa, leprosy cases are discovered in around half of the world's countries for instance, 50% of the cases in 8% of the population. Consequently, the total assessed incidence of five million many authorities think that it is too traditional and should be folded at least. Leprosy disease has been around frequently since ancient time enclosed by frightening, negative stigmas and tales of leprosy patients being shunned as outcast. However, the prevalence and incidence of leprosy as an infectious disease have decreased quite dramatically over the past 20 years. World Health Organisation (WHO), reported new case of leprosy in 2018 as many as 184 212. Therefore, this outbreak of leprosy has affected and panicked people on every continent. Unfortunately, the negative attributes attached to leprosy has not reduced although there is now good treatment linking to increased awareness of leprosy as curable disease in the community.

Zimbabwe grew into a huge leprosarium in the 1940s and 1950s with nearly one thousand survivors of leprosy and it attracted people from all around South Africa, Zambia, Malawi, Tanzania and Mozambique. According to the data which was collected since 2012 to date by the United States Agency for International Development (USAID), Africa University (AU), Ministry of Health and Child Care (MoHCC) and John Snow Inc (JSI) indicates that Matabeleland North

recorded the highest incidence in leprosy with 12 new cases between 2017 and 2021, Masvingo comes second with five cases that were recorded between 2014 and 2017 and four cases in Mashonaland Central between 2015 and 2020. Zimbabwe supposedly eliminated leprosy as a public health issue in 1992, but the nation is still at risk because of societal factors including hunger, overpopulation and poverty which still encourage the spread of the virus. Both Ngomahuru in the Victoria District (now Masvingo), which is now a psychiatric hospital and Mutemwa were designated as leprosy settlements.

In addition, according to Davies (1979), many people that were admitted there were part of the immigrant labour force employed in farms and mines and who lost their jobs because of the disability that was caused by the disease. Mutemwa Leprosy Catholic and Care Centre (MLCCC) is the only leprosy centre and is a registered welfare organisation PVO 408/68 in accordance with Section 9 of the Private Voluntary Organisation Act (Chapter 17:05), Subsection (5) working with the physically challenged, post lepers, destitute and the mentally challenged. The centre was established by a well-wisher in 1937 in Mutoko, 147km northeast of the capital. Thus, this research seeks to explore the experiences of people with leprosy living outside institutional care facilities.

1.3 Statement of the problem

UK studies states that 33% of care-leavers experience homelessness within two years of leaving the system, while Greaves (2017) found that 25% of all single homeless adults have experienced care at one point. This information shows that leprosy patients are prone to vulnerability after leaving care since access to better housing is a challenge to them. Although, the government of Zimbabwe, NGOs over the past years has made efforts to help the leprosy patients, the most notable being the adoption of leprosy control activities guided by Global Leprosy strategy of 2016

and 2020. This vision of the strategy is leprosy free world meaning that if the country reaches this target there will not be any new leprosy cases, zero deformities, zero disability due to leprosy, zero stigma and discrimination against leprosy.

Despite these efforts that were made by the government of Zimbabwe and NGOs to establish care institutions so as to provide care for the people living with leprosy, as it stands the main population of leprosy patients live outside care institution since the care institutions are few in Zimbabwe and the services offered at these institutions seems to be inadequate. People with leprosy living outside institutional care facilities face some plethora problems when it comes to integrating into the society due to lack of aftercare support because their relationship with the community is broken. These experiences include lack of access to basic medical care and fear of stigma and discrimination (Letta, 2020) although some of these experiences face them even when living at institutional care facilities. This is so because people in the community or society still think that the disease is contagious. Therefore, this research seeks to explore the experiences whether negative or positive that are faced by people with leprosy living outside institutional care.

1.4 Aim of the study

The aim of this study is to explore the experiences of people with leprosy staying outside institutional care. A case of Mutoko Centre.

1.4.1 Objectives

- ❖ To explore the experiences of people with leprosy living outside institutional care.
- ❖ To find the coping strategies adopted by leprosy patients after leaving care.
- ❖ To provide strategies to address the challenges mentioned by leprosy people.

1.5 Research questions

- ❖ What are the experiences faced by people with leprosy living outside institutional care?
- ❖ What are the coping strategies adopted by leprosy patients after leaving care?
- ❖ What are the possible strategies to adopt so as to address the challenges mentioned by care leavers?

1.6 Assumptions

The researcher assumes that in every nation, people with leprosy face challenges after leaving institutional care facilities and also the participants will be confident to trust the researcher. It also presupposes that those who have leprosy do not need to be quarantined because the medications used to cure it are exceedingly successful at eliminating the bacterium, making those receiving treatment immune and unable to spread the disease.

1.7 Justification of the study

The study seeks to explore a contemporary issue which has remained topical in both policy, scholarly and in public discourses on the experiences of people with leprosy living outside institutional care facilities in Mutoko centre so that proper support can be given to deal with the problem. Hence, this research study is also believed to be crucial as it will help in improving the living conditions of people with leprosy after they integrate into a society by increasing their self-esteem. This study is an eye opener to different stakeholders and the government in policy formulation for instance, in the implementation of policies concerning people with leprosy. The study will also benefit social work as a practice-based profession with information that can be used in the design of future intervention in quest to address the problems that are experienced by post

leprosy people. There are also various possible benefits that the World Health Organisation, Government of Zimbabwe and Ministry of Health and Child Care may get from the experiences that are faced by post leprosy people living outside institutional care facilities. Hence benefiting the people with leprosy living outside institutional care facilities to a larger extent.

1.8 Definition of terms

- ❖ **Institutional care facilities-** is a type of group housing where more than ten people live together without the help of family members and receive care from a considerably smaller group of professional (Browne, 2009).
- ❖ **Leprosy-** a mycobacterial infection that causes a persistent illness (Raphael, Cumber, Niyonzima, Ndenkeh & Kanjo-Cumber, 2017).

1.9 Proposed chapter outline

The proposal will take a structure as follows:

Chapter 1: Introduction and background of the study

This chapter is an introductory chapter that outlines the background of the study in light of the experiences of people with leprosy.

Chapter 2: Literature review

The researcher examines the available literature and theories on the experiences of people with leprosy in this chapter.

Chapter 3: Research Methodology

This chapter presents important approaches that the study has utilized to obtain satisfactory information necessary for answering the research questions.

Chapter 4: Data Analysis and Presentation/ Discussion of Findings

This chapter analyses and presents the information that will be gathered in Mutoko centre at Mutemwa clinic on the experiences of people with leprosy living outside institutional care.

Chapter 5: Conclusion and Recommendations

This chapter captures the summary of the findings and the conclusion drawn from this study. After examining the results, possible recommendations which could improve the study were made by the researcher.

1.10 Chapter summary

This chapter has offered the background to the study, statement of the problem, aim of the study, research objectives and questions, significance of the study, assumptions, definition of terms and chapter summary.

CHAPTER 2

LITERATURE REVIEW

2.0 Introduction

Creswell (2005) postulates that a review of literature is a written summary of journal articles, books and other materials that summarizes the previous and present level of knowledge, groups the literature into categories and establishes the necessity for suggested study. This chapter discuss the literature that has been conducted before by other researchers and writers on the experiences that are faced by people with leprosy living outside institutional care facilities. Thereby providing scholarly evidence that has been put forward by various professionals. Firstly, theoretical framework will be provided followed by review of the literature according to the objectives of the study.

2.1 Theoretical framework

Sekaran (2016) outlines that theoretical framework is a conceptual representation of how one theorizes or illustrates the logical plausibility of a relationship between a number of aspects or things that have been designated as significant for the study field. The study used Maslow's Hierarchy of Needs to explain the research problem that occurs under the study.

2.1.1 Abraham Maslow's hierarchy of needs theory

A five-tiered model of human wants, frequently portrayed as hierarchical stages within a pyramid, serves as the basis for Maslow's hierarchy of needs, a psychological theory of motivation. Maslow notes that in order for people to develop, they have some essential requirements that cannot be

disregarded (as mentioned on page 18 of Gething, Hatchard, Papalia and Olds, 1993). Maslow's hierarchy of needs is a diagram that lists a number of demands that people have in order to reach full development and self-actualization (Maslow, 1943). Lower needs in the hierarchy must be fulfilled before individuals can reach on the upper needs. According to Onah (2015), Abraham Maslow, a psychology professor Brandeis University and a famous expert in the study of human wants and motivation, developed his hierarchy of needs theory in 1943, the theory postulates that humans are driven by five levels of needs which include physiological, safety, love and belonging, esteem and self-actualization.

2.1.2 The hierarchy

Physiological needs: These are the basic necessities that are important for the survival of human beings. The needs consist of food, shelter, water, sleep and oxygen. If these needs are not met, they cause some deficiency in human's body and also human beings are improbable to intrinsically pursue higher needs.

❖ Safety needs

After accomplishing the basic needs of a person, safety needs arise and they include the need for security and safety. For a person to feel safe in an environment, they have to fulfil safety before attempting to meet any higher level of survival. Maslow believed that safety needs are essential in the health of people especially to those who have neurotic problems. Insufficient satisfaction of these needs causes frustrations and anxiety.

❖ Love and belonging needs

As soon as physiological needs and safety needs are fulfilled, the need for love and belonging appear. Human needs are interpersonal and it involves the desire for a sexual relationship with another person. Maslow emphasized that love can only be fulfilled only with sex. The sense of belonging has made people to be recognized in a group hence showing the feeling of wanted and loved.

