EXPLORING PERCEPTIONS OF MULTI DRUG RESISTANT TUBERCULOSIS PATIENTS AND THEIR SUPPORTERS ON HOSPITAL BASED AND AMBULATORY CARE TREATMENT MODELS

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By

Lucia Njovu

A Dissertation Submitted in (partial) Fulfillment of the Requirements for the Degree of Master of Arts (Health Policy and Management) of

Muhimbili University of Health and Allied Sciences

October, 2017

CERTIFICATION

The undersigned certifies that he has read and hereby recommends for acceptance by Muhimbili University of Health and Allied Sciences a dissertation entitled ***"Exploring Perceptions of Multi Drug Resistant Tuberculosis Patients and Their Supporters on Hospital-based and Ambulatory Care Treatment Models"*** in (partial) fulfillment of the requirements for the Degree of Master of Arts (Health Policy and Management) of the Muhimbili University of Health and Allied Sciences.

_____

Dr. Mughwira Mwangu, (PhD)

(Supervisor)

_____

Date

DECLARATION AND COPYRIGHT

I, **Lucia Njovu,** declare that this **dissertation** is my own original work and that it has not been presented and will not be presented to any other university for a similar or any other degree award.

Signature…… **Date**…….

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DEDICATION

This work is dedicated with love to my beloved family. It specifically goes to my daughters, Asmin and Abqurah, and my lovely husband, Ibrahim Mbinga, thank you for your prayers and support throughout my studies; May the Almighty God bless you!

ABSTRACT

Background: Despite the existence of several studies reporting on the challenges and benefits of MDR TB patients being treated under hospital and ambulatory care models, there is a dearth of information on patients' and treatment supporters' perceptions regarding the effectiveness of the models.

Methodology: A cross sectional study was conducted whereby thirty-six (36) participants were interviewed. This number included 21 males and 15 females from three Municipalities in Dar es Salaam and the Kibong'oto Infectious Disease Hospital. The selected facilities were chosen because, Dar es Salaam is one of the phase one ambulatory site and has many patients compared to other regions and KIDH was chosen because is the only facility where MDR TB patients are hospitalized. The data collected were analyzed using thematic approach. Permission to conduct this study was sought from the Institutional Review Board (IRB) at the Muhimbili University of Health and Allied Sciences (MUHAS). Permission to interview study participants was sought and granted using consent form. The study respondents were purposefully selected. In-depth interviews (IDIs) were used to collect primary data. Data was recorded, transcribed and later manually analyzed qualitatively.

Results: The analysis of the study findings has generated themes that explain the perceptions of MDR TB patients and treatment supporters' regarding the models. These themes are: - the first section presents introduction, the second section is on socio demographic information of the study participants, the third section presents patients' perceptions on ambulatory care model and hospital based model of MDR-TB treatment (care and treatment, opportunity to learn about drug use ,patients and relatives awareness of the model, stigma) . The fourth section addresses the treatment supporters' perceptions on the ambulatory care model and hospital based model (family support, economic status of relative, misconception about hospital care model). The firth section covers the perceived benefits for MDR TB patients receiving treatment under hospital and ambulatory care models (health improvements, availability of basic needs, close follow up by family members). The last section presents the results on the perceived challenges for MDR TB patients receiving treatment under hospital

and ambulatory care models (inadequate medication and supplies, distance to the facility, inadequate staffs, unfavorable environment and infrastructures and limited choice of food)

Conclusion and Recommendation: Perceptions of patients and supporters regarding the models, benefits and challenges faced by patients and relatives are worth explored because it will help to institute interventions or improvements that might be introduced as there are scientific evidences to support them, these models of MDR TB treatment are all of crucial importance for the betterment of patients' health. The models complement each other. Therefore, it is recommended that the Government should strategize i.e. increasing funding to TB clinics to utilize both models for the overall successful treatment outcomes.

In conclusion it can be argued that the perceptions of patients and their supporters on the benefits and challenges of the two models are both positive but also show challenges for both models. Both models are however considered important and complement each other.

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ABBREVIATIONS

DOT	Direct Observed Therapy
DR-TB	Drug Resistance Tuberculosis
DST	Drug Susceptible Testing
DTLC	District Tuberculosis and Leprosy Coordinator
FGD	Focused Group Discussion
HIV	Human Immunodeficiency Virus
KIDH	Kibong'oto Infectious Disease Hospital
KNCV	Koninklijke Nederlandse Centrale Vereniging tot bestrijding der Tuberculose
MDR TB	Multi-drug-resistant tuberculosis
MoHCDGEC	Ministry of Health, Community Development, Gender, Elderly & Children
MUHAS	Muhimbili University of Health and Allied Sciences
NTLP	National Tuberculosis and Leprosy Program
PATH	Program for Appropriate Technology in Health
PMDT	Programmatic Management of Drug Resistant Tuberculosis
RMP	Rifampicin
RTLC	Regional Tuberculosis and Leprosy Coordinator
TB	Tuberculosis
WHO	World Health Organization
XDR TB	Extensive Drug Resistant Tuberculosis

DEFINITIONS OF TERMS

Ambulatory care

The care that takes place as a day attendance at a healthcare facility or at the patient's home. Patient care is provided on an outpatient basis, including diagnosis, observation, consultation, treatment, intervention, and rehabilitation services. This type of care may include the use and application of advanced medical technology and procedures even when provided outside of hospitals.

