EXPERIENCES OF PATIENTS WITH EXTENSIVE DRUG-RESISTANT TUBERCULOSIS REGARDING PROLONGED ISOLATION IN A TB WARD AT A SELECTED HOSPITAL IN NAMIBIA.

A RESEARCH THESIS SUBMITTED IN PARTIAL FULFILLMENT

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ABSTRACT

The focus of this study is to understand the experiences of participants with Extensive Drug Resistance (XDR) regarding prolonged isolation. The participants with XDR-TB are admitted in isolation for a minimum of twenty (20) months in the hospital. Different factors contributed to the participants not adhering to the rules of isolation in the TB ward. The fact that the isolation TB ward does not have proper measures to keep patients enclosed imposes the risk of cross-infection to the public. The study aimed to explore and describe the experiences of patients with XDR-TB regarding prolonged isolation at a selected hospital in Namibia. The objectives of the study were to: Explore and describe the experiences of participants with XDR-TB regarding prolonged isolation at the TB ward at the selected hospital in Namibia. This study adopted a qualitative, explorative, descriptive, and contextual approach to understanding in-depth the participants' experiences of being isolated for a longer period. A purposive sampling approach was used to select the study participants and saturation was achieved at seventh (7th) participants. The data was collected using face-to-face individual interviews and analyzed using the thematic content method of analysis. Four main themes became apparent after the data was analyzed: Isolation, Challenges regarding basic needs, Psychological Support, and Improved health status. This study concluded that the participants experienced some psychosocial problems due to prolonged isolation. Living in isolation deprived them of a normal social lifestyle which resulted in pain, loneliness, anxiety, fear and depression. It was also revealed that participants believed that completing XDR-TB treatment guaranteed them cured.

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LIST OF ABBREVIATIONS AND ACRONYMS

AIDS: …… Acquired Immune Deficiency Syndrome

HIV: ……....Human Immunodeficiency Virus

KIH: ……Katutura Intermediate Hospital

MDR: …….....Multidrug Resistance

MOHSS: ……..…Ministry of Health and Social Services

TB:……..Tuberculosis

UNAM: ……. University of Namibia

WHO: ……World Health Organization

XDR: ……..Extensively Drug Resistance

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DEDICATION

I dedicate this thesis to my parents, Mr and Mrs Sirongo, for their unconditional love that motivated me to set higher targets. I also dedicate this thesis to all patients with XDR-TB who participated in my study. To my daughter Parcia who made it possible by reminding me every time to do my research while she was taking the responsibilities of house chores

DECLARATION

I, Eine Sirongo, hereby declare that 'Experiences of patients with Extensive drug resistance regarding prolonged isolation at TB ward in Katutura intermediate hospital, Windhoek" is a true reflection of my study and has not been submitted for any degree at any other university.

Eine Sirongo……Date……

CHAPTER 1

1. INTRODUCTION AND BACKGROUND OF THE STUDY

1.1 INTRODUCTION

Tuberculosis (TB) is one of the killer diseases worldwide that affects millions of people, and it was declared a global emergency in 1993 World Health Organization (WHO, 2013). The WHO estimated that 1,8 million people worldwide died of TB in 2015. Tuberculosis is an illness brought about by a bacterium (TB germ) called mycobacterium tuberculosis. It enters the body from the air that humans breathe in (and harms our lungs). It influences the lungs principally, yet other portions of the body can be affected, for example, joints, spine, sensory system, and different organs (Kodisang, 2013; WHO, 2013).

The WHO (2013) has defined XDR-TB as the TB that is resistant to almost all TB treatment including the two first-line drugs: isoniazid and rifampicin. XDR is as well resistant to the best second-line medications: fluoroquinolones and at least one of the three injectable drugs (for instance, amikacin, kanamycin, or capreomycin). XDR TB is basic in individuals who do not take their TB treatment normally or as they are told by their doctor or nurse. It can also occur in individuals who have created dynamic TB sickness again in the wake of having taken TB treatment previously or in individuals who have spent time with somebody who is a drug-resistant TB patient. The incidence of TB has been worsened by the HIV/AIDS pandemic in sub-Saharan Africa. It has been reported that a low treatment success rate of 70% is due to treatment defaulting (WHO, 2014). However, TB infection is known to be high in Namibia, and it was confirmed in the National Guidelines for managing tuberculosis (MOHSS, 2018).

Active tuberculosis treatment lasts for at least six to nine months of antibiotics, but this treatment is dependent on the patient's age, overall health, and the infection's location in the body.

Although a person who has taken the TB treatment for a period of two to three weeks becomes non-infectious, the person should continue to take their medication; even if they feel better. For TB management, sputum should be collected from patients who are on TB treatment and sent into the laboratory for investigation. The sputum should be negative after some time when the patient is on treatment, but positive sputum indicates that the TB bacteria are present and the patient needs to continue the treatment.

There is a treatment to cure TB, and TB patients must finish the full course of treatment as prescribed by the doctor. Stopping or skipping doses of TB treatment can allow the bacteria to be resistant to those drugs leading to the type of TB called Multidrug-Resistant Tuberculosis (MDR-TB), which is dangerous and difficult to treat. MDR-TB is when a TB patient defaults treatment and is likely to be resistant to the most important drugs which are known in the first-line medication namely, isoniazid and rifampicin (Ogunbanjo & Savva, 2011). When a patient is diagnosed with MDR-TB, the doctor or nurse should explain to the patient the causes, treatment, side effects, infection control as well as duration of hospitalization, immediately before admission. This will help to prepare the patient on how they will help themselves while on treatment. When managing MDR-TB, a patient has to be isolated. In the treatment of MDR-TB, a period of 8 months is suggested for most patients, and the duration may be changed according to the patient's response to the treatment. In addition, in the treatment of patients recently determined to have MDR-TB, a complete treatment term of 20 months is recommended for most patients, and the span might be adjusted by the patient's reaction to treatment (Nardel, 2011).

The symptoms of active tuberculosis, Multi-Drug Resistance (MDR-TB), and Extensive Drug Resistance (XDR TB) are the same, and these include general body weakness, weight loss, night

sweat, coughing, chest pain, and coughing up blood. Apart from pulmonary TB, other parts of the body which is affected by TB have different symptoms. If one experiences the above-mentioned symptoms or lived together with someone who was diagnosed with the disease, then they have to go to the doctor for a checkup.

The focus of this study is to understand the experiences of participants with extensive drug resistance regarding prolonged isolation. XDR-TB disease can seriously destroy one's emotions. This is because patients who are diagnosed with XDR-TB require prolonged isolation for treatment (MOHSS, 2012). Therefore, these patients experience disturbance in their lives from the sickness, which leads to psycho-social issues. Moreover, staying longer in isolation may lead to nervousness or dejection as resulting from the person's worries (Ogunbanjo & Savva, 2011). As a result, these patients should find ways to adapt while in isolation and this may not sound easy for them.

Prolonged isolation means that XDR-TB patients have to be alone away from their family members, jobs, school, and the entire society. As a result, XDR-TB patients turn to behave in a manner that is not acceptable by the health workers. As a researcher working in the TB isolation ward, it has been noted that absconding from the isolation ward has become common among XDR-TB patients. The fact that the isolation TB ward does not have proper measures to keep patients enclosed imposes the risk of cross-infection to the public. Another risk is from family members who move freely into the isolation ward while visiting their loved ones, as well as other health workers from the main hospital who use the route to enter and exit the hospital; the route was observed to be the short cut from the gate to the main hospital.

XDR-TB patients who have been on treatment for a long period and are having sputum positive may appear physically normal, and it is very difficult for any person to tell whether he/she has resistance to TB and can easily spread the infection. The doctors and nurses need to emphasize to the XDR-TB patients the issues of prolonged isolation because ignoring that will impose risks in the prevention and management of XDR-TB. It is not certain that the TB patients will comply with the TB treatment just because they have agreed to isolation hospitalization. For instance, the researcher observed (when she worked in an isolation ward) that some new XDR-TB patients were found with TB drugs kept under their pillows, lockers, or bags. The patients claim and reasoned that the medication caused them to vomit when they take it on an empty stomach. They indicated that night duty nurses just drop medication on their lockers and do not even wake them up to take their medications. They also felt that the medication was too much. The above information suggests that XDR –TB patients in isolation were not coping well regarding the treatment during the first months.

There are different reasons observed by the researcher why XDR-TB patients do not comply with the rules of isolation such as: to attend family funerals, missing their family members, collecting applications for disability grants, shopping, going to church, or going to solve issues with their employers. This has been very difficult for the nurses to control the movement of XDR-TB patients because they could sneak out without a word to the nurses. The exit door is always open and there is no control over it; therefore, anyone can move in and out as they wish.

World TB Day is celebrated on the 24th of March annually. On this day, health workers, JUmembers from Advanced Community Health Care Services Namibia (CoHeNa), and Global fund commit to improve people's understanding, teach them how to prevent, diagnose and treat all types of TB such as active tuberculosis, MDR-TB and XDR-TB. The XDR-TB is considered fatal in cases where the patient is HIV positive because TB and HIV/AIDS treatment are both strong and have side effects which put the patient's life in a worse condition.

According to Tadesse (2016), TB patients who were isolated experienced separation from their families and the community, as well as the financial crisis. Although patients are isolated to limit the spread of infections, Sotgiu, Pontali, and Migliori (2015) revealed that the response rate in isolated XDR-TB patients was very poor. However, the causes of poor response were not investigated. Therefore, the researcher deemed it necessary to explore the experience of XDR-TB patients regarding prolonged isolation

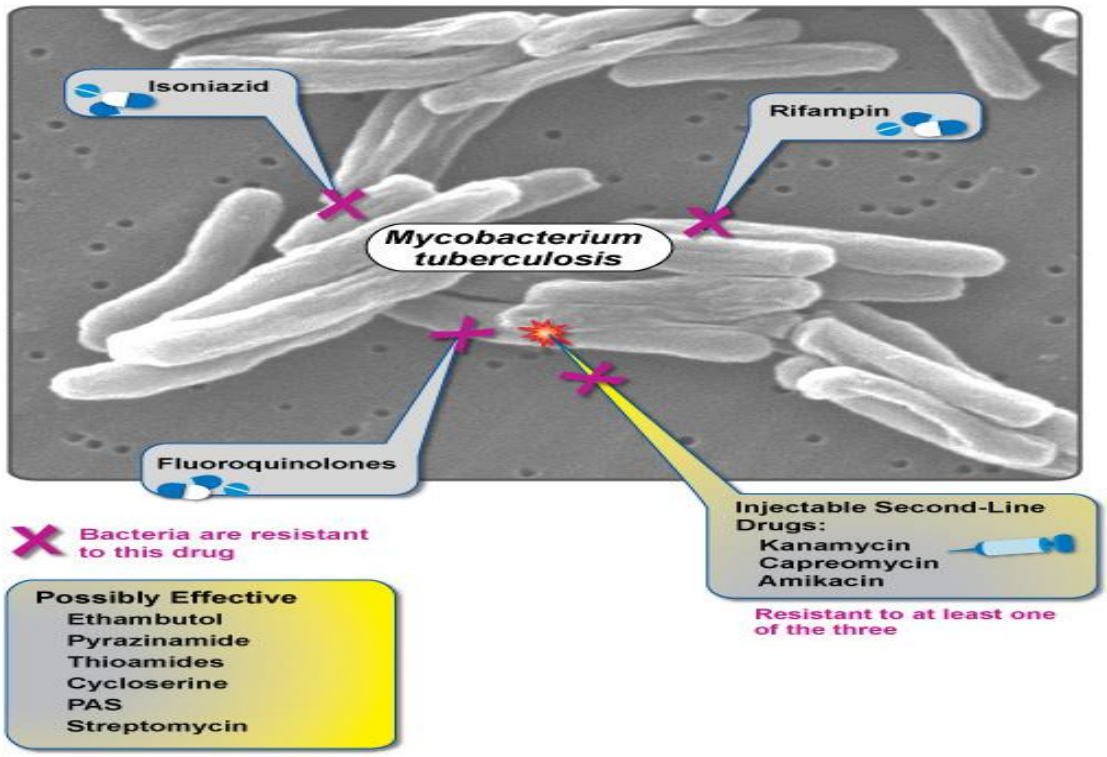


Figure 1.1: Mycobactrium Tuberculosis

https://www.google.com.wikipedia.org extensively drug-resistant tuberculosis & psig1620730589018000

The above diagram shows how tuberculosis develops resistance towards some drugs. Mycobacterium tuberculosis is intrinsically resistant to many antibiotics, limiting the number of compounds available for treatment. This intrinsic resistance is due to a number of mechanisms including a thick, waxy, hydrophobic cell envelope and the presence of drug degrading and modifying enzymes (Gygli, Borrell, Trauner, and Gagneux 2017).

1.2 BACKGROUND OF THE STUDY

According to WHO (2014), 15 of the 27 countries with the highest burden of MDR/XDR-TB are in the WHO's European region, which includes 53 countries in Europe and Central Asia. However, it is not clear whether these countries experience problems with the inpatients regarding prolonged isolation.

In Nigeria, the efforts at preventing and controlling TB as a matter of urgency have been done by providing a free directly observed treatment/therapy (DOT) to all sputum-positive patients and isolation hospitalization for MDR/XDR-TB patients. However, compliance remained a major challenge leading to poor response to treatment (Sotgiu et al, 2015). This was supported by a study conducted in Nigeria which concluded that some patients with XDR-T experienced psychosocial burden during prolonged hospitalization and decided not to comply with the rules of isolation (Oladimeji e al., 2016).

The Ministry of Health and Social Services reiterated in the "National guidelines for TB management" (2012) that TB can be treated with a course of four standards, or first-line, anti-TB drugs (for instance, isoniazid, rifampicin, and any fluoroquinolone). If drugs are misused or mismanaged, multidrug-resistant TB (MDR-TB) can develop. MDR-TB is treated with second-line drugs (for instance, amikacin, kanamycin, or capreomycin) which are expensive and have more side effects, and it takes longer to treat. XDR-TB can develop when 2nd line drugs are misused or mismanaged and require prolonged hospitalization.

In Namibia, TB treatment is free for all patients from the Southern African Developing Community (MOHSS, 2012). Namibia is the 4th worst TB affected country in the world, with 9 882 patients diagnosed with TB in 2014 (WHO, 2012). In addition, six (6) cases of XDR-TB (Extensive-Drug-Resistance) were detected in 2013 and 2014 whilst ten (10) more XDR-TB cases were reported in 2016 (MOHSS, 2018). Currently, there are 13 XDR-TB patients admitted to the TB isolation ward at a selected hospital in Namibia.

1.3 PROBLEM STATEMENT

Patients with Extensive Drug Resistant are admitted in the isolation section at the TB ward for a minimum of twenty (20) months in the hospital (MOHSS, 2012). Most of the patients with XDR-TB do not adhere to the setup rules of isolation, and they pressurize the doctors to discharge them for some days to solve their social problems. Patients with XDR-TB are sometimes seen at church and shopping malls, placing people in the community at risk of infection. It has been difficult for the health workers to control patients from mixing with people in the community as family members also come into the isolation ward to visit their loved ones. Information from the Health Information System [HIS] (2017) reported that 50% of patients with XDR TB forced the health care workers (doctors and nurses) to be given permission to go home during weekends. If so, this puts the community at risk of being infected. It is against this background that this study explores the experience of patients with XDR-TB regarding prolonged isolation at the selected hospital in Namibia.