❖ **Esteem needs**

The need to be respected, the need to be appreciated and the need for power are classified under self-esteem needs. These needs they make people to live freely and happily in a society or environment. Maslow highlighted that if a person is respected, they can acquire self-confidence and recognition if these needs are met, worthiness concerns arise.

❖ **Self-actualisation needs**

These needs consist of a person's desire to reach a certain level of success that he or she has been longing for. When these needs emerge, the individual works very hard so that they can fulfil their needs to actualize. Maslow describes this as the desire to accomplish everything that one can, to become the most that one can be.

2.1.3 Relevance of the study

Abraham Maslow emphasize in his theory that they are certain basic needs that are required for the survival of being and these needs cannot be ignored. Also he opines that in any society or environment lower needs must be met first before fulfilling higher needs. Physiological needs such as food and water keep the human body alive however if these needs are not fulfilled the individual will not pay attention to any other needs. Therefore, this goes in hand with the research topic, with

the theory throwing light on the experiences that are being faced by people with leprosy from Mutoko Centre after leaving institutional care.

In every continent, Abraham Maslow's hierarchy of needs shed light on the experiences of people with leprosy living outside institutional care facilities. In developing countries, it is hard to meet certain basic necessities due economic hardship whilst the developed countries basic necessities are willingly obtainable. People with leprosy living outside institutional care seems to lack these human needs after their transition to independent living which lead to their social malfunctioning and reckless in their social lives. There is also increase in susceptibility to chronic ulcers if care leavers fail to meet human needs. Hence, their character will be influenced thereby causing anxiety, depression and frustrations. Somar et al (2020) postulates that leper usually experience anxiety. According to Li and Wang (2020), patients with physical disorders have a large percentage of experiencing anxiety.

In addition, care leavers are less likely to intrinsically desire safety, belongingness, self-esteem and self-actualization if they are having difficulty meeting their physiological needs. However, in relation to this theory to care leavers situation, they are portrayed as a vulnerable group in the societies because they will no longer be functional to the society due to lack of these needs. Thus, it leads to an increase in displeasure within an individual meaning that the body of people living outside institutional care facilities cannot function ideally. For instance, they can be involved in shop lifting in order to fulfil human needs. The needs of people affected by leprosy should be met by their support systems such as families, relatives, employers and medical doctors. This is so because the support system helps in the acceptance of people with leprosy by the community.

The human needs are interpersonal and involves feeling of love and belongingness. In relation to the topic, people with leprosy living outside institutional care facilities needs acceptance amongst

social groups even if these groups are small or large. However, many leprosy patients living outside care centres become prone to loneliness, social anxiety and clinical depression in the absence of love and belongingness. Care leavers should be respected so that they can acquire self-confidence. Therefore, when people with leprosy living outside institutional care centres gain self-esteem, they can be able to stand up for themselves especially when they are opposed. Involving people with leprosy in the provision of services such as self-care, counselling and socio-economic rehabilitation should also be done to fulfil their needs.

2.2 Global concept on experiences of people with leprosy

Globally, Ethiopia is one of the 22 leprosy high burden countries, according to the statistics by Letta (2020), 3426 leprosy cases were reported to the national program in 2018-2019 of which 96.2 percent were newly diagnosed. Thus 15% were children younger than 15 years of age, and 14% had grade 2 disabilities at the time of diagnosis. Basing on these statistics we can generalize that the most affected age group are children meaning the children can constitute the largest number of people with leprosy who leave outside care institution. Thus, young leprosy affected kids have trouble when applying for school admission. Throughout the centre ages, leprosy patients put on unique clothing, rung bells to alert people when they were around and even stroll on a selected aspect of the road, relying at the course of the wind. WHO estimates that over the past 20 years, multidrug therapy (MDT) has successfully treated approximately 14 million lepers.

Moreover, leprosy is considered through many to be genetic, and parent-child transmission is unavoidable despite the fact that now it is no longer seen in a given time. Though leprosy happens once in a while, it is far taken into consideration generally as a disorder of poverty and related to the ones dwelling in bad hygienic environments or near soil. Letta (2020) identified gap,

challenges faced by people with leprosy and these include people not accessing the health systems. Consequently, displaying that people with leprosy are given less attention in the health sector globally. Letta (2020) postulates that there is high rate of relapse cases, this is attributed to patients lost to follow ups and inadequate follow up of clients released from treatment. However, programmes such as community health action model should be proposed in order to eliminate stigma (Sundao Rao, 2015). Education, female gender, rural residence and religion are factors that are responsible for stigmatization attitudes towards leprosy patients (Van Den Broek et al, 1998).

2.2.1 Regional concept on experiences on people with leprosy

Although some countries had reached the elimination threshold, prevalent pools still exist despite the success of multidrug therapy. The MDT was introduced in 1991 and 1995 and it was attained by a leprosy control programme. ILEP (2001) postulates that despite having leprosy below WHO elimination target, Nigeria is one of the countries with uneven distribution of leprosy, concealing high endemic areas at its local level. The disability associated with leprosy which is preventable by early treatment with MDT, mostly affects individuals in their most productive stage of life leading to loss of physical and economic independence thereby imposing a significant economic and social burden on those affected and their families (Niera, 2001). A study conducted by Alubo et al (2003) revealed how community members avoid exchanging greetings and even asking for anything from known leprosy patients for fear of getting infected. New sufferers of leprosy face a challenge of seeking health services and is because of lack of awareness amongst leprosy patients. Consequently, leprosy 's warning signs and symptoms require the cognizance and expertise of the affected person or neighbourhood in order to suspect leprosy. Awofeso (1995) outlines that poor knowledge is common among leprosy patients. The community's religion in its perceived efficacy

can be excessive and this makes leprosy sufferers pass for traditional medicine and that is because of fallacies. Reddy (1984) found that 47% of leprosy patients were detected late because they went to traditional healers first before coming to health facilities. Traditional medicines made sufferers of leprosy to postponement in seeking the health facilities. However, WHO (1997) on the other hand specifies that a medical evaluation, three essential signs from the underlying diagnosis including aesthetically pleasing skin rashes, expanded external nerves and acid-fast bacteria smear of blood in the should all be present. WHO Goodwill Ambassador for leprosy Elimination elevated a political and community cognizance and commitment on leprosy. Hence, early detection, treatment and prevention of disabilities and stigma can be improved by improving knowledge and skills of health workers especially those employed in health centres.

2.2.2 Related case study

In Uganda, at Kagando hospital 17 new leprosy cases were registered for the academic year 2010-2011 thus according to National Health Systems. Patients have been named long stay sufferers due to the fact that they have been hospitalized for a few months hence they were unwilling to go back to their residential homes when it comes to the period of discharge. Individuals were given the opportunity to narrate their lived experiences. Participants reported experiences such as coping with physical impairment, social challenges, financial struggles, a comparatively high level of social acceptability and residing in peace with both oneself and God. It can be showed that social rejection and isolation are the major problems being faced by people with leprosy. However, stigma affecting patients still continues in spite of the efforts that were done to facilitate the integration of leprosy sufferers into society.

2.2.3 Local concept on experiences of people with leprosy

In Zimbabwe, leprosy is endemic. Davies (1979) postulates that many people that were admitted at Mutemwa were part of the immigrant labour force employed in farms and mines and who lost their jobs because of the disability that was caused by the disease. Poverty forced sufferers to seek protection that is provided in residential care facilities. Although, the government of Zimbabwe, NGOs over the past years has made efforts to help the leprosy patients, the most notable being the adoption of leprosy control activities guided by Global Leprosy strategy of 2016 and 2020. This vision of the strategy is leprosy free world meaning that if the country reaches this target there will not be any new leprosy cases, zero deformities, zero disability due to leprosy, zero stigma and discrimination against leprosy. Many forms of remedy have been used. This includes, Chaulmoogra oil, that was acquired from *Hydnocarpus kurzii*. According to Lyons and Ellis (1982) sulphetrone and later dapsone were presented in Zimbabwe in the 1950s. Ministry of Health withdrew its guide from sufferers of leprosy at Mutemwa since the advent of a new drug reduced the number of cases and it was no longer contagious. Many sufferers of leprosy were discharged without an observe up treatment.

A study carried out in Zimbabwe confirmed that men feel pain more from multi-bacillary (MB) leprosy and delay in offering to health facilities in contrast to females. Mararike (2013) notes that leprosy sufferers were secluded in order to avoid contact with the rest of the group because they would typically pass away as there was no treatment for the condition. This has made the social life of post lepers lonely and stigmatized since they fail to gain support from family members or the society. Despite these efforts made by the government of Zimbabwe and NGOs to establish care institutions so as to provide care for the people living with leprosy, as it stands the main

population of leprosy patients live outside care institution since the care institutions are few in Zimbabwe and the services offered at these institutions seems to be inadequate.

2.4 Experiences being faced by people with leprosy living outside institutional care facilities

Leprosy patients encounter a variety of problems both at home and in the community. Leprosy sufferers go through a difficult process that is mixed with both negative and positive experiences. As a result, these experiences are believed to be typical in the leprosy context and they are considered to be an integral element.

2.4.1 People not accessing health facilities

Letta (2020) discovered although leprosy patients seek medical attention, their condition is often misdiagnosed. Leprosy patients are poorly managed, their wounds are not properly cared for, case holding and interrupter tracing interventions are not properly implemented and also prevention of impairment and disability activities are not properly implemented while they are receiving treatment. There is a significant rate of relapse cases, which is related to patients who are lost to follow-up with patients' who have completed therapy. Considering the distance, poor access to roads, and difficulty using vehicles, women with disabilities also face significant challenges in accessing healthcare (Schuller et al, 2010; Charles-Damte, 2016).