Community based model

It is a model in which patients receive full course of treatment under direct observation on an ambulatory basis, irrespective of their sputum smear/culture status, at a venue in the community, such as the patient's or relative's household, workplace, or even a nearby park. The venue is agreed between the patient and the DOT provider. The community-based care is used synonymously with the ambulatory care model.

Hospital based model

This is the model whereby patients stay in hospital only to receive treatment until the end of the intensive phase or until they convert to smear negative/culture negative status.

Tuberculosis

Tuberculosis (TB) is caused by bacteria (Mycobacterium tuberculosis) that most often affect the lungs. Tuberculosis is curable and preventable. TB is spread from person to person through the air. According to the World Health organization (WHO, 2015), when people with lung TB cough, sneeze or spit, they propel the TB germs into the air.

Multi Drug-Resistant tuberculosis (MDR-TB)

Multidrug-resistant TB (MDR-TB) is the type of TB that does not respond to at least isoniazid and rifampicin, the two most powerful anti-TB drugs. The bacteria that cause tuberculosis (TB) can develop resistance to the antimicrobial drugs used to cure the disease (WHO 2015).

Perception

Is the way in which a phenomenon is regarded, understood or interpreted. It is the act or faculty of apprehending by means of the senses or of the mind; cognition; understanding. (1)

Patient

A person receiving or registered to receive medical treatment.

Treatment supporter

A person who is accompanying the patient for daily treatment and follow up.

Patient's relative

A relative is a person who is part of the patient's family. Parents, siblings, uncles, aunts, grandparents, cousins, nieces and nephews are all relatives. A relative can be connected to a certain family through blood or by marriage.

CHAPTER ONE

1.0 INTRODUCTION

1.1 Background of the problem

Tuberculosis (TB) is caused by bacteria (Mycobacterium tuberculosis) that most often affect the lungs. Tuberculosis is curable and preventable. TB is spread from person to person through the air. When people with lung TB cough, sneeze or spit, they transmit the TB germs into the air (2). TB is a disease of poverty..It is widely recognized that the poorer the community, the greater the likelihood of being infected with the TB germ and developing clinical disease. A lack of basic health services, poor nutrition and living conditions all contribute to the spread of TB and its impact upon the community (3)

Multi-Drug-Resistant Tuberculosis (MDR-TB) is a form of TB disease caused by bacteria that are resistant to treatment by at least two of the most powerful first-line anti-TB drugs, isoniazid (INH) and rifampicin (RMP) (4). At the global level in 2015, there were reported an estimated 480 000 new cases of MDR-TB and an additional 100 000 people with mono-rifampicin-resistant TB (susceptible to INH) who were also eligible for MDR-TB treatment (4). India, China and the Russian Federation accounted for 45% of these cases (5). India, which is one of the leading countries in TB, carries one quarter of the global burden of multi-drug resistant TB (MDR-TB) accounting for 27% of global TB notifications in 2014 (4).

South Africa has one of the largest drug-resistant TB epidemics in the world whereby the KwaZulu-Natal Province has emerged as a global TB hotspot, drug-resistant TB, and MDR-TB mortality rates of 71% (6). Uganda is also having a high burden of TB with approximately 63 000 TB cases in 2011 (183/100 000 population). An estimated 1.4% of new and 12% of previously treated TB cases are MDR, which means that there were around 1000 new cases of MDR TB in 2011 (7). In Tanzania the number of MDR TB cases detected has been exponentially increasing every year from 15 MDR TB cases in 2009 to 272 in 2015 (8).

Management of MDR TB patients can be through different models depending on the patient's condition. If the patient is too sick, hospitalization is inevitable; but when the patient is

clinically stable, he/she can be served through ambulatory services (9). The ambulatory care model is of two types: clinic-based model whereby patients receive the full course of treatment on an ambulatory basis at an outpatient healthcare facility irrespective of the sputum smear/culture status. The other type is community-based model where patients receive full course of treatment under direct observation on an ambulatory basis irrespective of their sputum smear/culture status at a venue in the community such as the patients' or relatives' household, workplace, or even at a nearby park. The venue is agreed between the patient and the DOT provider.

Under the hospital based model, patients stay in the hospital only to receive treatment until the end of the intensive phase or until they convert to smear negative/culture negative status (10). In most cases, this requires 8 months hospitalization and thereafter the patient is discharged to receive care at nearby healthcare facility. Hospitalizing the MDR TB patients for intensive treatment is considered good except for the few challenges, such as limited bed capacity, encountered under this model. In Tanzania, the Kibong'oto Infection Hospital is the only facility for MDR TB patients in the country with only 90 bed capacity, a situation that causes delay in treatment initiation (11).