1.4 PURPOSE OF THE STUDY

The purpose of the study was to explore and describe the experiences of patients with XDR-TB regarding prolonged isolation at the selected hospital in Namibia. The researcher needed to learn and understand better the experiences of patients with XDR-TB's point of view regarding prolonged isolation.

1.5 OBJECTIVES OF THE STUDY

The objectives of the study were to:

- Explore the experiences of patients with XDR-TB regarding prolonged isolation at the TB ward, at a selected hospital in Namibia
- Describe the experiences of patients with XDR-TB regarding prolonged isolation at the TB ward, at a selected hospital in Namibia

1.6 SIGNIFICANCE OF THE STUDY

The findings of the study will provide a reference for avenues for future research. Moreover, the findings of the study helped the researcher to make recommendations to the MOHSS in terms of how health care workers can support participants with XDR-TB who have gone through prolonged isolation. Furthermore, the study findings will be available to the MOHSS for the integration of TB manuals and policy review. Sharing this study's findings may enable health care workers to have a clear understanding of the challenges experienced by the target population, render them support, and provide relevant information so that the target population understands the importance of being isolated for long.

1.7 LIMITATION OF THE STUDY

The study was limited by its sample size. Purposive sampling was used to select participants. This may have some bias in the selection of the sample because it was done based on the researcher's knowledge of the participants in the TB isolation ward. The researcher assumed that the participants would be in a better position, having their sputum negative at the time so that N 95% face masks would not be worn by the researcher and the participants during interviews. The face masks are to be worn to prevent cross-infection. Some participants had lost their hearing due to the TB treatment, and it was not possible for the researcher to put on a face mask during interviews as they had to comprehend the question asked reading the lips of the researcher.

The researcher had to write the questions down for the participants who lost their hearing for better communication during the interview. Moreover, this study's results will not be generalized to the population of Namibian participants with XDR-TB. Apart from the above limitations, the topic was good and interesting for a qualitative, explorative, and descriptive; therefore, the findings should be rigorous and trustworthy.

1.8 PARADIGMATIC PERSPECTIVE

Paradigm is referred to as putting theories together about the social world with specific ontological and epistemological positions along these lines (Matthews & Ross, 2010). The means, paradigms tend to reflect the interests and focus of researchers. This study was conducted to direct the research activities by helping to restructure the question posed to the participants to explore their experiences. A paradigm contains four components, namely: Ontological, axiological, methodological, and epistemological (Lincoln & Guba, 1985). These components

comprise the basic assumptions, beliefs, values, and norms that each paradigm holds. Brink, van der Walt, and van Rensburg (2012) describe assumptions as to the fundamental rules that humans tend to acknowledge confidence, underestimate or expect to be valid with no confirmation or check. Assumptions are essential components in proposals since they are required to empower and direct the research (Simon, 2012). In this study, assumptions are things that are to some degree out of the researcher's control; yet on the off chance that should, they disappear the study would end up being meaningless.

1.8.1 Ontological

Ontology is a branch of philosophy concerned with the assumption made to trust that something bodes well or is genuine, or the very nature of the social wonder being researched (Kivunja et al., 2017). It is the philosophical study of the idea of presence or reality, of being or getting to be, just as the essential classifications of things that exist and their relations. Moreover, it analyzes the researcher's underlying beliefs or framework as the researcher, about the nature of being and existence. Therefore, it forms the structure and nature of the real world and what is acceptable to be thought about that reality. Philosophical assumptions about the idea of the truth are difficult to know. These assumptions, ideas, or recommendations help to orientate the researcher's reasoning about the examination issue, its essentialness, and how it might be approached to add to its answer/solutions. Ontology is viewed as the investigation of being (Scotland, 2012). It is a designed arrangement of assumptions about the idea of the real world.

In this study, the researcher assumed that there were some realities in the different lives of participants with XDR-TB in the isolation ward, in the selected hospital in Namibia. The assumption was that every participant with XDR-TB had different experiences regarding

prolonged isolation. The researcher conducted face-to-face interviews and the participants were asked one central question: “What are your experiences regarding staying long in isolation?”

The assumption helped the researcher to understand how the research problem, its importance, and approaches will answer the research question, understand the problem studied, and contributions to its solutions (Kivunja, 2012). However, direct quotations from the interview were used to develop themes and sub-themes which gave a clear meaning to the experiences and reality of participants with XDR-TB (Burns & Grove, 2011).

1.8.2 Axiological

Axiology is a branch of philosophy that studies judgment about the values (Sounders, M. Lewis, P. & Thornhill, 2016). Correspondingly, axiology deals with the assessment of the researchers’ role by their values in the research. The researcher, health care workers, and the participants with XDR-TB come together, each with his/her value system and these values are the foundation of interpretational relationships. The persons’ views on health may be negative or positively influence by values (Sankombo, 2015). A person with TB who visits the hospital to get professional assistance may expect that his/her human dignity is respected by the health care provider. If not fairly treated, understood or respected the person may feel or become vulnerable. In this study, the researcher understands the research ethics and applied it accordingly, because the study involved human participants who are diagnosed with XDR-TB.

1.8.3 Methodological Assumptions

The methodological assumption is based on insight to gain an understanding of an individual's perception of reality (Nieświadomy, 2014.). The researcher guarantees that to gain insight and understanding, there should be an inquiry on the participants' side by asking them a question to acquire the information the researcher needs. The aim of the study is for the researcher to express the assumptions in attempting to understand the participant's experience (Kawulich, 2015).

In this study, it refers to the procedure used to investigate what was believed could be known, and the reasons behind these procedures. The researcher believed that people with XDR-TB become study participants to relate their own experiences through a qualitative approach.

1.8.4 Epistemological Assumptions

Epistemology deals with the nature of Knowledge and how knowledge is acquired (Ritchie, Lewis, Nicholls, Ormston 2013). Similarly, Kivundja (2012) explained that epistemology has its aetiology in Greek where the word epistemology is used to describe how something comes to be known, and knowing the truth or reality. Epistemology focuses on the nature of human knowledge and how the researcher or knower acquires knowledge and communicates it to extend or broaden it for better understanding. Kivundja (2012) emphasized that considering the epistemology of the study, the research can attempt to ask the following questions: Is knowledge something that can be acquired, or is it something that can be experienced personally? What relationship between the inquirer and what is known? It is useful for the researcher to ask such questions so that they place themselves in a context where they can examine or discover new knowledge, provided what is already known.

In this study, the researcher collected data via face-to-face individual interviews about the experiences of participants with XDR-TB regarding prolonged isolation in a selected hospital in

Namibia. Therefore, the researcher did not only gained knowledge about these patients, but the source of knowledge for this study is from empirical epistemology because it was derived from sense experiences, and objective facts of the participants with XDR-TB (Kivunja et al., 2017).

1.9 THEORETICAL FRAMEWORK

This study is primarily framed by Nightingale's environmental theory. According to nightingale, the environment has a greater role in providing safe care and prompt recovery. Environmental theory attempt to understand how a patient with XDR-TB will functions within their environment while isolated. There are some major concepts that Nigthingale emphasized such as: ventilation and warming, light and noise, cleanliness of the air, bed and bedding, health of houses, personal cleanliness, variety,food and social consideration which should be considered to prevent diseases and death.

There is a need to provide optimum environment for patients to recover from illness. Where environment is not optimum it interfears with recovery process. What was observed on the ground is that patients running away from the provided environment meaning there must be something wrong and the study was indended to find out what is the problem within the environment they were provided so that we know and prepare how to care for them in the future since their treatment requires isolation for a longer period of time.

1.10 DEFINITIONS OF CONCEPTS

Tuberculosis (TB)

Tuberculosis (TB) is an irresistible infection that normally affects the lungs but can affect practically any part of the body. Tuberculosis is spread from individual to individual through the

air. At the point when an individual with TB in their lungs or throat hacks, chuckles, wheezes, sings, or even talks, the germs that reason TB may spread through the air. On the off chance that someone else takes in these germs, they may end up contaminated with tuberculosis. It should be noted that there is a distinction between being contaminated with TB (latent TB) and having active TB disease. Contamination with TB (latent TB) means that a person is infected with Mycobacterium tuberculosis, but does not have active tuberculosis. Active tuberculosis can be contagious while latent tuberculosis is not, and it is therefore not possible to get TB from someone with latent tuberculosis. The body's immune system protects them from becoming sick and this is called latent TB (Kodisang, 2013).

Extrapulmonary tuberculosis

Extrapulmonary tuberculosis (EPTB) is any TB case with the involvement of organs other than the lungs, for example, pleura, lymph nodes, abdomen, genitourinary tract, skin, joints and bones, meninges (WHO, 2013)

Multidrug resistant tuberculosis (MDR-TB)

Multidrug-resistant tuberculosis (MDR-TB) is when a TB patient defaults treatment and is likely to be resistant to the most important drugs which are known in the first-line medication namely: isoniazid and rifampicin (Ogunbanjo & Savva, 2011).

Drug-resistant tuberculosis (DR-TB)

Drug resistance emerges as a result of not taking TB treatment as prescribed by the doctor. Resistance to anti TB drugs can happen when these drugs are abused or botched. Precedents incorporate when patients don't finish their full course of treatment; when health care workers

provide wrong treatment, the wrong dosage, or then again period for taking the medications; when the supply of medications is not constantly accessible; or when the drugs are of poor quality (WHO, 2013).

Extensively drug-resistant TB (XDR-TB):

Extensive drug resistance is resistance to any fluoroquinolone and at least one of three second-line injectable drugs (capreomycin, kanamycin, and amikacin), in addition to multidrug resistance (WHO, 2013).

Experiences

According to the Cambridge Dictionary, experience means (the way toward getting) information or aptitude that is acquired from doing, seeing, or feeling things or something that happens which affects a person.

Isolation

According to the Center for Desease Control and Prevention CDC (2018), isolation is the act of separating a sick individual with a contagious disease from healthy individuals without that contagious disease in order to protect the general public from exposure to a contagious disease.

Prolonged

The term prolong is defines prolonged as “continuing for a long time or longer than usual; lengthy”, by the oxford dictionary.

1.11 SUMMARY

In this chapter, the researcher introduced the topic and presented the significance of the study, research objectives, problem statement, limitations, and a summary of the theoretical framework, as well as definitions of key concepts such as TB, MDR-TB, DR-TB, XDR-TB, experience, isolation and prolonged. The next chapter focuses on methodology. It will describe how this study was carried out using qualitative research.

CHAPTER 2

RESEARCH DESIGN AND METHODS

2.1 INTRODUCTION

This chapter focuses on research design and methods employed in researching the experience of participants with XDR-TB regarding prolonged isolation. It includes the study's research design, population, sample, sampling, data collection, ethical considerations, as well as measures employed to ensure trustworthiness during the study (Holloway & Wheeler, 2013).

2.2 RESEARCH DESIGN`

Research design is the overall plan for connecting the conceptual research problems to the pertinent and achievable empirical research. It is an inquiry that provides specific direction for procedures in research (Creswell, 2014). While Kumar (2011) explained that research design is a plan, structure, and strategy of the investigation so conceived as to obtain answers to research questions or problems. A qualitative, explorative, descriptive and contextual design was followed using the phenomenological method to explore the lived experiences of patients with XDR-TB in isolation ward.

2.2.1 Qualitative research

Qualitative research emphasizes exploring and understanding the meaning of an individual or group ascribe to social or human problems (Cresswel, 2014). The study followed a qualitative research process to explore and describe the experiences of participants regarding prolonged isolation. Data was generated through interviews from each participant and themes and sub-

themes were formulated. The researcher used bracketing during the interviews(putting preconceived ideas aside) and intuiting (focused on the lived experience of participants). Interviews were conducted until data-saturated which revealed by repeating responses and not the number of interviews conducted. The researcher conducted and tape-recorded all the interviews by herself.

2.2.3 Explorative

According to Polit and Beck (2012), explorative studies are undertaken when a new area is being investigated or when little is known about an area of interest. In this study, the researcher explored the experience of participants with XDR-TB regarding prolonged isolation in the TB ward at a selected hospital in Namibia.

2.2.4 Descriptive

A descriptive design is useful when a study is focused on events, about who was involved, what was involved, and where things took place. The goal of descriptive design is a comprehensive summary, in everyday terms, of specific events experienced by individuals or groups of individuals (Lambert, 2012). The experiences of participants with XDR-TB regarding prolonged isolation are described and recommendations for improvement of the isolation are proposed.

2.2.5 Contextual

Burns and Grove (2019) emphasized that contextual research focuses on specific events in ‘naturalistic settings’. In addition, A naturalistic setting is an uncontrolled real-life situation

sometimes referred to as a field setting. In this study, the research was conducted in a selected hospital in Namibia with the aim of focusing on the experiences of the study participants regarding prolonged isolation.

2.2.6 Phenomenological

Phenomenological method was chosen in order to describe the lived experiences of patients with XDR-TB in isolation. What is phenomenological? It is very difficult to stand along with one fixed, final and acceptable for all answer to this question. Probably, the reason behind this argument is that every phenomenologist appears to come up with diverse styles of phenomenology. Giorgi and Giorgi (2003) observed that "a consensual, univocal interpretation of phenomenology is hard to find" (pp. 23–24). Husserl's phenomenological perspective is central to the concept of description of the invariant aspects of phenomena as they appear to consciousness. In addition, the method is descriptive because its depature point involves the concrete descriptions of experienced events from the perspective of everyday life by the participants, which results in a researcher describing the structure of phenomenon (Giorgi & Giorgi, 2003). In this study, phenomenological research method was used to as it provides the opportunity for the participants with XDR-TB to share their lived experiences with the researcher, without imposing views of the researcher. Phenomenology emphasizes descriptions of the phenomenon as consciously experienced, without theories about their causal explanation and as free as possible from the unexplained preconceptions and presuppositions. Moreover, the purpose of phenomenological enquiry is to explicate the structure or essence of the lived experience in the search for the meaning that identifies the essence of the phenomenon, and its accurate description through the everyday lived experience (Streubert & Carpenter, 2011).

2.3 RESEARCH SETTING

Halloway and Wheeler (2013) emphasized that the study setting is the physical location of the research. The study was conducted in a selected hospital in Namibia at the TB isolation ward in the Khomas region. A selected hospital in Namibia is one of the referral hospitals in Windhoek with a bed capacity of approximately 880 and about 330 registered nurses. There are different departments such as medical, surgical, orthopaedic, pediatric, head injury, high care, TB general/ TB isolation, theatre, casualty, gastro unit, pediatric outpatient, maternity, x-ray, physiotherapy, occupational health, dental clinic, pharmacy, the kitchen, laundry, works order, maintenance, human resource departments, and antiretroviral clinic. Nursing staff, doctors and cleaners work on a rotation basis in different departments.