However, leprosy hospitals should be built with the intention of giving persons with leprosy proper and respective care. According to the National Health Policy (2012), Zambia opened the Liteta Leprosy Hospital in 1959. According to the worldwide Strategy for 2016-2020, Health Ministries should continue to take the helm of the overall national response as outlined in a national leprosy plan. Women in rural Bangladesh were empowered to recognize leprosy's earliest symptoms and

lymphatic filariasis (LF) because these poor communities are frequently unreachable by health services (Joanna, 2016). Free leprosy testing and other illnesses like tuberculosis are offered since people in these areas avoid getting medical attention out of cost concerns. Bringing test camps and mobile education vans should be done to the most remote areas to ensure that there is no need for villagers to travel far.

2.4.2 Fear of stigma and discrimination

Stigma, according to Goffman (1963) is a spoiled identity. He divided those who participate in the process of stigma into three categories. 1) The stigmatized are those who experience rejection, scorn, ostracism and even murder ,2) those without stigma are considered to be normal and 3) and the intelligent are those among the norm who are recognised as cognizant of their predicament by the stigmatized. As a result, the majority of sufferers of leprosy experience shame because it is widely believed that the disease is spread through contact with infected individuals. People start to disregard them including family, friends and neighbours (Dako-Gyeke et al, 2017). Post lepers encounter daily discrimination including being denied access to the same kitchen utensils as other family members.

However, States have pledged to remove obstacles that prevent disability people from accessing justice since the ratification of the Convention on the Rights of Persons with Disabilities (CRPD) in 2006. The principle of the CRPD asserts that States should ensure no discrimination on the grounds of leprosy although people with leprosy especially women and children are at higher risk of suffering from discrimination. In order to reduce poverty and stigma, the global leprosy strategy was implemented.

2.4.3 Lack of education and employment

Leprosy patients who abandon their studies cite unjust behaviour from both educators and students (Cumber, 2017). Van Brakel argued that the stigma associated with leprosy interferes with education and those who have it. Leprosy's effects on productivity and scholastic issues that make it harder to get to work and results in poverty (Yirga, 2016). Thus, because some they do not have relevant courses and training which make them ready for employment (Rajasthan, 2019). Children whose family breadwinner has leprosy have their educational advancement hindered, as a result they quit school while they are very young Raphael et al (2017). However, some students are quitting school due to a long vision issue. Abedi (2013) postulates that people with leprosy are not accepted into the workforce, hence they are left without employment and income. However, Article 21 of the UNCRPD requires States parties requires to acknowledge that people with disabilities have the same right to employment as everyone else. This privilege entitles them to the capacity to support themselves through employment in a position they freely select or accept in a setting that is inclusive to those with disabilities. Hence, showing that the rights of people with disabilities are not explicitly recognised.

2.4.4 Financial difficulties

Leprosy sufferers experience severe physical limitations that make it difficult for them to perform manual labour that would generate income. This situation is made much worse by their inability to work because of leprosy. Community leaders who work in the food industry believe that leprosy can spread through consuming or giving certain foods, so they reject those with the disease (Peters et al, 2013). This is true because, as noted by Cumber et al (2017) anomalies in leprosy sufferers such severe hands crabbing and feet depend on others to survive. He also discovers that leprosy

patients struggle financially as a result of the negative effects of extended hospital stay, lack of economic recovery and children of leprosy sufferers have limited educational options. In a study of Abedi (2013), one respondent claims that since nobody desires to hire post lepers for jobs, those individuals are left without employment, hope and income. Financial burdens brought on by their poor living conditions and lack of employment lead to their inability to pay their bills. Despite providing free food to families of leprosy patients and financial support for leprosy, the Indian government schemes have a poor understanding of the problems (Guilbert, 2015). As proposed by Oktaria (2018), there is need to introduce food-based approaches because leprosy is linked to nutritional deficit.

2.4.5 Accommodation and housing

Another issue facing leprosy patients is housing and accommodations. Care leavers now face difficulties with paying rent since they are unable to find employment. Gender and social prejudice are additional problems that girls and women with leprosy must deal with. The Constitution of Zimbabwe (2001) states that everyone has the right to an appropriate standard of safe housing and the State is required to take reasonable governmental and other steps, within the limits of its resources, to gradually realize this right. Despite this, people with leprosy living outside institutional care facilities experience living in the streets hence they end up begging in the street as a way of surviving. The first Sustainable Development Goals is to eradicate poverty. Without access to basic human needs like food, shelter and healthcare, many are exposed to diseases and illnesses.

2.4.6 Mental health and well-being

Fife and Wright (2000:51) postulates that stigma is associated with serious disease has a particular nature that includes assigning blame to the patient, the threats the sickness poses to other people, and the threat it poses to the patient's competence. Leprosy patients who live independently may experience psychological issues such despair, anxiety, low self-esteem, and withdrawal. According to Somar et al (2020), post-leprosy patients typically experience anxiety. It is proven that in India, 13% of care leavers lacked sufficient cash for medical care, and 78% of care leavers lacked health insurance. The illness has a significant emotional impact on sufferers, making them feel inferior because of feeling of unlovedness, humiliation, denial, anxiety, depression and melancholy (Charles-Damte, 2016; Yirga, 2016; Dako-Gyeke et al, 2017).

As a result, living with family might cause emotions of guilt and a tendency to be quiet while speaking to strangers, which can have an adverse effect on psychological disorders (Schuller et al, 2010). Hence, they experience a sense of filth, so they isolate themselves at home to avoid being seen by others. A study done by Cassim (2020) showed that people with leprosy do not have access to medicine hence leading to poor health and well-being. Misuse of medication for intoxication due to unavailability of essential requirements such as food and services for health which led to mental disorder. Educating the locals in the area about the disease and training the local medical professionals are the activities that are being done to meet the basic needs of leprosy sufferers (Joanna, 2016).

2.4.7 Living with social dilemmas

Leprosy patients encounter social challenges like divorce, social rejection, loneliness, and sex denial (Cumber et al, (2017). Women are getting divorced after their partners discovers they have

leprosy. Likewise, males who contract leprosy are forbidden from having intercourse with their spouses. Similarly, leprosy patients (Kent and Tsutsumi, 2004) encounter insensitive responses, hatred and social rejection. When a partner files for divorce, it usually means that the husband has abandoned them and has driven them to do so. This is similar to the statement that was made by Sheih et al (2000) t leprosy patients can disrupt sexual relations and serve as a barrier to affectionate expressions like kissing and stroking. However, patients with leprosy also require a lot of social support from others, including their families, neighbours and health workers (Mahardita, Susanto, Wuryaningsih and Deviantony, 2019). Since family are the participants' primary source of support, they play a significant role in the program hence showing a research gap.

2.4.8 Living with physical disability

Patients with leprosy deal with pre-treatment symptoms, post-treatment symptoms, and disease exacerbating factors. According to Cumber et al. (2017) research, leprosy patients who left residential care or hospitals more prone to experience symptoms after treatment. One participant made the observation that their life had changed as a result of the medical care. They experienced some symptom relief, but they also developed painless skin blisters, and there was a slight reduction in the incidence of ulcers but not a complete cure. Additionally, they learn that there are things that make symptoms worse. Participants reported that after giving birth or when they stopped receiving treatment, their symptoms got much worse. However, the primary strategies for preventing the onset of physical disability continue to be early diagnosis, treatment and especially management of the illness and symptoms. Many leprosy patients in Mozambique are severely disabled due to the advanced stage of their illness (Joanna, 2016). In addition, community

education groups are assisting those that are affected through advocating for disability services and grants.

2.4.9 Living in peace with both oneself and God

People with leprosy lives in harmony with self and God (Cumber et al, 2017). This is accomplished through valuing oneself and showing respect for God, who gave them life. Some leprosy patients believe leprosy as God's will (Awofeso, 1995). This is in agreement with Van Brakel (2003) observation that people with leprosy turn to prayer and religious attendance as a form of therapy, and Sheih et al findings from 2000 that patients with leprosy could find emotional peace through prayer and religious attendance. However, some leprosy patients do not pray, they do not believe in God and have given up hope because of their conditions.

2.4.3 Relative social acceptance

Cumber et al (2017) research reveals that leprosy patients who have left residential care institutions are accepted in the society, get equitable treatment at social gatherings, and are respected by their neighbours. Some participants claimed to have received respect from others in their communities, even to the point of leading those who are not leprosy. However, Mararike (2013) postulates that leprosy patients were kept apart from the group so that they would not interact with anyone else because they would ordinarily pass away from the disease as there was no treatment. Kent and Tsutsumi (2004) postulates that leprosy patients encounter insensitive responses, hatred and social rejection. A study conducted by Nasir (2020) revealed that people with leprosy were left with their relatives as they were afraid of catching the illness. Additionally, despite having the right to voice their thoughts, they were not invited to participate in the discussion on inheritance, instead they were merely informed of the outcomes.

2.5 Coping strategies adopted by people with leprosy outside institutional care

In order to survive, leprosy patients who live outside of care institutions are more likely to participate in antisocial behaviours like crime and living in peace with both oneself and God. This is so because are unable to meet basic necessities like food, education, shelter and employment.