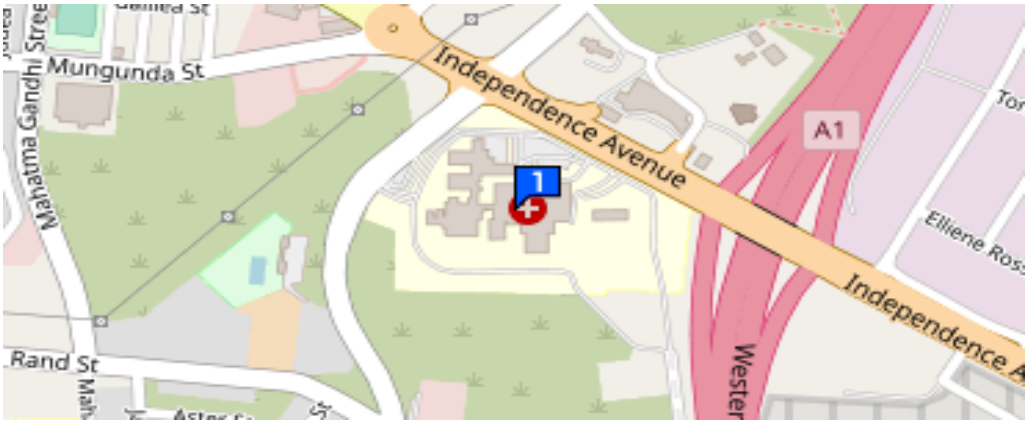


Figure 2.1 Selected hospital

https://www.google.com/urlkhomas- (Selected hospital)

The above map is of the selected hospital in Namibia, where the TB ward is. This study was conducted through face-to-face interviews of participants with XDR-TB at the TB isolation ward in a selected hospital in Namibia.

2.4 POPULATION

According to Brink et al. (2012) population is "the entire group of persons or objects that meets the criteria which the researcher is interested in studying"(p.24). The population for this study consisted of all male and female participants with XDR-TB admitted to the TB isolation ward in a selected hospital in Namibia. According to the Ministry of Health and Social Services (2017) Health Information System [HIS], a selected hospital in Namibia reportedly recorded thirteen cases of XDR-TB between the month of May and October 2017.

2.5 SAMPLING AND SAMPLE

2.5.1 Sampling

Sampling is the process used to select a portion of the population for a study (Polit & Beck, 2012) . Therefore, a purposive sampling technique was appropriate for this study to select all the participants with XDR-TB and admitted in isolation at a selected hospital in Namibia. Moreover, purposive sampling is sometimes called 'judgmental' sampling. This technique is based on the judgment of the researcher regarding participants or objects that are representative of the study phenomenon (Brink et al, 2012).

The participants were selected based on their particular knowledge of the phenomenon, for the purpose of sharing their knowledge and experiences with the researcher. The researcher recruited all thirteen participants diagnosed with XDR-TB at the isolation ward to be part of the study.

2.5.2 Sampling criteria

Sampling criteria is also referred to as eligibility criteria and includes a list of essential characteristics for membership in the target population. Therefore, inclusion criteria are

"characteristics that a subject or element must possess to be part of the target population" (Burns et al (2013)

In this study the inclusion criteria were:

- participants who were on XDR-TB treatment and admitted to a TB isolation ward in the selected hospital in Namibia.

2.5.3 Sample

A sample is a subset of the population that is selected to represent the population (Polit & Beck, 2012). The total population consisted of thirteen participants with XDR-TB. Whereby, a total of seven participants were interviewed and data saturation was achieved. Saturation of data means that respondents provide no new information or there is a redundancy of previously collected data (Burns, Gray & Grove, 2013). Those interviewed were three males and four females, with the age range between 24-52. The researcher requested participants to give a written consent for the interviews to be audiotaped.

2.6 PREPARATION OF THE RESEARCH FIELD

De Vos, Strydom, Fouche, and Delport (2011) emphasized that for data to be collected appropriately, crucial information should be obtained. This information provided the researcher with the direction on the situation of the participants regarding the field, and how to handle them during data collection.

The researcher prepared a quiet and conducive place that facilitated the process of data collection accordingly. Therefore, a private room was provided to the researcher where all the interviews were conducted by the researcher at the TB isolation ward. Factors like noise and privacy were considered and addressed. The researcher displayed a tag with the message" Do not disturb-interviews in progress" to prevent interruptions.

Face marks were made available to both the researcher and the participants to be used during the interviews for the purpose of infection control. With the participant's permission, the researcher used the tape recorder, field notes, a pen and the interview guide during interviews.

2.7 DATA COLLECTION

"The process of data collection is directly related to sampling and it is best viewed as complementary to it" (Whitehead & Whitehead, 2016, p. 127). In addition, data collection is also known as the process of gathering information on a topic of interest, to enable one to answer a stated research question and evaluate the outcomes.

In this study, the researcher conducted face to face interviews to collect data. The purpose was to explore and describe the experiences of participants with XDR-TB regarding prolonged isolation in the TB ward at a selected hospital in Namibia.

The researcher conducted single-session, face to face interviews with each participant at a scheduled time in the same room. The idea was to explore and understand the participant's experience in the TB isolation ward.

2.7.1 Data collection instrument

The researcher used an unstructured interview as the tool for data collection to ensure that all interviews were reasonably consistent (De Vos et al., 2011). Therefore, the aim for choosing face to face interviews is for the participants to share their experiences in their own words without the researcher forcing them to answer questions that might limit them. The use of probes was included in the interview protocol as some participants might have little information to say about the central phenomenon but the researcher included probes to expand the useful information (Creswell, 2018) See [ANNEXTURE 6]. Moreover, a tape recorder was used to record interviews with permission from the participants (Creswell (2014).

2.7.2 Face to face interviews

The researcher explained the topic, aim, and objectives to the participant to obtain consent to conduct interviews[refer to Annexure 1]. De Vos et al. (2011,) explained that when conducting interviews, "a suitable venue, which is comfortable, with privacy and non-interruptive should be used" (p. 513). The researcher used an audio recorder with permission from the participants to capture interview data for the purpose of preserving the participants' exact words (Halloway & Galvin 2016, Halloway & Wheeler 2013). Some of the participants listened to the recorded interview to ensure that the information provided was of the true version of themselves after their interviews. Moreover, the researcher conducted seven interviews, and saturation was reached.

Creswell (2014) emphasized that the advantage of the interview is to allow the researcher to have control over the line of questioning. After face to face interviews the recorded data verbatim. Transcriptions were made. During the interviews, the main question was asked to each participant. The question asked was '*what are your experiences regarding staying for a long in TB isolation ward?'* the researcher made use of some communication skills during the

interviews which were: keeping eye contact, questioning, clarification, reflection to facilitate and encourage participants to talk.

2.7.3 Field notes

Field notes are written by the researcher and this includes what the researcher sees, feels experiences during the interviews (De Vos et al; 2011). The purpose of taking notes during or immediately after the interviews is so that the researcher captures the observations while the memory is fresh. Therefore, helps the researcher to remember the words which are part of the rich data.

2.7.4 Pilot Study

Leon, Davis, and Kraemer (2011) emphasized that a pilot study is used to examine the feasibility of an approach that is intended to ultimately be used in a larger-scale study. A pilot of this study was conducted at the TB isolation ward to assess the adequacy and feasibility of the intended research (Moxham, 2012). Before the interviews commenced, the researcher conducted a pilot study of two participants to ensure the feasibility of the intended approach of study. The population of the pilot study consisted of two participants which were not included in the study because changes were made on the interview guide and this could have gotten different information. Pilot study interviews were recorded and field notes were taken to test the audio tape recorder and to assist the researcher with the techniques used in the actual study.

The finding of the pilot study revealed that the terms “isolation and experiences” were not well understood by the participants. Therefore, it was necessary that in the actual study the researcher

simplified the main question on the interview guide which was " Describe your experiences with regards to prolonged isolation in TB ward" to "What are your experiences regarding staying long in TB isolation ward". Finally, the researcher managed to rectify the concern before the main interviews commenced.

2.8 DATA ANALYSIS

Marshall and Rossman (2016:150) state that qualitative data analysis is a search for general statements about relationships among categories of data. In qualitative research, data analysis occurs simultaneously with data collection so that researchers can identify avenues that must be explored further and seek explanations for unexpected results (Schneider, Coates, & Yarris, 2017). Simingly, Burns et al (2013) emphasized that data analysis occurs concurrently with data collection in qualitative research. The audiotape recordings were transcribed verbatim for data analysis purposes.

In this study, the data which was collected during interviews on the experiences of participants with XDR-TB regarding prolonged isolation at the TB ward was analyzed. Data analysis was conducted according to Tesch method of data analysis of qualitative data and below are the steps:

Step 1: The researcher ought to read through all the transcripts and took notes. The transcripts were re-read one by one, line by line again carefully.

Step 2: The researcher picked one transcript and re-read it to understand the meaning of the data. Therefore, the positive experiences were highlighted in black ink and negative experiences were in red ink and this was done with all transcripts.

Step 3: The list of all topics or themes were made. The themes which were similar were clustered

together.

Step 4: The compiled list of topics or themes were used to compare the data and abbreviated into codes. These codes were written next to the segments of the text while seeing whether new categories and codes were emerging(codes were colour-coded i.e black for a positive experience and red for negative experience)

Step 5: The researcher assigned the most descriptive words for the topics and turned them into categories. In order for the researcher to reduce the list of categories, the topics which were related to each other were grouped.

Step 6: The decision was made by the researcher on abbreviating each category and alphabetized the codes.

Step 7: The data was analysed and explored to generate meaning.

Step 8: The existing data was recorded where necessary (Creswell, 2018, p196).

During the transcription process, the researcher specified in the written text that, "P" was used to represent the participant and "R" was used to represent the researcher (Polit& Beck 2012). In addition, the researcher transcribed data on her own to ensure the accuracy of the transcribed data.

2.9 MEASURES TO ENSURE TRUSTWORTHINESS

Brink, van der Walt and van Rensburg (2012) described trustworthiness as a way of ensuring data quality or rigour in qualitative research. According to Polit and Beck (2014), trustworthiness or rigour of a study refers to the degree of confidence in data, interpretation, and methods used to ensure the quality of a study (Polit& Beck, 2014). Criteria outlined by Lincoln and Guba (1985)

includes the following: Credibility, dependability, confirmability, transferability, and authenticity.

2.9.1 Credibility

Brink et al. (2012) refers to credibility as the "confidence in the truth of the data and the interpretation thereof". To increase the probability that credible findings were produced, the following activities were conducted: prolonged engagement, triangulation, peer debriefing, member checking (Tappen, 2011, p. 153). All participants were taken through the same main question. The participants were interviewed to the point that there was data saturation (prolonged engagement) no new information was raised. The researcher used a tape recorder to record the interviews and transcribed each one of the interviews (referral adequacy). The supervisor checked the data after transcriptions and any additional information was taken into consideration when analyzing (member check). The researcher went back to some of the participants, to ascertain whether the data which was transcribed was a truthful version of their experiences.

2.9.2 Dependability

Lincoln and Guba (1985) listed dependability as one of the criteria to establish the trustworthiness of the study. Brink et al (2012) explained that dependability refers to the provision of evidence in a way that, if it were to be repeated with the same or similar participants in the same or similar context, its findings would be similar. An audit trail should be created during the study of research (Tappen, 2011). An inquiry audit was done by the researcher's

supervisor checking the researcher's data, interpretations, transcriptions, documents and recommendations and findings which were made available and accessible to the supervisor. The goal of the audit inquiry was to examine both the process and product of the inquiry and to determine the trustworthiness of the findings (Korstjens & Moser 2018).

2.9.3 Confirmability

Confirmability is described as the potential for congruence of data in terms of accuracy, relevance, or meaning (Brink et al., 2012). The findings, conclusions, and recommendations are supported by the data and an internal agreement between the researcher's interpretation and the actual evidence. In this study, the researcher analysed data and the supervisor conducted an audit trail of the verbatim descriptions, themes and sub-themes. Finally, confirmability was established because credibility, dependability and transferability were all achieved.

2.9.4 Transferability

Transferability refers to the ability to apply the findings in other contexts or to other participants (Lincoln & Guba, 1985). Literature control was done whereas purposive sampling was used. A dense description of methodology was provided, participants background, the researchers context to enable one's interest in making a transfer to each conclusion about whether the transfer can be possible or not.

2.10 ETHICAL CONSIDERATION

The application of ethics in research requires some proficiency with the terminology of both ethics and research so that researchers are in a better position to identify possible ethical

problems resulting from research (Rensburg, 2011). Neuman (2011) explained that ethical issues are important in qualitative studies because they involve participant's lives. This is in keeping with Brink et al. (2012) who added that "researchers involved in research with human participants have a special concern related to the protection of human beings' rights" (p. 33). This study was guided by the three ethical principles of Belmond (1979) are as follows: the principles of respect of persons, beneficence and justice.

2.10.1 Permission to conduct research

The researcher obtained approval to conduct research from the Health Research Ethics Committee at the University of Namibia [See ANNEXURE 1]. The Ministry of Health Social Services through the executive directors' office granted the researcher permission to collect data [See ANNEXURE 3]. Furthermore, the researcher used the permission granted by the medical superintendent to share with the registered nurses in charge of the TB ward at a selected hospital in Namibia before data was collected [See ANNEXURE 4].

2.10.2 Informed consent

Informed consent is a perspective agreement to participate in a study as a subject (Burns & Grove, (2011, p. 122). This means that every participant should be given the opportunity whether to participate. The purpose of the consent form was to ensure that the participants understood what was expected of them and that they agreed to take part in the study. Therefore, written consent was obtained before data collection [See ANNEXURE 5].

2.10.3 Respect for the person

Research participants are autonomous individuals, they have the right to self-determination and decision making (Brink et al., 2012). The researcher explained the study purpose, objectives and significance to the participants, obtained a written consent from each participant to withdraw or participate in the study without the risk of penalty or prejudicial treatment see (ANNEXURE 5). The basic rule of research according to Mclean & Wilson (2011) is that study participants cannot be forced, coerced, and unduly induced to participate in a study. In this study, the researcher ensured that all study aspects were handled in a respectful way of the participants' human rights and needs. Furthermore, anonymity and confidentiality were maintained throughout the research process by using pseudo names and concealing the name of the study setting.

2.10.4 Principle of Beneficence

According to (Brink et al., 2012). the researcher needs to secure the well-being of the participants to adhere to the principle of beneficence. Study participants have the right to be protected from discomfort and harm. Additionally, beneficence is an ethical principle that addresses the promotion of the patient's well-being by the health care providers.

In this study, the researcher ensured the importance of keeping the identity of the participants confidential or anonymous and the assurance extended beyond protecting their names and also included avoidance of using self-identifying statements and information. Therefore, anonymity and confidentiality is the step in protecting participants from potential harm (Fleming & Zegwaard, 2018).

2.10.5 Principle of Justice

Justice refers to the participants' right to fair selection and treatment (Brink et al., 2012). The researcher put in mind that justice is considered by not discriminating against the participants on the grounds of such as gender, race, age, social status, or religion.

In this study, the researcher fairly selected the participants for the reasons directly related to the research problem and not because they were readily available or they could be manipulated easily. Moreover, the participants were selected by purposive sampling, as long as they fairly met the inclusion criteria without coercion.

2.11 SUMMARY

This chapter presented the research design of this study, which is qualitative, descriptive, explorative, and contextual in nature. The researcher outlined and described the process of data collection as well as measures to ensure trustworthiness and the applicability thereof. Moreover, the need for professional ethical guidelines in conducting health science research was presented in detail.

CHAPTER 3

DATA ANALYSIS AND LITERATURE CONTROL

3.1 INTRODUCTION

This chapter presents the analysis of data, findings, and discussion of findings which incorporates the relevant literature. Polit and Beck (2012) explain that the purpose of engaging literature in the presentation of findings is to extend the knowledge of the phenomenon from different perspectives, and this may include the sources from which the phenomenon is described. The key question for the research was: "What are your experiences regarding staying for a longer period in this TB ward?" In this study, data collection was done by the researcher followed by the analysis and transcriptions of the results for the experiences of participants with XDR-TB regarding prolonged isolation in the TB ward at a selected hospital in Namibia. Pilot testing of the questions was done on two participants with XDR-TB before the actual interview took place, to ensure the validity of the interview guide. The researcher used four criteria of trustworthiness in this study to ensure the quality of data.

3.2 DESCRIPTION OF RESEARCH FINDINGS

Burns and Grove (2011) explain that in a qualitative study, the interviews are transcribed to get experiences from the participants. The researcher presented data according to themes and sub-themes which were condensed after data analysis as presented in Table 3.1 below:

Table 3.1 Themes and sub-themes of the lived experiences of participants with XDR-TB regarding prolonged isolation in TB ward at a selected hospital in Namibia

Themes	Sub-themes
3.2.1. Isolation	3.2.1.1: Loneliness and boredom. 3.2.1.2: Experienced a feeling of imprisonment 3.2.1.3: Anxiety
3.2.2 Challenges in basic needs	3.2.2.1: Poor hygiene 3.2.2.2: Negative experience about food 3.2.2.3:Fear of losing belongings/properties (environmental safety and security).
3.2.3 Psychological support	3.2.3.1 Family support 3.2.3.2 Experiences of religious
3.2.4. Improved health status	3.2.4.1 Positive perceptions of getting cured

3.3 DISCUSSION OF THEMES AND SUB-THEMES

The findings of the study are presented based on the themes. The first theme was identified as "isolation, " with the sub-themes: loneliness and boredom, imprisonment, and anxiety. The second theme was identified as "experiences on basic needs" with sub-themes: hygiene needs, food/diet, and safety and security. Theme three was identified as "psychological support" with the sub-themes: experiences on family support and experiences of religion. Theme four was identified as "improved health status" with the following sub-theme: positive perceptions of getting cured.

THEME 3.2.1: ISOLATION

The psychological effects of isolation may cause stress, anxiety, depression, and loneliness among patients who are admitted for long in the hospital. Abad, Fearday, and Safdar (2010) advise that large studies should be carried out to assess the adverse effects of isolation but patients' education should be the first important step to mitigate the psychological effects of isolation.

XDR-TB patients are admitted in isolation to control infections to the visitors, family, and health care, workers. Therefore, the patient in isolation starts to live a new lifestyle where the environment is different and they have to abide by the rules of the hospital.

The analysis of data shows that, during the period of hospitalization, the patient may experience stress, anxiety, depression, or loneliness because he/she cannot cope with the disease or the change in the environment. Participants with XDR-TB are usually depressed as they spend more time away from their families. Another reason why these patients become depressed is that some of them were the breadwinners at home and to be isolated for this long leads them to lose their jobs. Therefore, their worries about how their family members are surviving usually affect them psychological resulting in depression.

Sub-theme 3.2.1.1: Loneliness and boredom

One of the purposes of isolation is to prevent the participants with XDR-TB from getting infections because their immune system is compromised (Vottero, 2012). Another reason for the isolation is to prevent participants with XDR-TB from infecting people in the community.

During isolation hospitalization, the participants are not involved in the usual activities of daily living leading them to feel lonely. While noting that loneliness can be experienced without being isolated, most patients in isolation experience loneliness due to different reasons. The participants shared experiences as follows:

"I am always having no one to talk to or anything to do. If I could have more money, I could have bought myself a television as there is no television for us here. All government televisions are broken; we just lay down." I just lay down [P7 male]

"I was saying that there must be something like television, not just laying down." [P5 female]

"….To be here! seems ok, but the problem is you feel that you are alone and no one to share anything with you no entertainment even movies to watch. You don't know how it feels to be here" [P4 female]

These responses suggest that participants felt that loneliness can be overcome by watching television. However, participants lay down most of their time which is not good for their health. They need to be mobile so that their lungs can function well. Moreover, some of the participants also share their experiences as follows:

"Ooh! I'm just in the hospital, I have no work, I just drink medicines, I lay down, eat and sleep." [P3 female]

"*For us, we are just sitting here without doing anything. We need sport even dominos or even a garden where we can grow vegetables like onions, tomatoes so we cannot waste money to go buy."* [P1 male]

The participant's responses reveal that they were experiencing boredom while in isolation. Boredom is not a good feeling especially to someone who is hospitalized in isolation as there is nothing to do and this may worsen their condition. A study on boredom argues that 'To achieve the goal, boredom does not motivate people to engage in one particular behaviour; it motivates people to engage in any activity that seems meaningful to them' (Tilburg & Igou, 2012). Conversely, it is difficult for the participants to engage themselves in any activity while isolated as there are no platforms of activities to do so.

Another study on boredom by Goldberg and Eastwood (2011) suggested that experiencing boredom may be associated with psychological, social, and physical difficulties like depression, and anxiety. This suggests that XDR-TB experiences boredom because they are either depressed or anxious. The health workers responsible for these patients do not realize the need for motivating activities within the isolation ward because of various reasons which may be overlooked according to data analysis.

This finding suggests the need for the TB isolation ward to provide activities and entertainment to prevent boredom and loneliness to isolated patients. If such provisions are not in place, then the patients will spend the whole day in bed or sleeping, leading to loneliness and boredom.

Sub-theme 3.2.1.2: Participants experienced a feeling of imprisonment

When some participants were asked to describe their experiences in isolation, they reported that they have experienced a feeling of imprisonment. Imprisonment is a feeling of not able to do anything because you are in a place where you are held. According to Collins dictionary (2020) "*Imprisonment means* putting someone in prison or in jail as lawful punishment. One of the participants indicated that:

"*My friends are working and I cannot go out and try to do something because I'm in the hands of the doctor."* [P3 female]

The experience above reveals that the patient seems to have no meaning to her life because all she can do is simple activities everyone can do. The participant may have felt demoralized as she compared her life to those of her friends who are not in the hospital but working to get some money for survival.

"*In December people were told by the doctor that whoever wants to go home will not be given medication.*" [P7 male]

"If I only knew that to accept staying here is this bad then I would have not agreed to stay because this is like a prison and it's what the doctor says not what you say. I have no choice but to stay and take my medicines" [P4 female]

The participants' response above shows a negative experience, resulting from a doctor who acted as if patients were being punished. The participants were allowed to go for the Christmas holiday without medication even if their sputum were negative. Medication is needed even if the sputum is negative because they need to complete the course of their treatment within a given period of time.

"The experience that I have is like I am in jail, cause I am isolated from people that I know and nurses don't even want us to go out (angry voice)." [P6 female]

The participant's response suggests that a feeling of imprisonment has been caused by participants' inability to contact or see their family members for a long time. It is important to note here that, in society, people tend to be used to live in a group. Being separated from society causes many difficulties as a person cannot cope with living alone without family members. It has been a big social detachment between the participant and the loved ones and this may have caused depression. Similarly, a study was done by Mutsonziwa, Nursing, Nursing, & Nursing, (2011) shows that MDR-TB patients in isolation go through some inhumane experiences such as lack of information, loss of control, feeling shut off, stigma, feeling dirty and dumped and anger.

The prolonged isolation of participants with XDR-TB is almost similar to that of the prisoners because of the same stigma, depression, and anxiety they go through (Weir 2012). This explains how painful it is for the XDR-TB patients to bear while admitted in isolation. Therefore, family members can be educated on ways to support their family members who are in isolation.

Sub-theme: 3.2.1.3 Anxiety

Chronic diseases, anxiety, and depression can be interrelated or interdependent (Dejean, Giacomini, Vanstone, & Brindisini, 2013). However, a doctor or nurse may not notice that the patient is suffering from anxiety or depression because of overlapping physical symptoms. The participants in this study reported that they experienced anxiety during hospitalization. This was echoed by one of the participants' responses below:

"*If you ask the doctors about your sickness then it will make you to be sicker, so I don't ask doctors anything related to my sickness. It is like you will hear what you didn't want to hear, therefore just better not to ask"* [P6 female]

One of the participants revealed that anxiety prevented her from acquiring knowledge of her disease. This fear can delay the patient's progress as she may not know how to protect herself further. Thus, the health care workers need to provide health education to all the patients so that they may not have such underlying problems.

Although participants are usually informed about their sputum culture results, awaiting these results causes them to be anxious all the time as they expect negative results. Some participants reported these:

"There were times I cried a lot because my results came out positive…. I cried because I know that I drink my medication well but when my results come they are still positive." [P3 female]

" I am not sure if the test they do to us is really true because as for me, I drink my medicine but the results come out positive and this worries me a lot. I don't know what is to believe anymore." [P4 female]

When the sputum culture results come out and are still positive, some participants stop taking their medication as they lose hope in them. However, other participants reported that:

"If I force myself to stay with my kids and run away from my health then I die soon then my kids can't stay with their father that's why it's forcing me to stay here." [P1 male]

*"The only answer is to stay here, continue medicine and listen to the doctors even if I am afraid because one will not know what tomorrow brings." [*P5female]

The response above explains that the participant has no other choice of defaulting treatment because he is aware that he will lose his life and his children will not have a father. This shows the participant's anxiety while they are aware of the importance of taking XDR-TB treatment as well as adhering to the rules of isolation. Another participant shared his experience of isolation differently as follows:

"As it is bad you are not together with your family in your house and first thing is that you are not together with your colleagues to work with them. And you cannot work anymore." [P2 male]

Based on the participant's response above, it could be deduced that isolation caused anxiety to the participants as they are separated from their family members and their careers. Since one's life is not the same again due to the prolonged isolation, a person's thoughts are different as they are sick and that they should adapt to the new environment. The participants need psychological support such as visits by social workers to share and discuss their concerns and come up with ways on how they can be helped. Kodisang (2013) concluded that "It is rare that a social worker can examine these concerns in a pristine form when working with troubled patients" (Kodisang, 2013, p. 124). Therefore, there must be ways on how to help such patients because they spend more than one year in isolation, and they are discharged with the same worries back to their homes.

Another participant explained her experiences regarding staying long in the TB ward as follows:

"Staying long in TB ward is not good, there are family members we are taking care of and they are outside and we stay two-to-three years without seeing them…. I am here and they are at home, the way they are surviving I don't know (tears in the eyes)." [P6 female]

The participant's anxiety is associated with family members whom she left home. The participant had no choice but to leave her children at home alone, and she could not visit them since she was in isolation. This finding calls for health care researchers to conduct clinical studies on whether XDR-TB patients could survive by taking treatment at home; if they are found to have negative sputum results consecutively, then they can spend time with family. Research has also recommended that "health policy planners and health professionals need to

recognize that factors such as fears, anxieties, and other social and emotional problems associated with TB are genuine and should be incorporated for clinical management" (Venkatraju & Prasad, 2013,p 20).

Anxiety was also revealed by another participant from a different perspective:

"Sometimes I am afraid to go home because there are kids and I can infect them with TB." [P3 female

This revealed that the participant had fear of coming closer to her family because she understood the risk of infections to the others. There was a need to educate the family at large so that they are aware of the risks.

XDR-TB patients in isolation experienced anxiety in many different ways and there is a need for family, nurses, and doctors to support them where possible. Through prolonged isolation patients should receive holistic treatment support which includes psychological, physical, spiritual, and emotional.

THEME 3.2.2: CHALLENGES REGARDING BASIC NEEDS

To understand the needs of the participants with XDR-TB data should be collected regarding their overall wellbeing during the period of hospitalization. Furthermore, physiological and safety needs provide the basis of nursing care (Toney-Butler & Thayer, 2019). In addition,

Jackson et al. (2014) explained that physiological and safety needs are some of the basic needs which need to be fulfilled. Since physiological and safety needs are vital in an individual's life, nurses should ensure that participants with XDR-TB receive proper care because they are not fully capable of helping themselves.

Sub-theme 3.2.2.1: Poor hygiene

The analysis showed that some of the participants with XDR-TB had negative experiences with the dirty surrounding in the TB ward. Donker, Wallinga, Slack & Grundmann (2012) described hospital-acquired infection as a result of poor hospital hygiene or unsafe practices. A dirty surrounding promotes infection growth which may put everyone in danger of hospital-acquired infections. To prevent infection, participants must encourage to take baths daily, ensure that the surrounding is clean, as well that maintaining regular changing of bed linen. When the participants were asked to explain their experiences in isolation, most of them expressed that their surrounding is dirty. The following quote is how some had to explain:

"The rooms there, someone vomits there or mess there, that person who cleans will not do her work when told to clean but says I have my qualifications." [P2 male]

"….the things are broken, they don't work anymore. You cannot use the toilet any longer but it's only a pipe needed……" [P2 male]

"…if we could be at our own houses then we will make sure that our surroundings are clean, but here we have no power to tell the cleaners so that they clean every day that is why there is too much dirt in here," [P4female]

"I also help to sweep the floor or mob when it's dirty because in weekends cleaners leave early or sometimes don't show up at all, leaving the floor, toilets and bathrooms very dirty" [P1 male]

Hygiene is crucial for the well-being of XDR-TB patients because their bodies produce more sweat at night. Therefore, participants with XDR-TB must take baths every day and stay in a clean surrounding. "In Nightingale's mind, the specific scientific activity of nursing hygiene was the central element in health care, without which medicine and surgery would be ineffective" (Smith & Parker, 2015, p 45). Other participants also described their experiences in isolation as follows:

".....As a TB patient then you need to bathe warm water, just because we have no hot water here we are discouraged to bath." [P6 female]

"*The hospital has cockroaches, dirty walls and floors that is why they stopped allowing people to cook in their rooms but rather eat food from the big kitchen."* [P7 male]

"A person like me cannot enjoy eating food if there is smell all over here…there must be strong soup to use when cleaning so that this smell goes away" [P3 female]

Participants with XDR-TB spent more time in the ward which suggests that they need a proper clean, well-ventilated environment to promote healing. A dirty environment is not safe for both health workers and patients; therefore, measures to improve this environment must be taken. Therefore, this study invokes Nightingale's words that "what nursing has to do… is to put the patient in the best condition for nature to act upon him"(Kamau, Rotich, Cheruiyot, & Ng'eno, 2015).

Hygiene is one of the most important factors that should be considered in the isolation ward because it contributes to infection control. Therefore, this study suggests that the participants with XDR-TB should live in a clean and well-ventilated environment because of the nature of their disease.

Sub-theme 3.2.2.2: Negative experience about food

Food is important in illness as it helps a patient recover. However, the preparation of food should be done properly so that it's delicious to encourage one to eat it. Some participants experience poor appetite which means that because poor appetite is one of the symptoms/signs of TB disease. if the food does not taste good, then they might not eat at all. For the fact that participants with XDR-TB tend to lose more weight, the nurses should consider their choice of food because they are the ones who order food for them every day.