2.5.1 Criminal activity

The statistics of care leavers who commit crimes can be concerning. According to Courtney et al (2019) analysis of the USA Midwest Study, 23% of male care leavers aged 23-24 reported having been convicted of a felony and 45% had spent at very least one night in jail. Young people frequently relocate far from residential care facilities after leaving the facility because these facilities are not funded and do not have a mandate to offer aftercare services. Although there are initiatives to create and enhance care-leavers' support services (Van Breda, 2019), these are still in the planning stages and are only available in specific local contexts. Tanur (2012) notes that care-leavers do commit crimes, particularly when they reside in drug- and crime-ridden neighbourhoods or streets. As a result, they end up misusing drugs, and for women, they end up turning to prostitution as a means of subsistence. Contrarily, not all care leavers struggle with life negatively; some do, as shown by those who transition out of care and show resilience by choosing better options.

2.5.2 Living in peace with both oneself and God

People with leprosy lives in harmony with self and God (Cumber et al, 2017). This is accomplished through valuing oneself and showing respect for God, who gave them life. Some leprosy patients believe leprosy as God's will (Awofeso, 1995). This is in agreement with Van Brakel (2003)

observation that people with leprosy turn to prayer and religious attendance as a form of therapy, and Sheih et al findings from 2000 that patients with leprosy could find emotional peace through prayer and religious attendance.

2.6 Strategies to address the challenges faced by leprosy patients

Mental health projects, improve to access health care, community based participatory approaches to eliminate stigma and social and economic rehabilitation are the strategies that were proposed by different scholars to address the challenges of people living with leprosy.

2.6.1 Mental health projects

In India, they suggested that in order to lessen the likelihood of additional stress and damaged attachments, trauma must be treated by expanding access to mental health support systems and by giving care leavers opportunity to retain contacts with WHO assistance (Meade & Mendes, 2014). Additionally, increased access to education, employment, housing, mentoring, life skills, health care accessibility, neighbourhood resources, and administration of cases enables care leavers to participate in a society. Support services are also provided by regional community networks and trained social workers (Mendes, 2011). Plans for leaving care, empowering care leavers for excellent social inclusion, advocacy, and re-engineering societal viewpoints are just a few of the laws and programs that have been put into place to support care. Pamidipani (2015) alludes that in order to change society's framework and eliminate leprosy stigma, re-education and reorientation are necessary. Zimbabwe should also use strategies from India to spread the health education messages and assist people with disabilities in managing self-care. For leprosy services, there is need for models of family-based interventions and techniques.

2.6.2 Improve access to health care

Rao (2015) proposed a community health action model that combines the community development process with an appropriate framework for assessment, planning, implementation, and evaluation. Using this model, the community takes ownership of, sets the direction for, and accepts responsibility for its activities and the outcomes through public participation. Due to the handicap caused by leprosy, Cumber et al (2017) recommended that a person who had leprosy should be treated and monitored by medical specialist for a considerable amount of time and if resources permit, even for the rest of their lives to address repercussions. To prevent patients from traveling great distances in pursuit of particular treatment facilities, healthcare professionals at the lowest levels of care should receive training in the care of leprosy persons. Social workers and medical professionals should be included in patient's treatment to address their requirements.

Therefore, the MoHCC was able to carry out leprosy activities in 2019 in Binga with support of Nippon Foundation (TNF). The training main goals were to improve the competence of the medical staff in Binga and diagnose leprosy patients, encourage early detection of leprosy suspect cases before they progress to grade two disabilities. The course was a part of the leprosy prevention program in Zimbabwe which sought to address the country's periodic resurgence of new leprosy cases. Additionally, after receiving training, the health workers shared their newfound knowledge with their colleagues at various clinics so that they could diagnose and manage leprosy.

2.6.3 Community based participatory approaches to eliminate stigma

According to Rao (2015) community based participatory strategies are particularly helpful to eliminate stigma. Israel et al put out the concepts and practice in a methodical manner and included numerous instances of successful initiatives. Leprosy stigma can be eliminated through genuine

community-based participatory initiatives, according to case studies offered by Raju et al for the Leprosy Mission Trust in India, which was established in 2005 and has been operating for about 7 years. A stigma-reduction organizing committee was set up in each hamlet with the help and input of local leaders. Several activities, including some involving leprosy patients, were planned. Rallies, mass gatherings, slogan-covered walls, plays, communal meals, and health camps are just a few examples of activities aimed at eradicating stigma. In order to reduce poverty and stigma, the global leprosy strategy was implemented.

2.6.4 Social and economic rehabilitation

Cumber et al (2017) postulates that physical disability drive leprosy patients to the brink of extreme poverty. Lack of basic human needs makes people more prone to develop chronic ulcers and having a protracted hospital stay. It has been observed that having access to basic needs increases social acceptance and respect among members of the society who do not suffer from leprosy. The best strategy to relieve leprosy patients' suffering is through economic rehabilitation is the most effective way to ease the suffering of l (Cumber, 2017). Leprosy patients are advised to pursue social and economic rehabilitation since it enables those who have the disease to support their local economies. The notion that providing handouts will enhance leprosy patients' well-being was refuted by Chens et al (2004), who established unequivocally that the only option to improve the financial status patients with leprosy is through economic rehabilitation.

Hence, supporting the idea of economic rehabilitation. Cumber et al (2017) suggested that due to the handicap caused by leprosy, a person who had leprosy should be treated and monitored by medical specialist for a considerable amount of time and if resources permit, even for the rest of their lives to address repercussions. It is obvious that leprosy patients live in extreme poverty as a

result of their1 impairments, so the government, charitable organizations, and other institutions should unconditionally support the economic rehabilitation of leprosy patients, their families, and their children. In the research conducted by Sand et al (2018), they discovered that certain respondents benefit from the financial advantages increased social empowerment after acquiring socioeconomic recovery from community service through microcredit and skill development (Ebenso et al, 2007).

However, Zimbabwe should also borrow a leaf from India since comprehensive rehabilitation facilities are very uncommon. This would enable the mentally ill to receive proper rehabilitation, fostering self-autonomy and independence, self-sufficiency and production (Zimbabwe National Health Policy). The principle of decentralization should be emphasized since there should a broad focus on community-based services with the limited resources available.

2.7 Chapter conclusion

This chapter looked at the theoretical framework and the experiences of people with leprosy living outside institutional care facilities as well as possible strategies had been put forth by different scholars.

CHAPTER 3

RESEARCH METHODOLOGY

3.0 Introduction

This chapter focused mostly on the anticipated research motion and the research methodologies. The study's goal was to reveal the experiences of people with leprosy living outside institutional care facilities and also to identify the possible solutions to enhance the quality of life for lepers in Mutoko Centre. The research methodology, data collection methods, ethical concerns, research design, sample size, sampling strategy, target population and data collection process are all briefly covered in this chapter. This chapter also outlined the validity and reliability of the findings.

3.1 Methodology

According to Creswell (2014), methodology is a procedure for comprehending a social or human issue that is based on creating a complete account of informants and taking place in a natural environment. The researcher adopted qualitative methodology in gathering information in the study. Qualitative research is empirical research where the data are not in forms of numbers (Punch, 1998). It entails gathering, processing and analysing textual material as well as spoken or written language. It emphasizes body language or other visual components and aids in the creation of a thorough account of a researcher's observation. Creswell (2014) postulates that qualitative strategies are regularly firmly connected with interviews and focus group discussions. The researcher chose qualitative methodology because the meanings associated with human behaviour were taken into considerations and during the interviews there was interaction between the researcher and the participant.

3.2 Research Design

A research design, sometimes referred to as a research strategy, is a technique for finding answers to a number of questions (McCombes, 2019). It is a framework with methods and processes for gathering, analysing and interpreting data. In other words, the study design is a description of how the researcher would approach the major issue at hand and is included in the research proposal. Descriptive design was used to collect data. Descriptive research is an intentional process of collecting, analyzing, classifying and tabulating information about current conditions, practices, processes, trends and cause- and -effect relationships and then providing an adequate and accurate interpretation of that information with or without or sometimes with only minimal, assistance from statistical methods (Calderon, 2006). The University of Southern California Libraries (2015), articulates that descriptive design helps to unravel responses to those who, what, when, where and how of a research problem. The researcher used descriptive in the study because it allowed the researcher to collect data on personal and emotional experiences.

3.3 Population under the study

Louise Barnsbee (2018) outlines target population as the group of people who will be the subject of the intervention's investigation and result. The target population under the study were all the people with leprosy, caregivers and the community since they were the critical sources of the investigation.

3.4 Sample size

Leavy (2017) notes that sample is the number of individual cases that is ultimately drawn from the data that is generated. The sample size was 16 participants (10 people with leprosy and 6 key informants which are the 2 nurses, 3 community members and 1 administrator of Mutemwa clinic).

3.5 Sampling method

Purposive sampling and snowball sampling were utilized in the study. Both of these methods are non-probability samples. Indore (2020) notes that the process of selecting a sample from the population is called sampling.

3.5.1 Purposive sampling

Patton (2015) articulates that purposeful sampling is predicated on the idea that selecting the best instances for the study yields the best data and the research findings are directly related to the cases sampled. In this investigation, the researcher chose judgmental method to select 6 key informants. The researcher utilized this method to choose respondents who are likely to provide accurate information by using her judgment. Therefore, 2 nurses, 3 community members and 1 administrator from Mutemwa clinic were chosen using purposeful sampling.

3.5.2 Snowball sampling

Snowball sampling is a sampling strategy in which one case organically leads to another (Patton, 2015; Babbie, 2013). It is used when potential participants are difficult to find. Through this technique, the researcher identified three leprosy patients who visited Mutemwa clinic and they also referred the researcher to other leprosy patients. 10 people were picked using the snowball

technique. The researcher selected snowball sampling because it commences with few people and extends out based on links or referrals.