When participants were asked to share their experience in isolation, their responses were shared in the statements below:

"The routine of food is just the same every day… food is very bad because the way it is prepared is not good." [P 6 female]

"…If there is specific food I have ordered and they don't give it to me, then I will not eat that food." [P7 male]

"We get tired of the food, they don't cook nice." [P5 female]

Similar comments were observed from the following participants:

"*When the food comes, it comes from the same pot…. Some of us need salt but the food does not have salt. So! that is the problem we have."* [P1 male]

"Food sometimes is fine, sometimes the food they bring is the food you don't eat. So you just throw away because you have no choice." [P2 male]

"I only eat because of medication which cannot be taken without eating or else I cannot eat such food because its very bad" [P4 female]

Nightingale's model emphasized that monitoring of a patient's expenditure of energy, regular anthropometric measures monitoring like weight and body mass index are done as most participants with XDR-TB tend to waste away (Kamau et al., 2015). Therefore, if participants do

not eat a healthy balanced diet while taking strong drugs then the side effect of nausea and vomiting which they experience could worsen, leading to extreme weight loss. The analysis shows that participants with TB have various preferences for food, and they do not eat all kinds of food. Although the hospital (kitchen) provides food to the participants, they reported negative experiences about the type and the preparations of food. For example, participants tend to have a poor appetite and they eventually lose more weight. Therefore, this study suggests that the preparation of food is improved to the benefit of the patients so that the patients in isolation and do not develop reasons to sneak out and get better food elsewhere. For participants to get cured, an improvement in nutritional status should be one of the strategies (Matteelli, Roggi, & Carvalho, 2014).

Sub-theme 3.2.2.3: Fear for losing belongings/properties (environmental safety and security)

Health care institutes are meant to provide a safe and secure environment for all their users (State of Victoria, 2016). Some of the participants in this study experienced the fear of losing their belongings/properties during hospitalization in the TB ward. Since there were no door locks in patients' rooms, it was easy for any person to enter and steal. This especially possible when patients are gone for shopping/church service, visiting others in different rooms, or when they are outside for sunbathing. In addition, this is an indication that there are poor safety and security for these patients. Safety is the state of being safe and protected from danger or harm. Security is the activities involved in protecting a building or person against attack, danger, etc (Hornby, 2010). Therefore, both terms show that a person is protected without any risks. In contrast, some

of the participants revealed that they are not protected as they have fear of losing some of their belongings.

Correspondingly, a study conducted by (Boafo & Hancock 2017; Okeke & Mabuza 2017) showed that among the nursing and administrative personnel, only 2.71% and 2.77%, respectively, trusted the safety of the hospital surroundings. This is to show that the safety and security of patients are at risk. Therefore, if the hospital does not have proper, safe, and secured physical infrastructure, this exposes patients to greater risks such as losing their belongings; because other people from the community come in at any time to steal. The patients' concern over safety was evident in some of the participants' responses below:

"It's not safe here, because the rooms are not locked. I lost about four cell phones on different days in my room, I cannot keep losing phones because they are expensive. how much is one phone and I cannot stay without communicating with my kidand the phone is the only way. Even sugar was stolen from my locker because I don't have a padlock for the cupboard." [P1 male]

"*Volunteers, some of them are thieves because they know that they don't get paid therefore they do such things(steal), they take thing(participants' belongings) to their sharks (houses)…"* [P2 male]

The safety of participants belongings is at risk because they move around in other people's rooms leaving their rooms closed but not locked and there is nobody to guard their belongings. The following is what a few participants had to say:

"Yes! Some people are coming from the location and come steal (speaking with anger). We need police officers to be here and some people are coming to fight here. A lot of us lost cell phones, shoes, and money…" [P5 female]

"I lost my identity card, FNB card, standard bank card, post office card, and election card here. When I woke up to go buy my glossaries, then I found out that everything was gone." [P7 male]

The responses above demonstrate the fear of participants regarding the likely loss of belongings/properties; this has a negative implication on their safety and security while in isolation. Hence, if the isolation ward does not provide patients with proper infrastructure, the patients' safety and security remain at stake.

THEME 3.2.3: PSYCHOLOGICAL SUPPORT

Englar-carlson and Kiselica (2013) revealed that people tend to gain strength and confidence through the support of others. This may include encouragement and support from family that brings comfort to chronically ill people. Therefore, psychological support is needed for the XDR-TB patients in isolation, so that they do not feel neglected by family or health workers.

A study conducted on uncured XDR-TB revealed that improved psychosocial support can increase patient adherence, reduce transmission, provide income, and relieve the burden on family members (Senthilingam et al., 2015). If all family members of people with chronic illness conditions could understand the importance of supporting the patients, then most of the burdens could be reduced. Senthilingam et al. (2015) further reported that family members displayed a

lack of knowledge and a lack of concern about the transmission. This concludes that family members do not support the patients in any way. This could also be the reason why family members have no knowledge or concern regarding the transmission of the bacteria.

It is therefore important to highlight that there are different ways to provide psychological support to the participants with XDR-TB by their family members or health care workers. Such support may include: encouraging patients to take their treatment, sending them positive quotes for encouragement, providing them with quality cancelling, and most of all to be present in their disease process and not discriminate against them.

Sub-theme 3.2.3.1: Family support

The support most people get when they are sick comes from their family members. Therefore, in this study, some participants described their experience in isolation as not good because they miss their family and want to complete their treatment just to go back home where everyone is. On probing questions some have revealed that they too provide financial assistance to some family members in a form of money. The following is what was shared:

"*It becomes difficult because I used to send money, but I don't know whether the money I send is used for good reasons. It's better if you are around to see how the money is being used."* [P2 male]

"So! I need to be with my kids. The way I'm getting money also, I feel like throwing the money away. I don't know how they are using the money. So I want to be with my kids. So we can buy together what we need for a house. So I'm not happy about it. But the other hand, you know my health is very important." [P1 male]

"I get some help from my family which send me some few money to buy my small things like sugar and other toiletries.I sometimes send them money that I get as incentives so it can help where necessary. Let me say we help one another" [P4 female]

The responses above show that participants continued to support their families financially because they still received their salaries. This was the only support they could provide to their children during isolation because they do not go home nor does family visit them. This is a concern for the participants though they have no choice but to remain in the isolation ward.

As a parent, providing money for your family is maybe appreciated but not sufficient, because being physically present in the children's lives matters the most. The participants were also concerned about providing money to the family and they are not sure how the family would spend it. Some of the participants shared their experiences as follows:

"Some of my family members come and visit but not often" [7 male]

"My family and neighbour have accepted that I have TB. They can sit aside while I am seated far away but we can communicate. The elders always tell me that it is not good for me to seat far from everyone because if the disease was on, then let it be." [P3 female]

"I feel bad because my family is far in Rehoboth. They feel bad… and they support more, they support me" [P5 female]

The experiences presented above show that some family members have positive support towards the patients. The family member accepted the patient's disease; hence, they either visit or allow them to visit the family members. Psychological support can be accepting one without stigmatization (Sadeghian, Rostami, Shamsaei, & Tapak, 2019). This was reported as follows:

"We sit around under the shades as if we are family, and we all feel good. It is like we come from the same house. Drinking the same medication, we also help one another so that we all drink our medication as told." [P3 female]

This response suggests that family support does not necessarily mean that the support must come directly from the blood-related members, but it can also be the care and support offered by other people from your surroundings. The need for support has also been documented in the literature, For example, Chen et al. (2019) reported that caregivers of schizophrenic patients suffered from heavy life burdens and had negative experiences concerning obtaining social support, and they emphasized that they would require more support. Their study revealed that some participants did not receive support from their families; instead, they have the burden of supporting their

families out there. Secondly, only a few participants get support from family. Therefore, patients should be supported by their family members in different ways and not rely on them because they have incentives from the government. Other forms of support can also be vital, like accepting the condition of the participant and communicating with them via cell phones.

Family members of the participants with XDR-TB should be involved in supporting them. It should be noted that isolation is the only way to help their beloved ones through the treatment process. If family members cannot be involved in the participant's treatment process, then they may be more vulnerable while in isolation.

Sub-theme 3.2.3.2: Religious belief

The question of whether or not religion is more effective in treating depression is not known because there is no empirical research to answer this question (Pearce, Koenig, Pearce, & Koenig, 2013). However, a study about cognitive behaviour therapy for depression reported that religious involvement is associated with positive emotions and faster remission of depression symptoms.

In this study, some participants shared their experience regarding what they do on a daily basis that they could not do before they came in isolation and some of them have stated as follow:

"……As now, the time I became very sick is when I believed that God existed because I could see it as a punishment, but now that I'm better I pray every time. I don't miss church and I pray when I drink medicine and whenever I get up from the bed." [P2 male]

".....I used to see like a black cloud over my eyes… since 2005 until 2018 July as I started going to universal church that's when it stopped. Until now I'm just focusing on TB so I get well." [P3 female]

"I experience that God is with me since I came here. I have also started going to church and read the bible each day. Ohh! I know it will be well because my health has improved well as I have accepted him in my life" [P5 female]

The responses above reveal that religious behaviours supported the participants to strengthen their hope and belief in getting cured. Similarly, Koenig, King and Carson (2012) emphasized that religion plays a role as a coping behaviour, including religious resources in therapy to help speed the resolution of depression and help to normalize endocrine and immune dysfunctions than conventional treatments. Additionaly, Worthington, Hook, Davis, and McDaniel's (2011) meta-analytic review of 46 therapy outcome studies revealed that patients who were in spiritually integrated psychotherapy showed greater improvement than patients in alternate psychotherapies.

Other participants shared more experience regarding religious behaviours as follows:

"Yes, there is also one pastor from Evangelical church because I'm from Evangelical. Every day, he sends verses for me to read, but now I'm going to this church called University or whatever." [P1 male]

"This year I decided to go to church, God knows all my needs…. my problem is that I lost my hearing and there is nothing I hear in church, but I keep on attending church service because I always ask the next person to show me the bible verses for that day and I will read on my own…. I lost my hearing in 2013." [P4 female]

Since participants stayed longer in isolation, going out to church could be a way to acquire positive emotion which they can use as a coping behaviour. So far, it is evident that it is difficult for people to live in isolation, and that is why the participants with XDR-TB cannot abide by the rules of isolation but rather go out to seek ways on how they will cope with isolation. One of the participants indicated that:

"I go to church as if I'm going to my family, I can't use a mask. The mask is to be worn by people who have just arrived in the ward" [P7 male]

The participants also registered their concerns about being treated differently in a public place, for example when they are seen wearing a mask in public places like the church. However, one of the participants acknowledged that:

"What I have noticed is that, if they see you having a mask then they help you fast. At Nampost they also help us fast with a mask on." [P6 female]

It is evident from the participants' responses that they acquired different mechanisms to help them cope in isolation. This may be similar to the management of the COVOD-19 outbreak

where people are quarantined for a certain period, and they cannot be with their family members. In both situations, it's not the person's will to be quarantined or isolated, but because there is a need to control infections. It remains a challenge for the participants with XDR-TB to cope in isolation, especially given that their treatment requires a minimum of 24 months.

THEME 3.2.4: IMPROVED HEALTH STATUS

This theme focuses on how the participants experienced health improvement in the TB isolation ward. The data analysis showed that the participants experienced positive feelings after realizing that XDR-TB treatment has improved their health status during hospitalization. The participants shared their experiences before admission and during isolation in the TB ward, that they exceedingly appreciated the improvement in their health.

According to the participants, the only reason they were still in the ward is that they have no choice but to remain in isolation to receive treatment from the health care workers. Having a positive feeling toward their health can promote speedy recovery from XDR-TB. Participants' views on their health status were supported by the fact that they adhered to the treatment for XDR-TB.

Sub-theme 3.2.4.1: Positive perceptions of getting cured

Some TB control programs have shown that cure is possible for an estimated 30% to 50% of affected people with XDR-TB (Matteelli, Roggi & Carvalho, 2014). In addition, successful

outcomes depend on many different factors such as adherence to treatment, drug-resistant, weakened immune system, and the severity of the disease.

The participants revealed positive perceptions of getting cured because they improved physically compared to when they got admitted to the TB ward.

Although being in isolation is a challenge to the patients, it is the only way of controlling TB infection in the community at large. It emerged from the analysis that many patients with XDR-TB do not conform to the rules of isolation and they believe that once their treatment is complete then they will be cured. This was revealed from some of the participants' responses as follows:

"You should put your thoughts together and say 'I will drink my medicine until I get healed". I think that I will be healed. Why did others get healed?' Ehee! If it is not your time to die, it is not." [P2male]

"…..*that time until now I feel better now….. But nowadays I think the treatment I got for this sickness is TB treatment. I feel happy for it and I think in this ward all of us…" [P1 male]*

"*I have no choice but to remain here until I complete my medicine as the doctor and nurses are saying in order for the doctor to release me."* [P3 female]

" *…….just because I stayed long here I got bad spirit saying that I can just drop treatment and go home… later on I realized that I was very sick when I got here because I could hardly walk, but because of treatment I am convinced that I will be cured as I can go shopping on my own now ….. and I'm waiting to get cured then I go home."* [P4 female]

"The problem is not staying long….. I just want to complete my treatment and go home, because I don't want to die. I want to live for my children, that is what I want." [P5 female]

The participants' responses demonstrated that most of the participants believed that completing XDR-TB treatment guarantees them to be cured of the disease. Some of the participants further reported that isolation is not a problem for them because they believe that completing their treatment guarantees them to get cured. However, the severity of side effects of XDR-TB treatments such as hearing loss, depression or psychosis, kidney impairment, skin darkening gastrointestinal issues, rash, and drug-induced hepatitis may lead to death.

3.5 SUMMARY

The focus of the study was the description of the experiences of participants with XDR-TB regarding prolonged isolation. This chapter examined and presented themes emerging from the data analysis. The key themes were namely: experiences on isolation, experiences on basic needs, psychological support, and improved health status. The chapter focused on the analysis, findings, and discussion which incorporated relevant literature. The data reveals that participants with XDR-TB deal with many other concerns and not only the disease.

CHAPTER 4

CONCLUSIONS, LIMITATIONS, AND RECOMMENDATIONS

4.1. INTRODUCTION

The results of the experiences of participants with XDR-TB regarding prolonged isolation were analysed in chapter three, Four main themes that emerged from the study analysis were discussed with literature control. Therefore, this chapter will discuss the conclusion, recommendations and limitations of the study. The main purpose of this study was to explore and describe the experiences of participants with XDR-TB regarding prolonged isolation at a selected hospital in Namibia.

4.2 CONCLUSIONS

The following conclusions were derived from the findings of the study and are discussed as per objective:

4.2.1 Explore the experiences of participants with XDR-TB regarding prolonged isolation at TB ward, at a selected hospital in Namibia.

This study concluded that the majority of the participants with XDR-TB had negative experiences in isolation. The negative experiences affected them psychologically and socially which resulted in them being depressed. It was revealed that the participants lived in TB isolation ward with no proper information regarding the length of stay. Secondly, the dirty surrounding made it uncomfortable for them to live in the isolation as the floor, walls, bathrooms were dirty. The dirty surrounding may contribute to infections and in this regards the isolation does not promote infection control. They have also reported that the bathrooms and toilets were out of

order most of the time and the hospital management could not do anything about it. Thirdly, nutrition plays a bigger role in participants with XDR-TB as they report poor appetite which is one of the symptoms of their disease. It has been difficult for the participants to have hospital meals as the cooks don't prepare them well. The above reasons raised a need for the participants to go out of isolation to get their food.

Another serious concern revealed were the participants having been allowed to go for the weekends while in isolation. The doctors were supposed to put up strong measures which could discourage participants from asking permission to go home because it seemed as if the participants lacked proper information regarding infection control. It is, therefore, suggesting that the participants risked the people from the community including their family members as they were coming in contact with them.

The study revealed that some participants experienced some degree of physical discomfort as a result of side effects from the XDR-TB treatment, such as hearing loss, eye problems, depression or psychosis, kidney impairment, skin darkening gastrointestinal issues, rash, and drug-induced hepatitis. The researcher suggests that on admission, every participant with XDR-TB should be educated on the rules of isolation, the importance of treatment and the side effects of the treatment so that they are aware. This will help them(participants) on how they can make their decisions better.

4.2.2 Describe the experiences of patients with XDR-TB regarding prolonged isolation at TB ward, at the selected hospital

It was concluded that even though most of the participants had negative experiences in isolation there were a few of the participants who appreciated isolation as they have reported that seeing other people take their treatment encouraged them to do the same. What contributed to resistance was poor adherence to TB treatment. Therefore, isolation helped the participants to encourage one another to take their treatment as this helped many of them to recover. This study does not provide the knowledge and understanding of the participants with regard to isolation. However, little is known about whether the participants were informed about the rules of isolation or not. The study also concluded that a clean environment contributes to the healing of a person. Therefore, the need for, cleanliness, lighting, clean water, security/safety, sanitation, and a balanced diet are what Nightingale found to be important within the environment which can also contribute to the healing of a person. According to this study, most of the participants reported that their surrounding was dirty, their diet was poor as most of them chose not to eat hospital food, and they were not comfortable as their belongings were stolen. Moreover, the hospital was supposed to ensure that the environment provides what Nightingale suggested in order to promote healing.

The study also concluded that isolation affected the participants psychosocially which resulted from loneliness, anxiety, depression e.c.t. It was revealed that participants struggled to cope with new lifestyles as they were detached from society. It is very difficult for one to live in isolation because humans belong to a group of people within the society. The moment the participants realized that they were isolated then they started experiencing boredom and loneliness. Even

though their lives were difficult in isolation, the participants found hope and comfort in God. They have revealed that their faith in God helped them to be strong and continue taking their treatment.

Furthermore, the participants' overwhelming experiences of prolonged isolation was aggravated by uncertainty waiting since they did not know when will their hospitalization will come to an end. Thereby, causing them anxiety, confusion and pain because they were in the suspension of not knowing when to be released from isolation but hoping to get cured someday. Some of the participants revealed that they had no choice but to remain in isolation as they were still receiving treatment from the health care workers. The study also concluded that most of the participants believe that completing XDR-TB treatment guarantees them cured of the disease.

4.3 RECOMMENDATIONS

Based on the conclusion of the study, the following recommendations were made on management education and research as follows:

4.3.1 Management

- The MoHSS should consider renovations of the TB isolation ward to allow patients to be nursed in a safe, cleaned, and conducive environment.
- Considering what is learned from the study about the psychological challenges patients encountered, it is recommended that an assessment tool to identify the challenges of patients to prolonged isolation from XDR-TB needs to be developed by the MoHSS. The purpose of the tool is to ensure that the patient's psychological needs are given the

necessary attention, and ensuring that patients receive continued emotional and psychological support.

4.3.2 Education

- It is suggested that a training program should be developed and endorsed by the relevant structural bodies to all XDR-TB patients on admission regarding the duration of treatment, dangers of defaulting treatment, side effects of treatment, and the rules of isolation. This may require translation in all Namibian languages and each patient will be required to sign and use a thumb in a case where one cannot read or write.

4.3.3 Future Research

Future research is recommended

- On this topic in the other regions of Namibia which could then be compared with the findings of this study
- On the guidelines for psychological support for caring of participants with XDR-TB in isolation.
- On assessment of doctors and nurses regarding their experience of caring for XDR-TB patients in isolation.

4.4 LIMITATION

Population effect:

The population studied was relatively small and limited to a selected hospital in Namibia. The scope of a contextual study should be made sufficiently large for instance, covering participants with XDR-TB from other regions to make the generalisation of the results fair.

Data collection and data analysis:

The interviews were conducted in English and it was not a mother tongue for the participants. Therefore, there is a possibility of losing the original main idea when transcribing.

Participant Effect:

The risk of the Hawthorn effect was noted as the researcher was known to some of the participants as she put on the uniform for the nurses and they may have reported more anxiety as this may have affected their responses, and give answers which designed to please the researcher.

The researcher felt like the participants hide some of the information concerning their experiences because they knew that the researcher was one of the health care workers and that if they reveal everything then they will be scolded. The findings reveal that the participants wanted to be heard in their own voices and they even wished that if they could be given an opportunity to share their experiences in isolation with other people in the society it will be a good thing.

4.5 FINAL CONCLUSION

Extensive drug-resistant tuberculosis is a dangerous stage one will live with because its treatment is very overwhelming. One may not cope with the side effects as the liver functions are affected, the skin changes and some people report that their skin darkens and itches, their eyes lose sight and loses hearing etc. Therefore one has to take medication as prescribed the first time you are

diagnosed with tuberculosis because poor adherence will result in drug resistance which is difficult to cure.

The need for this study was developed because since the researcher once worked in the TB ward many years ago noticed that a person to be hospitalized for a long may have effects on this person, therefore, raised a need to conduct a study on how participants experience isolation. The other reason was that the same patients which were in isolation could be seen in shopping malls, churches and on open markets.

This study concluded that the participants experienced some psychosocial problems due to prolonged isolation. Living in isolation deprived them of a normal social lifestyle which resulted in pain, loneliness, anxiety, fear and depression. It was very difficult for the participants to share their experiences with anyone else as they only knew that to remain in isolation was the only hope to get cured as long as they were given their treatment. The health care workers didn't think of assessing the participants psychological being but only concentrated on their physical needs. If the participant complains of itching eyes then they were referred to the eye doctor but if they had some psychological problems, nobody tried to assist them.

It was also revealed that participants had no idea of how long they will stay in isolation because they thought that they had no choice but to stay there and listen to what the doctors will tell them. The study reveals that the participants had no proper information regarding the length of stay in isolation, side effects of treatment and facts about their disease(DRT-TB).

Finally, this study may contribute to the understanding of experiences of participants with XDR-TB and its findings together with recommendations may be used to serve as a basis to help improve the living standard of people in isolation wards.

REFERENCES

Abad, C., Fearday, A., & Safdar, N. (2010). Adverse effects of isolation in hospitalised patients: a systematic review. *The Journal of Hospital Infection, 76*, 97 - 102.

Almalki, S., Centre, E. L., Arabia, S., & Centre, E. L. (2016). Integrating quantitative and qualitative data in mixed methods research: Challenges and Benefits, *5*(3), 288–296. Retrieved from https://doi.org/10.5539/jel.v5n3p288

Astalin, P. K. (2013). *Qualitative research designs: A conceptual framework. International Journal of Social Science & Interdisciplinary Research*, *2*(1), 118–124. ISSN 2277- 3630 IJSSIR,

Boafo, I.M. (2016). Ghanaian nurses' emigration intentions: The role of workplace violence. *International Journal of Africa Nursing Sciences, 5*, 29-35.

Brink, H, Van der Walt, C. & Van Rensburg, G, (2012). *Fundamental of research methodology for health care professionals*. (3rd edition.) Cape Town: Juta.

Burns, N. and Grove, S.K. (2011). Understanding nursing research: Building an evidence-based practice. 5th ed. Atlanta, GA: Elsevier

Burns, N., & Grove, S. K. (2019*). The practice of nursing research: Appraisal, synthesis, and generation of evidence* (8th ed.). United States of America: Saunders Elsevier.

Grove, S. K., Burns, N., & Gray, J. R. (2013). *The practice of nursing research: Appraisal, synthesis, and generation of evidence* (7th ed.). China: Saunders Elsevier.

Centres for Disease Control and Prevention. (2018, October 3). Quarantine and Isolation.*The Lancet*.Infectious Diseases, *18,* 516-525.

Chen, L., Zhao, Y., Tang, J., Jin, G., Liu, Y., Zhao, X., Chen, C., & Lu, X. (2019). The burden, support and needs of primary family caregivers of people experiencing schizophrenia in

Beijing communities: a qualitative study. *BMC Psychiatry, 19*.

Creswell, J. W. (2014). Research design: Qualitative, quantitative, and mixed methods approaches (4th ed.). United Kingdom: Sage Publications.

Creswell, J.W. and Poth, C.N. (2018) Qualitative Inquiry and Research Design Choosing among Five Approaches. (4th ed.): SAGE Publications, Inc., Thousand Oaks.

Collins English Dictionary.(2020).Collins dictionary. (12th ed.).

DeJean, D., Giacomini, M., Vanstone, M., & Brundisini, F. (2013). Patient experiences of depression and anxiety with chronic disease: a systematic review and qualitative meta-synthesis. *Ontario health technology assessment series, 13 16*, 1-33

De Vos, A.S., Strydom, H., Fouche, C.B., & Delport, C.S.L. (2011). *Research at grassroots: for the social sciences and human service professions* (4th ed.). Pretoria: Van Schaik.

Donker, T., Wallinga, J., Slack, R., & Grundmann, H. (2012). Hospital networks and the dispersal of hospital-acquired pathogens by patient transfer. *PLoS ONE, 7*.

Englar-Carlson, M., & Kiselica, M.S. (2013). Affirming the strengths in men: a positive masculinity approach to assisting male clients. *Journal of Counseling and Development, 91*, 399-409.

Experience Distinct from Apathy, Anhedonia, or Depression. (n.d) *Journal of Social and Clinical Psychology, 30*, 647-666.

Fleming, J., & Zegwaard, K. (2018). Methodologies, Methods and Ethical Considerations for Conducting Research in Work-Integrated Learning.

Gygli, S.M., Borrell, S., Trauner, A., & Gagneux, S. (2017). Antimicrobial resistance in Mycobacterium tuberculosis: mechanistic and evolutionary perspectives. *FEMS Microbiology Reviews, 41*, 354–373.

Giorgi, A., & Giorgi, B. (2003). The descriptive phenomenological psychological method. In Qualitative research in psychology: Expanding perspectives in methodology and design. Ed. P. Camic, J. Rhodes, & L. Yardley, Washington, DC: American Philosophical Association, 243–273.

Goldberg, Y., Eastwood, J., LaGuardia, J.G., & Danckert, J. (2011). Boredom: An Emotional experience distinct from apathy, anhedonia, or depression. 30(6), 647-666

Holloway, I., & Galvin, K. (2016). Qualitative Research in Nursing and Healthcare. New Jersey, US: John Wiley & Sons. [Google Scholar]

Holloway, I., & Wheeler, S. (2013). Qualitative research in nursing and healthcare (3rd ed.). Oxford, UK: John Wiley & Sons. [Google Scholar]

Jackson, J., Santoro, M.J., Ely, T.M., Boehm, L., Kiehl, A., Anderson, L., & Ely, E. (2014). Improving patient care through the prism of psychology: application of Maslow's hierarchy to sedation, delirium, and early mobility in the intensive care unit. *Journal of critical care, 29 3*, 438-44.

Kamau, S.M., Rotich, R.J., Cheruiyot, B., & Ng'eno, L.C. (2015). Applying Florence Nightingale's model of nursing and the environment on multiple drug-resistant tuberculosis-infected patients in the Kenyan setting. *Open Access Library Journal, 2*, 1-10.

Kivunja, A. C., Ahmed, A., & Kuyini, B. (2017). *Understanding and applying research paradigms in educational contexts*, *6*(5), 26–41. https://doi.org/10.5430/ijhe.

Kodisang, P. (2014). An existentialist study on prolonged hospitalization for drug-resistant tuberculosis.

Koenig, H. G., King, D. E., & Carson, V. B. (2012). *Handbook of religion and health* (2nd ed.).

New York, NY: Oxford University Press.

Korstjens, I., & Moser, A. (2018). Series: Practical guidance to qualitative research. Part 4: Trustworthiness and publishing. *European Journal of General Practice, 24*, 120 - 124.

Kumar, R. (2011). *Research methodology a step-by-step guide for beginners* (3rd ed.). New Delhi: SAGE Publications.

Lambert, V., & Lambert, C. (2012). Qualitative descriptive research: an acceptable design. *Pacific Rim international journal of nursing research, 16*, 255-256.

Leon, A. C., Davis, L. L., & Kraemer, H. C. (2011). The role and interpretation of pilot studies in clinical research. *Journal of psychiatric research, 45*(5), 626–629. https://doi.org/10.1016/j.jpsychires.2010.10.008

Lincoln, Y.S., & Guba, E.G. (1985).*Naturalistic inquiry.* London: SAGE Publications

MacLean, R., & Wilson, S. (2011). *Research methods and data analysis for psychology*. United Kingdom: McGraw-Hill Education.

Marshall, C. & Rossman, G. (2016) Designing qualitative research. 6th ed), SAGE, Thousand Oaks

Matteelli, A., Roggi, A., & Carvalho, A.C. (2014). Extensively drug-resistant tuberculosis: epidemiology and management. *Clinical Epidemiology, 6*, 111 - 118.

Matthews, B., & Ross, L. (2010). *Research methods: A practical guide for the social sciences*. United Kingdom: Pearson Education..

Ministry of Health and Social Services.(2017). Health information system.Katutura intermediate hospital. Namibia

Ministry of Health and Social Services(2018). National Guidelines for managing tuberculosis. Katutura intermediate hospital. Namibia.

Ministry of Health and Social Services (2012) National Guidelines for managing tuberculosis.

Katutura intermediate hospital. Namibia.

Morrow, M.R. (2017). A Book Review of Nursing Theories and Nursing Practice (4th ed.), by Marlaine C. Smith and Marilyn E. Parker (2015). Philadelphia, PA: FA Davis. *Nursing Science Quarterly, 30*, 186 - 187.

Moxham, L. (2012). *Nurse Education, Research and Evidence-Based Practice*. In A. Berman, S. J. Snyder, T. Levett-Jones, M. Hales, N.Harvey, Y. Luxford, L. Moxham, T. Park, B. Parker, K. Reid-Searl and D. Stanley (eds), Kozier and Erb's Fundamentals of Nursing (2nd vol. 1). Frenchs Forest, Sydney: Pearson Australia.

Mutsonziwa, G.A., & Green, J. (2011). Colonised and isolated: a qualitative meta-synthesis of patients' experiences of being infected with multiple drug-resistant organisms and subsequent isolation. *Healthcare Infection, 16*, 147-155.

Nardell, E. (2011). Programmatic management of multidrug-resistant tuberculosis--15 years later. *The international journal of tuberculosis and lung disease: the official journal of the International Union against Tuberculosis and Lung Disease, 15 10*, 1280.

Nieświadomy, M.R. (2018). *Foundations of nursing research.*(7th ed.), REVEL: Pearson

Neuman, W.L. (2011) *Social Research Methods: Qualitative and Quantitative Approaches*. (7th ed.), Boston: Pearson.

Ogunbanjo, G., & Savva, H. (Eds.). (2011). *Management of drug-resistant tuberculosis: Policy guidelines.* Pretoria, Republic of South Africa: National Department of Health.

Okeke, S. O., & Mabuza, L. H. (2017). Perceptions of health care professionals on the safety and security at Odi District Hospital, Gauteng, South Africa. *Afr J Prm Health Care Fam Med. 9*(1), a1441. Retrieved from https://doi.org/10.4102/ phcfm.v9i1.1441

Oladimeji, O., et al. (2016). Psychosocial wellbeing of patients with multidrug-resistant

tuberculosis voluntarily confined to long-term hospitalisation in Nigeria. *BMJ global health, 1*(3), e000006. https://doi.org/10.1136/bmjgh-2015-000006.