3.6 Data collection method

Data collection is a procedure for obtaining and analysing particular information in order to provide answers to pertinent queries and evaluate the outcomes. Creswell (2014) postulates that data collection richly capitalises on instruments which enable the researcher to extract information from the participants. The study utilized in-depth interviews as a data collection method.

3.6.1 In-depth interviews

Roller and Lavrakas (2015) postulates that in-depth interviews is a way when information is analysed in order to create a story or narrative that conveys an understanding of some topic of interest. The researcher interviewed 10 participants (PWL) and 6 key informants (2 nurses, 3 community members and 1 administrator from Mutemwa clinic) to gather adequate information thereby understanding participants deeper. Interviews for people with leprosy were conducted in Shona for 20-25 minutes in the comfort of their homes and also key informants were interviewed for 20-25 minutes in their offices in order to safeguard confidentiality. The researcher made use of recording instrument and also taking notes on the responses of participants. Interviews helped the researcher to get a summary of individual's views on the experiences that they are facing after leaving institutional care.

3.7 Research instruments

A research instrument is a tool that is used to collect, measure and analyse data related to a subject. Some examples of research instruments include interview guide, questionnaires and surveys. Two

interview guides for people with leprosy and key informants were used as a research instrument by the researcher.

3.7.1 Interview guide

Etikan (2017) notes an interview guide as a set of structured questions that serves as a direction for researchers and interviewers in gathering information on data on certain subject. Two interview guides were used which consists of structured questions for key informants and unstructured questions for sufferers of leprosy. In qualitative research, interviews are conducted when the researcher as one or more participants broad, open-ended questions and record their response (Phillips, 2016). The researcher interviewed 16 participants. The interview session was conducted for 20-25 minutes and the researcher made use of recording and also taking notes on the responses of participants.

3.8 Data collection procedure

McCombes (2021) asserts that data collecting is the act of acquiring and analysing information on relevant variables in a systematic and established manner in order to answer specific research questions and analysing results from a hypothesis test. The researcher obtained a research letter from Bindura University of Science Education. Additionally, the researcher wrote a letter explaining her research plans and activities. A consent form was signed between the respondents and the researcher. Recording and taking notes from the respondents was done by the researcher after explaining the research aims and objectives to the respondents.

3.9 Data analysis and presentation

Bell (2015), states that data analysis is the organisation and classification of data to produce knowledge. Data analysis aims to describe, discuss and explain the context of generated data in the study (Bryman, 2012). Qualitative data is used in this study was analysed thematically to provide feasibility to the study. According to Clarke (2012), thematic analysis is usually applied to a set of texts such as interview transcripts and it also allows the researcher to closely examine the data to identify common. A series of texts, such as interview transcripts are typically subjected to thematic analysis, a technique for analysing qualitative data. The researcher utilized thematic analysis so as to analyse data and interpret it. When conducting this thematic analysis familiarization, coding, generating themes, reviewing themes, defining and naming themes and writing up are various steps to follow.

❖ Familiarisation

Braun, Clarke and Weate (2016) postulates that familiarisation is a process of deeply immersing with data so that one can become intimately familiar with their content. The researcher became familiar with the data that was acquired, comprehended the activities, and also understood the responses that respondents gave. Every comment the interviewee made was recorded by the researcher, who also took initial notes and largely browsed the material to become familiar with it.

❖ Coding

Creating coding groups and choosing valuable data from less useful data allow for the identification of codes (Clarke, 2012). At this stage, the researcher acquired information

through recording or highlighting crucial topics in a collection of data. The researcher organized all the information she received from respondents into different classifications. Each section's pertinent data was coded by the researcher.

❖ **Generating themes**

The researcher explores the codes made from the previous stage, identifies the pattern among them and creates themes (Clarke, 2012). Problems being faced by people with leprosy living outside institutional care facilities were observed and possible strategies were made.

❖ **Reviewing themes**

Braun, Clarke and Weate (2016) outlines that, this stage entails modifying the coded data before returning to the entire dataset. Phase 4 starts after a collection of potential topics has been created and involves both the development of those concepts and their refinement. The researcher gathered data that is pertinent to each theme and then compared it to the information to see if the subjects were indeed present. Color-coding was used to identify the data for each theme.

❖ **Defining and naming themes**

The purpose of this final iteration of the themes is to pinpoint the essence of what each topic is all about (Braun and Clarke, 2006). The researcher reviews the final list of themes, identifies each one and defines it. The optimal situation was to speak with each participant individually during the interview session to get their comments. In order to prevent participants from being recognised in the publication, privacy was crucial.

❖ **Writing up**

The researcher analysed data and presented it in a report. Braun, Clarke and Weate (2016) states that this stage involves compiling, developing and editing existing analytic writing and situating it within an overall report.

3.10 Ethical considerations

Bhandari (2022) postulates researchers and scientists must always follow the set of ethical guidelines when collecting information from subjects. Seeking informed permission was done to the participant by the researcher before conducting face to face interviews. According to Swanson and Betensky (2015), consent forms are used by researchers to maintain participant privacy and guarantee their rights are upheld. Also acquiring informed consent requires explanation. Consequently, confidentiality, privacy and no harm were assured in all interviews. Ethics differentiate between right behaviour and wrong behaviour.

❖ **Confidentiality**

Leavy (2017) explains confidentiality as the ethical protection where participant identity is kept anonymous in any publications or presentations. The researcher ensured that there was high level of confidentiality since people with leprosy are discriminated from the society. Pseudo names were used to uphold confidentiality in the study.

❖ **Informed consent**

Its purpose is that participants can enter research without any force (voluntarily) with full information about what it means for them to take part and they also give consent before they

enter the research. British Psychological Society (2010) note that researchers should ensure that every person from whom data is gathered should freely agree to contribute to the research. This was explained to all the respondents (key informants and post leprosy patients).

❖ **Voluntary participation**

According to Leavy (2017) participation must be strictly voluntary and can be withdrawn at any time without consequence. The researcher explained to the participants how the study is going to benefit their society. The individuals participated voluntarily and they were given a chance to withdraw during the process if they were not comfortable with the discussions. Hence, upholding the principle of respect for autonomy and dignity for all respondents which goes in line with voluntary participation. Ethical standard request researchers not to put participants in situations that they might be at risk of harm.

❖ **Avoidance of harm**

De Vans (2011) postulates that avoidance of harm refers to not doing actions, which will result in harming the subjects of the research. The participants were protected from any forms of exploitation. The researcher avoided harming the participants by following ethical considerations thorough out the research.

3.11 Feasibility of the study

The targeted research respondents agreed to take part in the research since it would be beneficial to the community, making it practical. It was doable because Mutemwa clinic gave the researcher permission to carry out the data collecting.

3.11.1 Credibility

As postulated by Polit and Beck (2014) the most crucial factor is the study's credibility, or the degree to which one has faith that the study's conclusions are accurate. The Maslow hierarchy of needs was employed by the researcher as a theoretical framework to understand the experiences of people with leprosy living outside institutional care facilities. The researcher gained credibility by performing in-depth interviews that allowed individuals to reveal their experiences of living with leprosy. The researcher actively listened during the interviews, noting both verbal and non-verbal cues.

3.11.2 Transferability

Polit and Beck (2014) expressed that the character of transferability is the degree to which conclusion are beneficial to people in other aspects of research in that readers actually determine how applicable the findings are to their situations. The study was carried out with Mutemwa clinic's approval and as a result, it produced reliable data that encouraged transferability. Each participant was given the opportunity to share their experiences by the researcher until no further information could be shared.

3.11.3 Confirmability

Connelly (2016) articulate that confirmability is the neutrality or the degree findings are consistent and could be repeated. Note taking and recording were done during the data analysis. To promote neutrality in the selection of the results, the researcher utilized a non-probability sampling technique. The participant's narrative was used by the researcher to draw conclusions. During data analysis, the researcher avoided bringing in previous ideas and assumptions about leprosy sufferers

and focused on the information provided by the participants to avoid interpreting the phenomenon incorrectly.

3.12 Limitations of the study

Theofanidis (2019) cites limitations as potential flaws in a study that are typically uncontrollable and directly related to the design strategy that was selected. The researcher encountered few limitations while working on the research. Most notably, several respondents were noted as not being particularly eager to disclose information about their experiences due to the sensitive nature of the research being conducted. Due to few studies about people with leprosy in Zimbabwe, the researcher's options were limited. There was communication barrier since most sufferers of leprosy are from Mozambique.

3.13 Delimitations of the study

The researcher chose Mutoko centre which is in Mashonaland East since there is a residential care for people with leprosy. The study focused on the experiences of people with leprosy when integrating into the society.

3.14 Chapter conclusion

The chapter has provided an overview of methodologies, research designs, data analysis techniques, limitations, delimitations and ethical concerns that were used by the researcher to examine the experiences of people with leprosy living outside institutional care facilities in Mutoko centre. The validity and dependability of the results were also emphasized in the chapter.

CHAPTER 4

DATA ANALYSIS, PRESENTATION AND DISCUSSION OF FINDINGS

4.1 Introduction

This chapter contains information that was collected from the research. The chapter analyses, presents and interprets data that was attained from research participants in Mutoko centre through the use of interviews. The study was guided by the three themes which include: to explore the experiences of people with leprosy living outside institutional care; to find the coping strategies adopted by leprosy patients after leaving care and; to provide strategies to address the challenges mentioned by leprosy people. The researcher gathered data that is pertinent to each theme. Data was gathered from 10 people with leprosy and 6 key informants who are 3 community members, 2 nurses and 1 administrator from Mutemwa clinic.