Pearce, M., Koenig, H. G., Pearce, M., & Koenig, H. G. (2013). Cognitive behavioural therapy for the treatment of depression in Christian patients with medical illness, *4676*. Retrieved from https://doi.org/10.1080/13674676.2012.718752

Polit, D. F., & Beck, C. T. (2012). Nursing research: Generating and assessing evidence for nursing practice (9th ed.). China: Lippincott Williams & Wilkins.

Polit, D. F., & Beck, C. T. (2014). *Essentials of nursing research: appraising evidence for nursing practice.* 8th ed. Philadelphia: Wolters Kluwer Health /Lippincott Williams & Wilkins.

Rensburg, G.V. (2011). Ethics in healthcare, 3rd edition, S.A. Pera & S. van Tonder (Eds.), revised by J.M. Oosthuizen and D.M. van der Wal : book review. *Africa journal of nursing and midwifery, 13*, 135-137.

Ritchie, J., Lewis, J., Nicholls, C., & Ormston, R. (2013). Qualitative Research Practice: A Guide for Social Science Students and Researchers.

Sadeghian, E., Rostami, P., Shamsaei, F., & Tapak, L. (2019). The effect of counseling on stigma in psychiatric patients receiving electroconvulsive therapy: A Clinical Trial Study. *Neuropsychiatric Disease and Treatment, 15*, 3419 - 3427.

Sankombo, M.T. (2015). Experiences of parents with congenital abnormalities at Oshakati Intermediate hospital, Oshana region. University of Namibia.

Schneider, N., Coates, W., & Yarris, L. (2017). Taking Your Qualitative Research to the Next Level: A Guide for the Medical Educator. *AEM Education and Training, 1*, 368 - 378.

Scotland, J. (2012). Exploring the Philosophical Underpinnings of Research: Relating Ontology and Epistemology to the Methodology and Methods of the Scientific, Interpretive, and Critical Research Paradigms. *English Language Teaching, 5*, 9-16.

Senthilingam, M., Pietersen, E., McNerney, R., Riele, J., Sedres, P., Wilson, R., & Dheda, K. (2015). Lifestyle, attitudes and needs of uncured XDR-TB patients living in the communities of South Africa: a qualitative study. *Tropical Medicine & International Health, 20*.

Simon, B. M. (2012). Assumptions, Limitations and Delimitations. In *Assumptions, Limitations and Delimitations*. Dissertation Success, LLC.https://doi.org/10.13140/RG.2.1.5089.0960

Sotgiu, G., Pontali, E., & Migliori, G. (2015). Linezolid to treat MDR-/XDR-tuberculosis: available evidence and future scenarios. *European Respiratory Journal, 45*, 25 - 29.

Sounders, M. Lewis, P. & Thrornhill, A. (2016). *www.acetxt.com* (7th edition). Harlow, England: Pearson education limited.

State of Victoria. (2016). Security and safety at hospital: Better health channel Retried from https://www.betterhealth.vic.gov.au/health/…/security-and-safety-at-hospital?viewAs [Google Scholar] [Ref list]

Streubert, H. J., & Carpenter, D. R. (2011). Phenomenology as method. Qualitative research in nursing: Advancing the humanistic imperative. 5th ed. Philadelphia: Lippincott Willians & Wilkins, 72-95.

Tadesse, S. (2016). Stigma against tuberculosis patients in Addis Ababa, Ethiopia. *PLoS ONE, 11*.

Tappen, R. M. (2011). *Advanced nursing research: From theory to practice*. Sudbury, MA: Jones & Bartlett Learning.

Tilburg, W.V., & Igou, E. (2012). On boredom: Lack of challenge and meaning as distinct boredom experiences. *Motivation and Emotion, 36*, 181-194.

Toney-Butler, T., & Thayer, J. (2019). Nursing process: Understanding and creative treatment of pediatric tuberculosis. *ScienceDaily*. Retrieved April 13, 2020, from http://www.sciencedaily.com/releases/2015/11/151115192158.htm

Venkatraju, B., & Prasad, S. (2013). Psychosocial trauma of diagnosis: a qualitative study on rural TB patients' experiences in Nalgonda district, Andhra Pradesh. *The Indian journal of tuberculosis*, *60*(3), 162–167.

Vottero, B., & Rittenmeyer, L. (2012). The hospitalised patients' experience of being in protective/source isolation: A systematic review of qualitative evidence. *JBI Database of Systematic Reviews and Implementation Reports, 10*, 935–976.

Weir, K. (2012, May). Alone, in 'the hole'. *Monitor on Psychology*, *43*(5). http://www.apa.org/monitor/2012/05/solitary

Whitehead, D., & Whitehead, L. (2016). Sampling data and data collection in qualitative research.

World Health Organization. (2014). WHO Handbook for guideline development. (2nd ed.). WHO: Geneva Switzerland

Word Health Organization. (2013). Definitions and reporting framework for tuberculosis – 2013 revision process. ACCRA, Ghana: World Health Organization.

World Health Organization. (2011). World Report on Tuberculosis, Geneva: World Health Organization.Availableat:http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf accessed on 10th June 2011

Worthington, E. L., Hook, J. N., Davis, D. E., & McDaniel, M. A. (2011). Religion and spirituality. *Journal of Clinical Psychology*: *In Session, 67,* 204–214.

APPENDICES

Annex 1: Ethical clearance certificate

UNAM
UNIVERSITY OF NAMIBIA

ETHICAL CLEARANCE CERTIFICATE

Ethical Clearance Reference Number: SON /523/2019 **Date: 13 November, 2019**

This Ethical Clearance Certificate is issued by the University of Namibia Research Ethics Committee (UREC) in accordance with the University of Namibia's Research Ethics Policy and Guidelines. Ethical approval is given in respect of undertakings contained in the Research Project outlined below. This Certificate is issued on the recommendations of the ethical evaluation done by the Faculty/Centre/Campus Research & Publications Committee sitting with the Postgraduate Studies Committee.

Title of Project: Experiences of patients with extensive drug resistant Tuberculosis (TB) regarding prolonged isolation at TB ward, Katutura Intermediate Hospital, Windhoek

Researcher: EINE K. H. SIRONGO

Student Number: 200207989

Supervisor(s): *Dr L. Nelumbu (Main) Ms C Mbapaha (Co)*

Faculty: School of Nursing

Take note of the following:

(a) Any significant changes in the conditions or undertakings outlined in the approved Proposal must be communicated to the UREC. An application to make amendments may be necessary.

(b) Any breaches of ethical undertakings or practices that have an impact on ethical conduct of the research must be reported to the UREC.

(c) The Principal Researcher must report issues of ethical compliance to the UREC (through the Chairperson of the Faculty/Centre/Campus Research & Publications Committee) at the end of the Project or as may be requested by UREC.

(d) The UREC retains the right to:

(i) Withdraw or amend this Ethical Clearance if any unethical practices (as outlined in the Research Ethics Policy) have been detected or suspected,

(ii) Request for an ethical compliance report at any point during the course of the research.

UREC wishes you the best in your research.

Dr. J.E. de Villiers: Chairperson

Ms. P. Claassen: Secretary

Annex 2: Research permission letter from postgraduate study

CENTRE FOR POSTGRADUATE STUDIES

University of Namibia, Private Bag 13301, Windhoek, Namibia
340 Mandume Ndemufayo Avenue, Pioneers Park
☎ +264 61 206 3275/4662; Fax +264 61 206 3290; URL: http://www.unam.edu.na

UNAM

RESEARCH PERMISSION LETTER

Date: 30/09/2018

Centre for Postgraduate Studie
Office of the Director
2018 -10- 03
University of Namibi
UNAM

Student Name: Sirongo E K 11

Student number: 200207989

Programme: Master in Nursing Science

Approved research title: Experiences of patients with extensive drug resistant tuberculosis regarding prolonged isolation at TB Ward, Katutura Intermediate Hospital, Windhoek

TO WHOM IT MAY CONCERN

I hereby confirm that the above mentioned student is registered at the University of Namibia for the programme indicated. The proposed study met all the requirements as stipulated in the University guidelines and has been approved by the relevant committees.

The proposal adheres to ethical principles as per attached Ethical Clearance Certificate. Permission is hereby granted to carry out the research as described in the approved proposal.

Best Regards

05/10/18

Prof Marius Hedimbi
Director: Centre for Postgraduate Studies
Tel: +264 61 2063275
E-mail: directorpgs@unam.na

Date

Annex 3: Permission letter from the Ministry of Health and social services

REPUBLIC OF NAMIBIA

Ministry of Health and Social Services

Private Bag 13198 | Ministerial Building | Tel: 061 – 203 2562
Windhoek | Harvey Street | Fax: 061 – 222558
Namibia | Windhoek | E-mail: haangombe@gmail.com

OFFICE OF THE PERMANENT SECRETARY

Ref: 17/3/3 EKHS
Enquiries: **Dr. H. Nangombe**

Date: 05 February 2019

Ms. Eine K.H. Sirongo
P.O. Box 26964
Windhoek

Dear Ms. Sirongo

Re: Experiences of patients with extensive drug resistant tuberculosis regarding prolonged isolation at TB ward, Katutura Intermediate Hospital, Windhoek.

1. Reference is made to your application to conduct the above-mentioned study.
2. The proposal has been evaluated and found to have merit.
3. **Kindly be informed that permission to conduct the study has been granted under the following conditions:**

3.1 The data to be collected must only be used for academic purposes;
3.2 No other data should be collected other than the data stated in the proposal;
3.3 Stipulated ethical considerations in the protocol related to the protection of Human Subjects' should be observed and adhered to, any violation thereof will lead to termination of the study at any stage;
3.4 A quarterly report to be submitted to the Ministry's Research Unit;
3.5 Preliminary findings to be submitted upon completion of the study;

3.6 Final report to be submitted upon completion of the study;

3.7 Separate permission should be sought from the Ministry of Health and Social Services for the publication of the findings,

4. All the cost implications that will result from this study will be the responsibility of the applicant and **not** of the MoHSS.

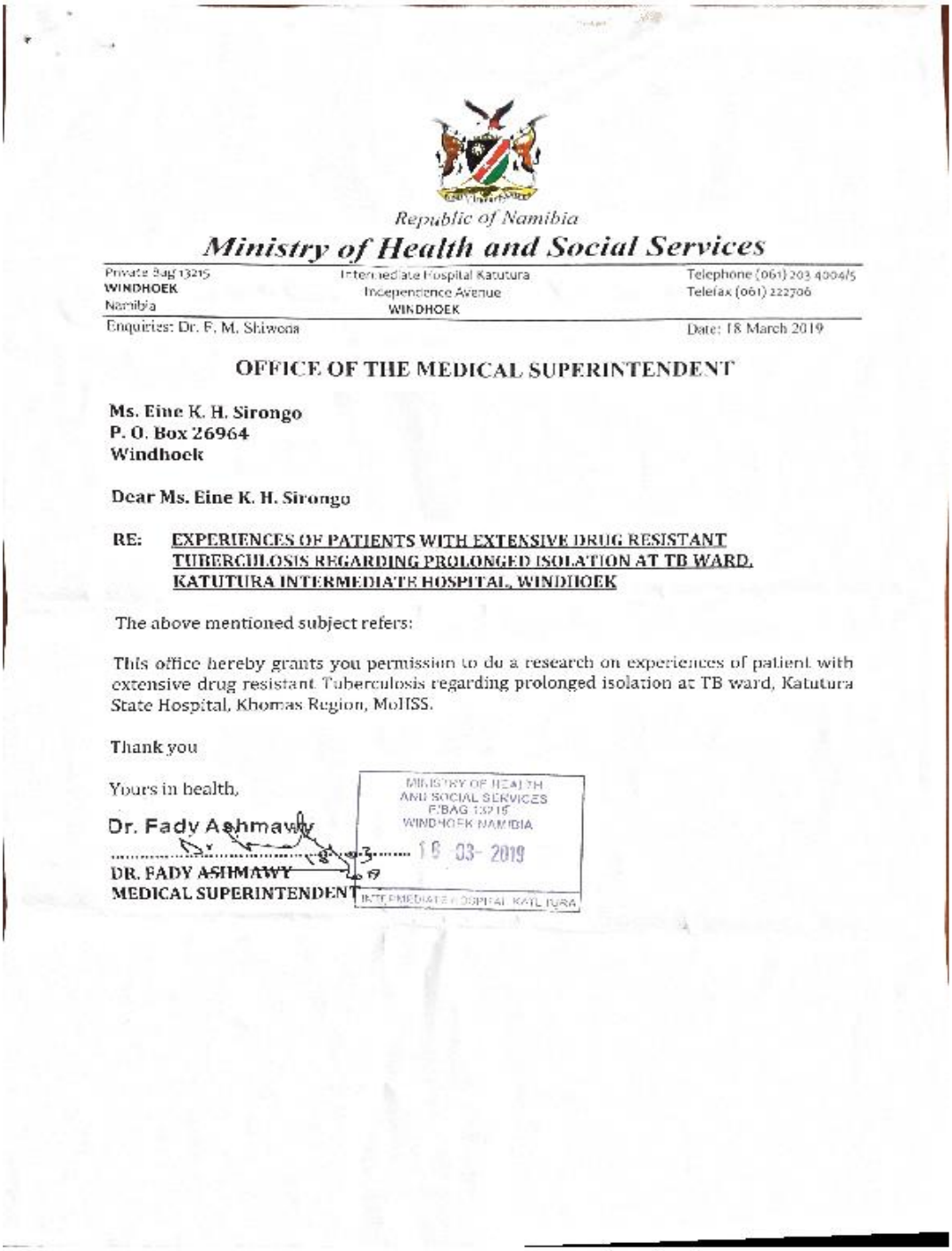
Yours sincerely,

PERMANENT SECRETARY MINISTRY OF HEALTH & SOCIAL SERVICES

Mr. Ben Nangombe
Permanent Secretary

"Health for All

Annex 4: Permission letter from the superintendent at ba selected hospital in Namibia



Republic of Namibia

Ministry of Health and Social Services

Private Bag 13215
WINDHOEK
Namibia

Intermediate Hospital Katutura
Independence Avenue
WINDHOEK

Telephone (061) 203 4004/5
Telefax (061) 222706

Enquiries: Dr. F. M. Shiwona

Date: 18 March 2019

OFFICE OF THE MEDICAL SUPERINTENDENT

Ms. Eine K. H. Sirongo
P. O. Box 26964
Windhoek

Dear Ms. Eine K. H. Sirongo

RE: EXPERIENCES OF PATIENTS WITH EXTENSIVE DRUG RESISTANT TUBERCULOSIS REGARDING PROLONGED ISOLATION AT TB WARD, KATUTURA INTERMEDIATE HOSPITAL, WINDHOEK

The above mentioned subject refers:

This office hereby grants you permission to do a research on experiences of patient with extensive drug resistant Tuberculosis regarding prolonged isolation at TB ward, Katutura State Hospital, Khomas Region, MoHSS.