4.2 Demographic information of respondents

The section displays the participants' demographic information. In the research study, the information is crucial since it aids in the data interpretation and the creation of conclusion from data results.

4.2.1 Demographic of the total respondents

Figure 4.2.1

Respondents	Sex	Intended	Actual total
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	Male	Female		
Administrator from Mutemwa clinic		1	1	1
Community members	2	1	3	3
Nurses		2	2	2
People with leprosy	6	4	10	10
Total	8	8	16	16

Fig 4.2.1 above illustrates that 1 Administrator from Mutemwa clinic and 3 community members which included 2 males and 1 female took part in the study. It also shows that 2 nurse females partook in the study and 10 leprosy people which comprised of 6 males and 4 females. The researcher included both females and women in the study because leprosy affects both of them.

4.3 Qualitative data presentation

The research aimed to explore the experiences of people with leprosy living outside institutional care facilities in Mutoko centre. Purposive sampling was used to interview 6 key informants which are 2 nurses, 3 community members and 1 administrator from Mutemwa. Snowball sampling was used to interview 10 people with leprosy. This was done in order to avoid interpreting the phenomenon incorrectly on the experiences that are being faced by people with leprosy. The researcher made use of recording instrument and also taking notes on the responses of participants.

4.4 Experiences of people with leprosy living outside institutional care facilities

In this part, community members, administrators, nurses and post lepers examined the various experiences of leprosy patients living outside institutional care in Mutoko centre. Disability, drug shortages, homelessness, isolation, lack of education, mental health, social acceptance and unemployment were prevalent experiences.

4.4.1 Disability

The majority of respondents asserted that disability occurs when leprosy affects people. Even though the disease will soon manifest, they claimed that cutting toes and fingers helps to slow its spread. One participant said that:

“Muchindiona kudai ndine makore makumi matanhatu nemashanu uye ndakatanga kurapwa chirwere chemaperembudzi ndine makore gumi. Zvisinei handichanyatsonzwa zvakanaka uyezve handichakwanise kuona zvinhu zvinenge zviru kure” (“As you can see, I am 65 years old and was given a leprosy diagnosis when I was 10 years old. However, I have lost my sense of hearing and am unable to see objects in the distance well.”)

People who have leprosy have also hinted that they were detected too late because they first experienced skin blisters and mistakenly believed that they had another illness. One leprosy sufferer mentioned that:

“Ndakatanga kubuda mapundu mumuviri wangu, uyezve ndakazoenda kuchipatarwa ndikabatwa kuti ndine chirwere chemaperembudzi apa ndainge ndatorasikirwa nemimwe yangu yose apa ndisati ndatombotanga kurapwa” (“I began to develop skin blisters and

when I went to the hospital, I was informed that I had leprosy and had already lost all of my fingers before treatment.”)

4.4.2 Drug shortages

Thirteen respondents stated that there are times when hospitals run out of medications. Three key informants clarified that there were instances when they did not administer medication to patients because they were given short supply of drugs. The administrator of Mutemwa clinic stated that:

“Mutemwa clinic receives its medication from the Tropical Disease Unit (T.D.U) or donors and because the medications are expensive, there is a limited amount available.”

People with leprosy emphasized that they stopped taking their medications as a result of medicinal shortages. One participant said the following:

“Ndakamira kunwa mapiritsi mwedzi miviri yapfura nekuda kwekuti kuchipatara kwanga kuisina mapiritsi nekuda kweizvozvo ndakarasikirwa nemimwe yangu” (“I stopped taking my medication for two months because the hospitals and clinics were out of it, and I lost my fingers as a result.”)

4.4.3 Homelessness

Lack of accommodation is another experience of leprosy sufferers who reside outside of institutional care facilities. This illustrates that they end up living on the streets because they have nowhere else to go and their relatives do not want to take them in. One community member mentioned that:

“Due to lack of housing, some leprosy patients live on the streets, they occasionally discover that they are unsafe especially in rainy seasons.”

This demonstrates unequivocally that leprosy patients live on the streets because their relatives have abandoned them. One leprosy patient said that:

“Ndinogara mumigwagwa sezvo hama dzangu dzakanditiza, kunyangwe ndikapiwa mishonga hazvibatsire chinhu nekuda kwekuti maronda angu anonayiwa nemvura zuva rimwe nerimwe” (“I live in the streets since my relatives left me and even if I am given medication, it will not help because I get drenched in the rain every day, which prevents my wounds from healing.”)

4.4.4 Isolation

Isolation was another experience mentioned by the respondents as they explained that once some relatives learned that a person had leprosy infection, they abandon and mistreat the person. As a result, this has rendered leprosy sufferers’ social lives lonely and stigmatized. One respondent revealed that:

“Mudzimai wangu akandiramba akaenda nevana vangu vaviri uyezve akati ndisazofe ndakamutsvaga uye ndisave netariro yekumuona zvakare, nekuda kwekuti akaona muviri wangu washata nechirwere chemaperembudzi” (“My wife divorced me, left with my two children and assured me to never look for her again because she found out that I had a skin ailment which was leprosy.”)

Another female leprosy patient mentioned that:

“Murume wangu akaramba kuita bonde neni paakaziva kuti ndine chirwere chemaperembudzi, uyezve aitya kutapukira hutachiona hwemaperembudzi” (“My husband refused to have sex with me when he found out I had leprosy because he was worried, I would infect him.”)

This was strengthened by one male leprosy patient who said:

“Ndinoenda kukereke kunyangwe vamwe vandinopinda navo vachindiseka, nekuti ndinozviona ndiri mutana ndakasimba kunyangwe ndane makore makumi mana ndichirarama ndine kuremara” (“I still go to pray even if my fellow church members tease me on the way there because I see myself healthy though I have lived with deformities for the past 40 years.”)

4.4.5 Lack of education

Two respondents highlighted lack of education as one of their experiences. One of the most crucial things is education because it affects every person’s future. Although education is important as it affects the future of a person, leprosy sufferers admitted in an interview that their children drop out of school because they are unable to find employment to cover their tuition. One respondent state that:

“Maoko angu akaremara zvekuti handichakwanise kushanda kuti ndiwane mari, nekuda kwedambudziko iri vana vangu vakabva vamira kuenda kuchikoro” (“My hands are paralyzed and I can no longer work to make money, so my children stopped attending school.”)

Another leprosy patient in this situation claimed that he stopped going to school as a result of how he was treated by both his classmates and teachers. He said that:

“Ndakamira kuenda kuchikoro nekuda kwekuti ndaive ndakaiswa kure nevamwe vana kudzivirira kutapukira kwechirwere ichi. Vadzidzisi vangu vanoita kuti ndigare kumashure uye hakuna mwana anotaura neni asi vanotondiseka, dai pasina chikonzero chekusekwa ndakapfurira mberi nezvidzidzo zvangu kunyangwe ndichirwara” (“I stopped going to school because I was isolated from other students. My teachers put me on the last bench and no students ever talked to me instead my classmates used to make fun of me. If that had not been the case, I would have continued with my studies despite my illness.”)

4.4.6 Mental health

All two nurses who participated in the study highlighted that mental illness affects patients with leprosy as well. They said that post leprosy patients experience psychological issues hence they isolate themselves. One nurse said that:

“A person’s thought, perceptions, feelings and behaviour are all affected by mental illness.”

4.4.7 Social acceptance

All ten leprosy sufferers who participated in the study indicated that they are well respected in their societies and they are allowed to participate in decision making process. One leprosy patient said that:

“Kunyangwe ndisina mwana anodzidza pachioro ipapo, ndakakokwa kuchikoro kumatare eko uyezve ndakapiwa mukana wekuonesawo mafungiro angu pahurongwa watainge tichikurukura nezvawo” (“Despite not having a child enrolled there, I was invited to the school meeting and offered the opportunity to share my opinions on a particular subject that was being discussed.”)

4.4.8 Unemployment

Unemployment is another experience that is being faced by people with leprosy living outside institutional care. One of the respondents in the study stated that despite being educated they are not desired as employees. One respondent said that:

“Leprosy people are unable to get employment and support themselves since no one wants to hire them.”

Two key informants also added that the MTD medication frequently results in gastrointestinal like lethargy and dizziness. Leprosy patients now find it challenging to lead normal lives and to find employment as a result of this. One nurse mentioned that:

“It has been challenging for leprosy patients to work because they have gotten weak after taking their treatment.”

4.5 Coping strategies adopted by leprosy patients after leaving care

The coping strategies adopted by leprosy patients after leaving institutional care are explained below.

4.5.1 Begging

All respondents of leprosy highlighted that they beg on the streets to support themselves.

According to six key informants, leprosy patients have reportedly been seen begging in the streets.

One respondent mentioned that:

“Ndakatanga kuita zvekupemha kubva zuva randakarasikirwa nevabereki vangu apo ndaive nemakore makumi matanhatu” (“I have been begging daily since I lost my parents when I was 16 years old.”)

4.5.2 Stealing

All respondents highlighted that people with leprosy end up stealing in order to survive. One of leprosy patient was asked for his motivation for engaging in theft and he said:

“Handishande saka ndinoona kunge kuba ndiyo nzira chete yekuti ndikwanise kuriritira mhuri yangu” (“I don’t have a job, so I consider stealing as my only alternative because I have kids to take care of.”)

4.6 Strategies to address the challenges mentioned by leprosy people

Various strategies to address the challenges mentioned by leprosy people are presented below.