Thank you

Yours in health,

Dr. Fady Ashmawy

MINISTRY OF HEALTH AND SOCIAL SERVICES P/BAG 13215 WINDHOEK NAMIBIA
19 03 2019
INTERMEDIATE HOSPITAL KATUTURA

DR. FADY ASHMAWY
MEDICAL SUPERINTENDENT

Annex 5: Consent form

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

ANNEX 5

UNAM
UNIVERSITY OF NAMIBIA

TITLE OF THE RESEARCH PROJECT: Experiences of Patients with Extensive Drug Resistant Tuberculosis regarding prolonged isolation at TB ward, Katutura Intermediate Hospital, Windhoek

REFERENCE NUMBER:

PRINCIPAL INVESTIGATOR: Ms. Eline Sirongo

ADDRESS: Po box 26964, Windhoek

CONTACT NUMBER: 0813822126

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the Research Ethics Committee at The University of Namibia and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and Namibian National Research Ethics Guidelines.

1. What is this research study all about?

a) *Where will the study be conducted; are there other sites, total number of participants to be recruited at your site and altogether.*

The study will be conducted in Katutura Intermediate hospital at TB isolation ward. The number of participants will be determine by data saturation.

b) *Explain in participant friendly language what your project aims to do and why you are doing it?*

The aim of this study is to find out how you feel about staying for long in the hospital. The purpose of the research is to gain insight into the experiences of people who have been admitted for a long period in isolation. The study will contribute to create awareness of the experiences of being admitted in isolation. That will help to get a better understanding of how to take care of you when you are admitted for a long period of time.

Explain all procedures.

The participation in this study will require 40-50 minutes of your time. The procedure includes responding to questions on how you feel being isolated for a long period of time..

c) *Explain any randomization process that may occur.*

The process of data collection will not use the process of randomization

d) *Explain the use of any medication, if applicable.*

No medication will be used in this study.

2. Why have you been invited to participate?

a) *Explain this question clearly.*

You are invited to participate because you have the experience of being isolated for long

3. What will your responsibilities be?

a) *Explain this question clearly.*
This study wants you to answer a question you will be asked and depending on your answer, some questions will rise up so that you will answer them again.

b) *Explain the duration the participant is expected to participate in the study (i.e. 2 hours, 4 days, etc.)*

The study will allow you to answer questions which will last between 40 to 50 minutes.

There will not be any insurance to cover you. You will be monitored for any signs of distress, should distress occur, the researcher needs to refer you for counselling.

9. Will you be paid to take part in this study and are there any costs involved?

You will not be paid for taking part in the study and there is no fees that you will be charged for taking part in this study.

10 Is there anything else that you should know or do?

The study procedures will comprise of non-invasive and health risk-free interviews. Therefore, there is no need to inform your family practitioner and the medical insurance company that you are participating in a research study. However, if you have any concerns or complaints that have not been adequately addressed by the investigator, you can contact the Centre for Research and Publications at +264 061 2063061; pclaassen@unam.na. In addition, you will receive a copy of this information and consent form for your own records.

11. Declaration by participant

By signing below, I ..... agree to take part in a research study entitled

Experiences of Patients with Extensive Drug Resistant Tuberculosis regarding prolonged isolation at TB ward, Katutura Intermediate Hospital, Windhoek

(insert title of study).

I declare that:

a) I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.

b) I have had a chance to ask questions and all my questions have been adequately answered.

c) I understand that taking part in this study is **voluntary** and I have not been pressurized to take part.

d) I may choose to leave the study at any time and will not be penalized or prejudiced in any way.

e) I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ..... on (*date*) ..... 2019.

c) I understand that taking part in this study is **voluntary** and I have not been pressurized to take part.

d) I may choose to leave the study at any time and will not be penalized or prejudiced in any way.

e) I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ..... on (*date*) ..... 2019.

....

Signature of participant Signature of witness

12. Declaration by investigator

I *(name)* declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use a interpreter. (*If a interpreter is used then the interpreter must sign the declaration below.*

Signed at (*place*) ..... on (*date*) ..... 2019.

....

Signature of investigator

Signature of witness

13. Declaration by interpreter

I *(name)* declare that:

a) I assisted the investigator (*name*) ..... to explain the information in this document to (*name of participant*) ..... using the language medium of (Portuguese, Oshiherero, Afrikaans, etc.)

Annex 6: Interview guide with questions to ask participants during interviews

INTERVIEW GUIDE

Topic: Experiences of patients with Extensive Drug-Resistant Tuberculosis regarding prolonged isolation in TB ward at a selected hospital in Namibia.

1. **Data collection instruments**

- Pen
- Audiotape/ Cellphone
- Fieldnotes
- Interview guide
- A consent form

2. **Introduce myself to the participant.**

- The researcher introduces him/herself and explains the purpose of the interview, address terms of confidentiality, indicate how long the interview will take,
- Emphasize the ethical aspect of research which are
    - ✓ Privacy and confidentiality
    - ✓ Autonomy- voluntary withdrawal at any time from the study.
    - ✓ Anonymity- their identity is going to be safeguarded.
- Sit in a quiet room
- Inform the participants how to get in touch later if they want to and ask them if they have any questions before they both get started.
- Start the tape recorder and start with the interview

The main question:

- What are your experiences regarding staying long alone in the TB ward?

- Could you tell me your daily routine in the ward?
- Can you explain to me the first day how you arrive in the TB ward?
- Can you describe the condition from the time you arrived in the TB ward until this moment?
- What do you say about how your life changed before the sickness and now?
- Tell me, if you could be given a chance to share your experiences with the people who never had your condition, what will you tell them?
-

3. Probing questions

- Can you say more about……?
- Did I hear you well…….?
- Can you explain the part where you said…?

4. **Clarifying questions**

- Am I right if I say you mean…….
- Do you mean**……?**

5. Closing questions

- Is there anything you would like to add?
- Have we missed something you think is important?

Annex 7: Extract from face-to-face individual interviews

1. Demographic Data of P: 2

- Age:……..53 Years
- Gender:…….Male
- Marital status……Married
- In isolation:……..8 months
- Medications:…….....On treatment for XDR-TB
- Education……:……Attended primary only

2. An interview

R: **Can you explain what are your experiences regarding staying long in the TB isolation ward?**

P2: Aye (clearing throat)! when I came in, I came from my the hospital in my region. It is where I started medication. I was put that side (pointing at TB general ward). Yaa, there I was told I had liver disease together with TB. I spent 4 months staying at TB general not knowing where I was until the 5th month is when I knew where I was.

R: **Are you saying that when you were admitted at TB general you did not know where you were for that long?**

P: All 4 months just sleeping in the bed not knowing where I was. The 5th month is when I knew where I was. There (pointing to the side of TB general ward) is where I was diagnosed with liver disease and all other TB and from there I spent 8 months in general TB. They

did not see that I had dangerous TB. From there I left but I could not walk. I started seating and later using a wheelchair. I started using a walking ring. I was there and I started walking, I give thanks because it is not how I was before. For me to come here, yaa, I came looking bad, but now I'm ok because of the medicine I receive, aye! I'm just walking. The help that I got here with the treatment I can see that it brought me to the right way. Because even my weight is about to reach where it was long time there are only few kilograms to reach there

R: **You have mentioned that the medication that you receive here helps you, can you explain how you get this medication?**

P: Anh, yaa! We get medicines on time, most of us get medicine almost at 5 o'clock. They are supposed to bring that time but some nurses instead of bringing it at 5 they bring it at 6 but it is supposed to be like you should have a break before you drink other medicine at 9h00. From the beginning of treatment,if you take medicine without eating then it makes you feel dizzy and nauseas. If food could be nicer then I could not have a problem because sometime they bring food that I don't eat then I just throw it away as I had no choice. Food from home is more nicer than hospital's, there are some of my relatives who used to bring me food from home that is when I can eat and enjoy.

R: **Do you want to say that if your family don't bring you food then you will not eat hospital food?**

P: I have managed to buy myself a frying pan that's where I prepare my own food.

R**: How do you get food to cook for yourself?**

P: I use to go to the market stores to buy my vegetables and all other things.

R: **It is ok if you can explain to me how you get money to buy your glossaries if live here?**

P: Actually, I receive my salary every end of the month as I am a soldier in the government. As you know, we are the people who fought for this country. I did not go ahead with my education because I spent most of my time in exile fighting for this country. There was no time for school…….

R: **If we can both recall, you have mentioned medication used to make you feel dizzy and nauseous. Was there medication to drink or to be injected?**

P:But there are also other medication I get which nurses inject in this small drip (pointing at a heplocl in his chest) here but I don't think it gives me trouble.

R: **Can you explain when that drip was put, and for how long you will have it?**

P: It was put up by the doctor after my medication started and I was told that it will last for a period of two years. This one is good not like injection I used to get on my buttocks for many months back at my region.

R: **Are you saying that you used to get injections on your buttocks for many months? Tell me specifically, for how long have you been injected on your buttocks?**

P: I took it for about eight to nine months and the doctors stopped it because it was giving me problems with hearing……

R: If I heard you correctly, are you saying that the injections you were receiving in the past affected your hearing?

P: Yes

R: **Did the doctor confirmed that it was the injections that caused you to have problems with hearing?**

P: Not really, but the doctor explained to me before I started with the injections that I might have problems with hearing well because that is how the medicine works.

R: **Are you saying that the injections have side effects of damaging your ears?**

P: Yes that's correct.

R: **You have told me that you still receive your salary while you are here, explain to me a little about your family.**

P: I am a married man and I have children and a home.

R: **How do you assist your family while you are here?**

P: Now I have no choice because I am in the hospital, I need to complete my treatment, I always contact the nurses if I have a problem and they always contact the doctor. The doctor can decide whether I can go out of the hospital if my sputum is negative.

R: **Do your family come and visit you here or not?**

P: No, my wife is here and she comes and visit me but not the children. Just as I said, we go to the doctor to ask for some days to go home and doctor may allow me or rejects. The doctor can also allow us (referering to others as well) to go home but we have to listen to doctor as we cannot decide for ourselves.

R: **This means that you can only see your children the time you go home if the doctor allows you to go. How does that make you feel?**

P: It becomes difficult because I used to send money but I don't know whether the money I send is used for good purpose or not. It's better if I am around to see how the money is spent. I cannot go home every time because i want to finish my treatment.

R: **There is a policy that talks about people in your condition should receive incentives from the government in order to assist themselves financially? Do you receive such money?**

P: No, they say that if that person still work then he/she cannot get that money because the salary still come to him/her and cannot be paid double.

R: **Oho, ok are you saying that if you still get your salary then you cannot get that money. Please explain to me how you spend your time in this ward?**

P: In the past I used to stay all day long in the room because if I go out my things will be stolen. There are people who can steal our things here but for now, I can leave the room and go to the barthroom os shoping malls or at church. Because in the room I was put, I got a lock for it so I lock it, but in other rooms others lose their things because they don't lock their rooms. There are some patients who spent 6 months or 8 months sent here are also thieves.

R: **Can you give me examples of what you or other people lose while staying here?**

P: We lost a fridge where we used to put even our cool drinks or cold water but now there is nothing. Even food or cell phones can be stolen.

R: **If I head you well you have mentioned that you can go to church. How often do you attend church services?**

P: But me. I was not a person who used to go to church because I never believed in it, but since I became very sick it is when I believed that God existed because I could see it as my sickness was may be a punishment and now that I am better I pray every time. I don't miss going to church and pray……..

R: **Explain to me in short, how your life is and before this condition that brought you here?**

P: My life has changed (coughing), from the beginning, I used to drink alcohol but now, I decided that alcohol is a problem. I pray that others who are still drinking, I know TB comes from the air but the first thing is that air if that alcohol is too much then it becomes worse. It is bad luck for the ones who don't take alcohol but it becomes well. TB is not something good. It causes one's life. I have to take my medicines. Medicine becomes alot sometimes, even two tablets are too much. It is because of your health it's good to others and even me as we are discharged then I say I am fine then I start drinking alcohol like that it's me bringing problems to yourself. I see that it is my luck to reach up to here because I could have died long back. I see that I must stop drinking alcohol completely so that I stay with my wife and my children unless there is maybe an accident but not in the name of alcohol, I don't see that coming.

R: **Ok, for you to stay in the hospital for long, how does that make you feel?**

P: It is bad because I am not together with my family in my house and secondly thing is that I am neither with my colleagues to work and i cannot be able work while in this condition.

R: **What really gives you hope to go on?**

P: Yaa, I thank God I can see that there is nothing that cannot finish. It will come to an end we will meet when God calls us. It is really a long time I am sick. What gives me courage is talking my medicines and eating food because such condition asks one to eat and it likes you to drink water so that water remains in your body.

R: **Are you saying that what gives you hope is that you are able to drink your medication, drink water and eat food?**

P: And also have a good relationship with others because I have not seen other people not working together here. But there are some people who did not accept to take medicines because they just put them(referring to medicine) in their bags. Doing that shows that a person himself does not understand.

R: **Are you saying, if I correctly heard you well that there are people given medicine to drink but they hide them?**

P: Yaa, a person like that (referring to people who throw/ hidde their medicines) does not understand and they also do not want their life. You must continue taking medicine until you become well and if you see that medicine is making you not to feel better, just tell the doctor to change them……, to stay here, some people who never wanted to take their medication lost their live……., we lost others just in the name of not wanting to drink medicine…….. How can a person get well if he/she does not take medicine? I see that they have no knowledge.

R: **If you were to share your experience with other people in the community, what will you tell them?**

P: What I can tell them is that, if a person did not suffer from the same condition then they will not know. This condition is not caused by a person him/herself but it is by God. …….Just drink your medicine (repeating the words)……..You should put your thoughts together and say I will drink my medicine until I get healed..... There is nothing that does not come to an end…….My brother and sisters just try stop drinking alcohol and consumme fruit and eat good healthy food……, It is this drinking alcohol which is not good. Nhn! like that you are just killing your body then you end up no way while you were supposed to progress. These are the advices I can give others unless you have something else.

R: You are saying "if a person did not suffer from the condition, then they will not know how it feels" I understand that you are the best person to explain the condition because you went through the experience and have more to share, can you please elaborate more on this?

P: The thing I want to add is that I see that I know my condition very well. I need when I live this place to join others at work I will be the one to give advice to them….. I could tell them how good the state hospital manage this condition compare to the private hospital…… I want to be involved in the ministry so we can advise the people for example the good time to share my experiences is on the day we commermorate tuberculosis…….

R: **Is staying long in this place good for you?**

P: No! Yaa, the thing is, staying here is ok but, you feel alone and you just the days are longer as we spend most of our time sleeping and eating. The other problem we have here is that sometimes the place is very dirty and if I may to take you to the bathrooms you will see it

for yourself.The young people who got the job for cleaning don't even do it. We need some little things like gym, but we need some other things so that if one needs to run (pointing at one big machine) some of those machines don't even work. There are a lot of things needed here…….. the things are broken, they don't work anymore. You cannot use the toilet any longer but it's only a pipe needed. Hnn there is no hot water during winter. The geysers are there but no hot water and we cannot bath cold water during cold season…..It's only plastics covering them but the toilets are just an easy thing to fix. Properties of the hospital like those benches (pointing at the benches). No one locks them, all locks are taken.

R: **In your opinion, who do you think caused all these problems?**

P: May be they were taken by other people like volunteers, they are very dangerous.

R: **Why do you say that volunteers are very dangerous?**

P: Some volunteers are thieves because they know that they don't get paid therefore they do such things(steal), they take things to their sharks (corrugated houses). The government should use people who are not volunteer instead of them because if you use a volunteer what do you expect.

R: **Ayee, we spoke many things. Now we are finished I thank you so much.**

P: Ok, I thank you more.