4.6.1 Improve health facilities

All respondents in the research argued that hospitals should be created together with better health care facilities for leprosy patients in order to lessen the disease’s impact on society. They said that leprosy patients should receive medications from hospitals or clinics so that they can receive care when they go to the hospital. One post leper state that:

“Tikaenda kuchipatara tichida kurapwa tinoudzwa kuti havana mushonga wekutipa wakaita seglycerine neichthamol nebetter din. Dzimwe nguva kana uchida kutorapwa zvakanaka tinofanirwa kuenda kuParirenyatwa nekuti ndiko kuna chiremba anoona nezvevanhu vane leprosy uyezve zvipatara zvinofanirwa kuvakwa kuitira kuti tisafambe mitunhu yakakurisa” (“If we go to the hospital for treatment, we are told that they have no drugs such as glycerine and ichthamol and better din. When we need a leprosy specialist, they occasionally recommend that we travel to Parirenyatwa hospital so in order to reduce walking long distances health facilities should be improved.”)

This was further supported by 3 key informants which are 2 nurses and 1 administrator who highlighted those injections, glycerine and ichthamol was a challenge in hospitals and sometimes they cannot treat these people but they can only trim their wounds to reduce the pain.

4.6.2 Income generating projects

Ten respondents mentioned that people with leprosy should be taught on how to start their own businesses like raising chickens, knitting, sewing and candle making so they can support themselves. One respondent remarked that:

“Ndine chivimbo chekuti ndikadzidza kusona hembe nekuita zvekupfuya huku ndinokwanisa kuriritira mhuri yangu” (“I believe that learning how to sew or raise chickens will truly help us to take care of ourselves.”)

Another respondent mentioned that:

“Kuva nenzvimbo yandinoti yangu kunondidzivirira kuti ndisapemhe, saka chishuwo changu ndechekuti dai tawana rubatsiro rwemari yekuti titange mabhizimusi edu tiwane

kuunganidza mari yemabhizimusi aya” (“Having my own land would prevent me from begging, so I wish we could receive financial assistance to own land and launch small businesses that generate revenue.”)

4.6.3 Leprosy Day should be celebrated

All key informants said that world leprosy day should be observed and commemorated. They also highlighted that this will help to increase public awareness of leprosy and this is a way of sharing message to people who thinks that leprosy do not exist. One nurse said that:

“Leprosy day should be observed annually to educate people about the disease’s persistence and the harm it continues to do to lives.”

4.6.4 Medical and educational assistance

All the people with leprosy that participated in the research mentioned that they should receive medical and educational support since they have trouble paying their medical expenditures. They said that financial aid for schooling should be offered since some of them have stopped attending classes due to lack of funds. One respondent state that:

“Pandaive muzvidzidzo zveform 1 ndakamira kuenda kuchikoro nekuda kwekushaya mari yekubhadhara kuti ndipedze chikoro” (“When I was in form 1, I stopped going to school because I didn’t have enough money to pay for my tuition.”)

Key informants (6) further supported the need for the government to provide grants or include leprosy patients in food aid programs as it will benefit them since some of them cannot work due to disability. One respondent said that:

“The government or NGOs should assist post lepers with grants or they should include them in food aid programmes.”

This was further strengthened by one of the leprosy people who said:

“Hurumende inofanirwa kutibatsira isu vane dambudziko remaperembudzi nekutipa rubatsiro panyaya yezvekudzidza kuti tippedze zvidzidzo zvedu” (“Government should help us people with leprosy with educational assistance so that we can successfully complete school.”)

4.7 Discussion of findings

The research concentrated on the experiences of people with leprosy living outside institutional care facilities. The study was guided by three themes which include: to explore the experiences of people with leprosy living outside institutional care; to find the coping strategies adopted by leprosy patients after leaving care and; to provide strategies to address the challenges mentioned by leprosy people. The researcher interviewed 10 participants (PWL) and 6 key informants (2 nurses, 3 community members and 1 administrator from Mutemwa clinic). All three objectives from the findings presented above were understood by the researcher.

The researcher managed to utilize Abraham Maslow’s theory of needs. Maslow notes that in order for people to develop, they have some basic needs that cannot be disregarded (as mentioned on [page 18 of Gething, Hatchard, Papalia and Olds, 1993]). Physiological needs such as food and water keep the human body alive however if these needs are not fulfilled the individual will not pay attention to any other needs. Through, this theory the researcher managed to understand the

absence of basic needs and how the desire to obtain these basic needs can influence the behaviour of people living with leprosy.

Findings from the research expressed that people with leprosy living outside institutional care were going through difficult process that is mixed with both negative and positive experiences. These experiences include disability, drug shortages, homelessness, isolation, lack of education, mental health, social acceptance and unemployment. Homelessness was supported by UK researches who specified that, one third of care leavers (33%) become homeless after leaving care in two years and it is evidenced by Greaves (2017) that, 25% of all single homeless people have been in care at some point. Maslow's theory of needs emphasized that shelter is the basic needs of every individual hence this issue of lack of accommodation simply illustrates the absence of something Maslow advised.

Disability is another experience that affects people with leprosy. People with leprosy were detected late because they first experienced skin blisters and mistakenly believed that they had another illness. This is supported by Reddy (1984) who notes that 47% of leprosy patients were detected late because they went to traditional healers first before coming to health facilities. From the findings, disability occurs usually when people are diagnosed with leprosy. This is in line with the findings of Joanna (2016) who mentioned that many leprosy patients in Mozambique are severely disabled due to the advanced stage of their illness. Due to the handicap caused by leprosy, Cumber et al (2017) recommended that a person who had leprosy should be treated and monitored by medical specialist for a considerable amount of time and if resources permit, even for the rest of their lives to address repercussions.

The research revealed that people with leprosy are being isolated from other people because they are afraid of being infected. This is in line with the study of Alubo et al (2003) who revealed how community members avoid exchanging greetings and even asking for anything from known leprosy patients for fear of getting infected. This also goes hand in hand with the study that was conducted by Nasir (2020) that revealed how people with leprosy were left with their relatives as they were afraid of catching the illness. As a result, sufferers of leprosy experience shame because non leprosy people believed that the disease is spread through contact with infected individuals. Though States have pledged to remove obstacles that prevent disability people from accessing justice since the ratification of the Convention on the Rights of Persons with Disabilities (CRPD) in 2006.

Another challenge that was presented above is lack of education and employment. Many leprosy patients have dropped out of school because of the way they were treated by their classmates and teachers. As a result, this has made people with leprosy not to be educated hence no one wants to hire them. This was supported by Abedi (2013) who postulated that people with leprosy are not accepted into the workforce, hence they are left without employment and income. Van Brakel also argued that the stigma associated with leprosy interferes with education and those who have it. Thus, because some they do not have relevant courses and training which make them ready for employment (Rajasthan, 2019). However, Article 21 of the UNCRPD requires States parties requires to acknowledge that people with disabilities have the same right to employment as everyone else. This privilege entitles them to the capacity to support themselves through employment in a position they freely select or accept in a setting that is inclusive to those with disabilities.

Furthermore, from the findings it was noted that leprosy patients are also accepted in their communities. People with leprosy are respected in their communities to the extent of being involved in decision making. This matches with the research of Cumber et al (2017) who revealed

that leprosy patients who have left residential care institutions are accepted in the society, get equitable treatment at social gatherings, and are respected by their neighbours. Some participants claimed to have received respect from others in their communities, even to the point of leading those who are not leprosy.

Furthermore, the researcher found out the coping strategies that were adopted by leprosy patients. These include, begging and stealing. People with leprosy living outside institutional care relied on stealing as a way of survival. This is consistent with the research from the USA Midwest Study of Courtney et al (2019) who articulated that at age 23–24, 23% of male care leavers reported being convicted of a crime and 45% reported being imprisoned for at least one night. Also this concurs with the study of Tanur (2012) who postulated that care-leavers do commit crimes, particularly when they reside in drug- and crime-ridden neighbourhoods or streets. Contrarily, not all care leavers struggle with life negatively; some do, as shown by those who transition out of care and show resilience by choosing better options.

The study also revealed the strategies to address the challenges mentioned by leprosy people. These strategies include improvement of health facilities, income generating projects, medical and educational assistance and celebrating leprosy day so that people would be able to know that leprosy still exist. This is consistent with the research of Joanna (2016) who articulated that educating the locals in the area about the disease and training the local medical professionals are the activities that are being done to meet the basic needs of leprosy sufferers. To prevent patients from traveling great distances in pursuit of particular treatment facilities, healthcare professionals at the lowest levels of care should receive training in the care of leprosy persons. Social workers and medical professionals should be included in patient's treatment to address their requirements.

4.8 Chapter conclusion

The chapter has analysed and presented the information that was gathered in Mutoko centre on the experiences of people with leprosy living outside institutional care. The researcher managed to put aside preconceived notions and assumptions about those who have leprosy and focused on the information provided by the participants on the experiences of people with leprosy living outside institutional care facilities.

CHAPTER 5

SUMMARY OF FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

5.0 Introduction

This chapter captures the summary of the findings on the experiences of people with leprosy living outside institutional care, a case study of Mutoko Centre. Its conclusion is based from the research findings such as the experiences of people with leprosy living outside institutional care, their coping strategies, strategies to address the challenges mentioned as well as possible recommendations which could improve the research study.

5.1 Summary of findings

The study targeted to explore the experiences of people with leprosy staying outside institutional care, a case study of Mutoko Centre. The three objectives that guided the research study were as follows: to explore the experiences of people with leprosy living outside institutional care, to find the coping strategies adopted by leprosy patients after leaving care and to provide strategies to address the challenges mentioned by leprosy patients. Abraham Maslow hierarchy of needs was utilised as a theoretical framework because it throws light on the experiences that are being faced by people with leprosy. Data were presented and analysed using qualitative technique. 10 leprosy patients were sampled using snowball sampling and purposive sampling was used to sample 6 key informants.

5.1.2 The experiences of people with leprosy living outside institutional care

The study revealed that people with leprosy living outside institutional care facilities have a variety of negative and positive experiences at home and in the community. These experiences range from incapacity of drug shortages, disability, homelessness, lack of education, social acceptance, unemployment, isolation and mental health. Some of these experiences have made post lepers to be abandoned and mistreated by their relatives or the community. The key informants highlighted that due to mental illness people with leprosy experience psychological issues hence they end up isolating themselves. People with leprosy indicated that they are respected in their communities to the extent of being involved in decision making. Due to disability that is caused by leprosy, post lepers find it challenging to live normal lives and also to find employment despite being educated because the MTD medication often results in gastrointestinal like lethargy and dizziness. Leprosy sufferers indicated that due to unemployment their children drop out of school because they cannot cover their tuition. The study found out that hospitals run out of medications since they were given short supply and due to this people with leprosy indicated that they stopped taking their medications.

5.1.3 The coping strategies adopted by leprosy patients after leaving institutional care

The study clearly brought out the coping mechanisms that are being adopted by post lepers after leaving care in order to meet their needs. Stealing and begging were observed by the researcher as the coping mechanisms. Other respondents indicated that people with leprosy have engaged themselves in activities like stealing in order to survive. People with leprosy indicated that they consider stealing as their only alternative since they have kids to take care of. The study found out

that since post lepers despite being educated they are not desired as employees, they have decided to beg in order to sustain themselves.

5.1.4 Strategies to address the challenges faced by leprosy patients

Findings of the research revealed that improving healthcare facilities is necessary to lessen the disease's impact on the society. The study found out that people with leprosy should receive medical and educational support since they have trouble paying their medical expenditures and as a result some of them have stopped attending classes due to lack of funds. Due to post-leper population's desire to increase their income in order to survive, the question of income generating projects was brought up by the respondents. Leprosy day should also be observed, according to the participants, to increase awareness of the disease and to send a message to those who believe leprosy does not exist.

5.2 Conclusion

Conclusively, people with leprosy living outside institutional care facilities have a variety of negative and positive experiences. The study came to the following conclusion;

The study concluded that, experiences of people living outside institutional care facilities in Mutoko centre are marked by disability, drug shortages, homelessness, lack of education, social acceptance, unemployment, isolation and mental health. The research brought to light that leprosy can result in loneliness because people with leprosy are being rejected and mistreated by their relatives or society. Due to disability that is caused by leprosy, post lepers find it challenging to live normal lives and also to find employment despite being educated because MTD medication often results in gastrointestinal like lethargy and dizziness. The study realized that hospitals run

out of medications since they were given short supply and due to this people with leprosy indicated that they stopped taking their medications.

The research concluded that leprosy patients are consequently forced to seek coping mechanisms in in order to deal with these difficulties. Some leprosy patients who are not under institutional care end up stealing because it is how they can make money to survive. The study found out that since post lepers despite being educated they are not desired as employees, they have decided to beg in order to sustain themselves.

Government's poor policies for tackling these problems at their source led to these effects. At the end, the research concludes that the government of Zimbabwe and NGOs should assist post lepers with medical and educational assistance since they have trouble paying their expenditure. Since there were drug shortages and some people with leprosy were referred to Parirenyatwa for treatment, the research concluded that healthcare facilities should be improved. Leprosy day should be celebrated to increase awareness of the disease. The research highlights income generating projects issues in order to meet the needs of post lepers.

5.3 Recommendations

After presenting and analysing data on leprosy patients in Mutoko centre who were living outside institutional care, the researcher developed recommendations on how to better meet the requirements of these patients. Here are some recommendations:

- ❖ Traditional healers and the leprosy control program should work together to identify and send patients with leprosy to medical facilities. This will speed up the diagnosis process.

- ❖ Leprosy patients who receive appropriate counselling will be able to deal with the stigma attached to the condition.
- ❖ The government of Zimbabwe and NGOs should help leprosy patients and their families in recovering their economic stability as well as unconditionally providing for their children's educational needs since it is apparent that leprosy patients live in extreme poverty to their condition.
- ❖ To prevent patients from travelling long distances in pursuit of particular treatment facilities, healthcare professionals at the lowest levels of care should receive training in the care of leprosy patients.
- ❖ Adoption of socio-economic policies that fund former lepers with grants and enable leprosy patients to become economically independent through self-help endeavours like candle making, poultry, knitting and sewing.
- ❖ The study suggests educating leprosy sufferers and the communities in which they live. By raising public and patient knowledge of the condition, leprosy case identification will increase.

5.4 Chapter summary

This chapter captured the summary findings of the whole study. Conclusion and recommendations to improve the needs of people with leprosy living outside institutional care was highlighted in this chapter. It showed the experiences of people with leprosy living outside institutional care which includes drug shortages, unemployment, disability, isolation, mental health, lack of education, homelessness and social acceptance. It showed how the framework underpinned the study. Lastly, the chapter recommended educating leprosy sufferers and the communities, adopting socio-

economic policies, training health care professionals at the lowest levels and providing counselling to post lepers so that they can deal with stigma.

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List of Appendices

Interview guide for people with leprosy, nurses, community members, secretary and administrator of Mutemwa clinic.

My name is Annah V Dzimunwe, a fourth-year student currently studying Bachelor Honors Degree in Social Work at Bindura University of Science Education. I am carrying a study on the topic entitled, “**THE EXPERIENCES OF PEOPLE WITH LEPTROSY (PWL) LIVING OUTSIDE INSTITUTIONAL CARE FACILITIES IN MUTOKO CENTRE**”. Informed consent will be obtained thus involves explaining the benefit of the research topic and also you are allowed to withdraw during the process if you are not comfortable with the discussions. All the information that will be collected during the study will be kept confidential meaning that your names will not be disclosed in any publications hence you will be protected from any harm. If you agree to participate, please sign the consent form below.

I.....consent to take part in this research under the terms mentioned above. I have added my signature below willingness.

Interviewee’s signature..... Date...../...../.....

Interviewer’s signature..... Date...../...../.....

Research Objectives

- ❖ To explore the experiences of people with leprosy living outside institutional care.
- ❖ To find the coping strategies adopted by leprosy patients after leaving care.
- ❖ To provide strategies to address the challenges mentioned by leprosy people.

Research Questions

- ❖ What are the experiences faced by people with leprosy living outside institutional care?
- ❖ What are the coping strategies adopted by leprosy patients after leaving care?
- ❖ What are the possible strategies to adopt so as to address the challenges mentioned by care leavers?

Appendices (i)

Interview guide for nurses, community members, secretary and administrator of Mutemwa Clinic.

SECTION A: Demographic information (fill in the gaps).

1. Sex.....
2. How long have you been working with people with leprosy?.....
3. How long have you been taking care of people with leprosy?.....
4. What is your relationship with them?.....

SECTION B: To explore the experiences of people with leprosy living outside institutional care facilities.

5. What are the experiences of people with leprosy living outside institutional care facilities?
6. How does leprosy affect a person's daily life?

SECTION C: To find coping strategies adopted by people with leprosy after leaving care facilities.

7. What are the main leprosy prevention methods?

8. What are the coping strategies that are used by people with leprosy to survive?
9. How effective are these strategies?
10. What are the challenges faced by people with leprosy?
11. How do they overcome these challenges and where do they seek help?

SECTION D: To provide strategies to address the challenges mentioned by leprosy patient.

12. What methods are you employing to deal with the problems of people with leprosy living outside care.
13. What can be done by the government and NGOs to address the challenges of leprosy patients?

THE END.....THANK YOU

Appendices(ii)

Interview guide for people with leprosy living outside care facilities.

SECTION A: Demographic information (fill in the gaps).

1. Sex.....

2. When were you diagnosed with leprosy?
3. How long have you been living with leprosy?
4. Who do you stay with?
5. Do you work?

SECTION B: To explore the experiences of people with leprosy living outside institutional care facilities.

6. What are your experiences as a person living with leprosy?
7. Which challenges have you been facing?
8. How did you overcome these challenges?

SECTION C: To find coping strategies adopted by people with leprosy after leaving care facilities.

9. Do you seek help when you are in need? Was the help given effective.
10. Which life skills did you acquire after care?

SECTION D: To provide strategies to address the challenges mentioned by leprosy patient.

11. What kind of assistance do you need to live well in modern society?
12. Can you point out, how the government and NGOs should provide for you?

THE END.....THANK YOU

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Date

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TO WHOM IT MAY CONCERN

Dear Sir/Madam

REQUEST TO UNDER TAKE RESEARCH PROJECT IN YOUR ORGANISATION

This serves to advise that, Dzimonwas Anandhi Registration No.
B.1406818 is a BACHELOR OF SCIENCE HONOURS

DEGREE IN SOCIAL WORK student at Bindura University of Science Education who is
conducting a research project.

May you please assist the student to access data relevant to the study and where possible
conduct interviews as part of the data collection process.

Yours faithfully

M. Zembere

Dr. M. Zembere
A/CHAIRMAN

05 DEC 2022

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