In Tanzania, ambulatory care for initiation model is currently being introduced whereby seven regions, including Dar es Salaam, are in the first phase of implementation. In Dar es Salaam, the implementation roll out takes place in Temeke Municipality (Rangi Tatu Hospital and Tambukareli Dispensary), Ilala Municipality (Prison Dispensary) and Ubungo Municipality (Sinza Hospital) (11). MDR TB cases detected and the enrolment for treatment in Tanzania are shown in Figure 1 below. The numbers show that from 2009 to 2015 enrolment for MDR TB treatment has been exponentially increasing.

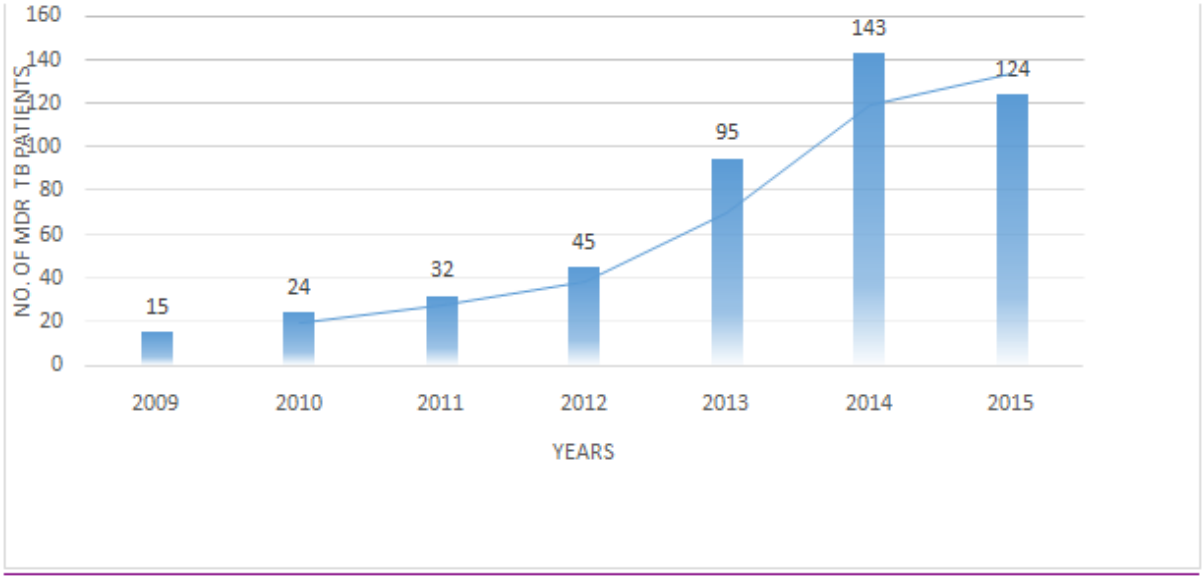


Figure 1: Trend of MDR TB Patients Enrolment 2009 – 2015

Source: NTLP Annual Report, 2015 (12)

In order to scale up the ambulatory model of TB care in efforts to augment the existing limited hospital-based model capacity with other models and ensure a patient-centered approach, it is important to explore the experiences and perceptions of both the patients and their supporters on the two models. This exploration will provide the necessary insights which could form the basis for improving the interventions, particularly the ambulatory model.

1.2 Problem Statement

Studies show that understanding patient' and treatment supporters' perceptions regarding the models is pertinent toward successful delivery of healthcare services to MDR TB patients. Such understanding provides the basis for formulating appropriate strategies for improving access to care and enhancing uptake of the services (7).

In Tanzania, MDR TB patients are being hospitalized at the Kibong'oto Infectious Disease Hospital for 8 months for the intensive phase, followed by 12 months of ambulatory continuation phase. Currently, Tanzania has introduced the ambulatory care model for the treatment of multi-drug resistant tuberculosis in order for patients to receive care during the initialization/intensive phase at nearby locations. However, there is a dearth of empirical research on MDR TB patients' and treatment supporters' perceptions regarding the effectiveness of the models being implemented.

Each model has its own benefits and challenges. The hospitalization model has admittedly led to better treatment outcomes as it has resulted in low default rates (benefit). However, the current situation shows that the Kibong'oto National TB Hospital has a limited bed capacity of 90 beds to accommodate all the MDR TB cases in the country. This situation results in the hospital not admitting other patients who could equally qualify for intensive care These issues need to be explored further to generate a better understanding of the advantages and challenges of the two models.

So far, little is known about patients' and their supporters' perceptions regarding the two models of MDR TB care in Tanzania. This situation could mean that any interventions or improvements that might be introduced would be lacking scientific evidence, especially from the perspectives of the beneficiaries (patients and their care takers). Therefore, this study was intended to explore patients' and supporters' perceptions about the models of MDR-TB patients who are receiving treatment under hospital-based and ambulatory care models so as to help formulate appropriate strategies for improving access to care and enhance uptake of the services.

1.3 Conceptual framework

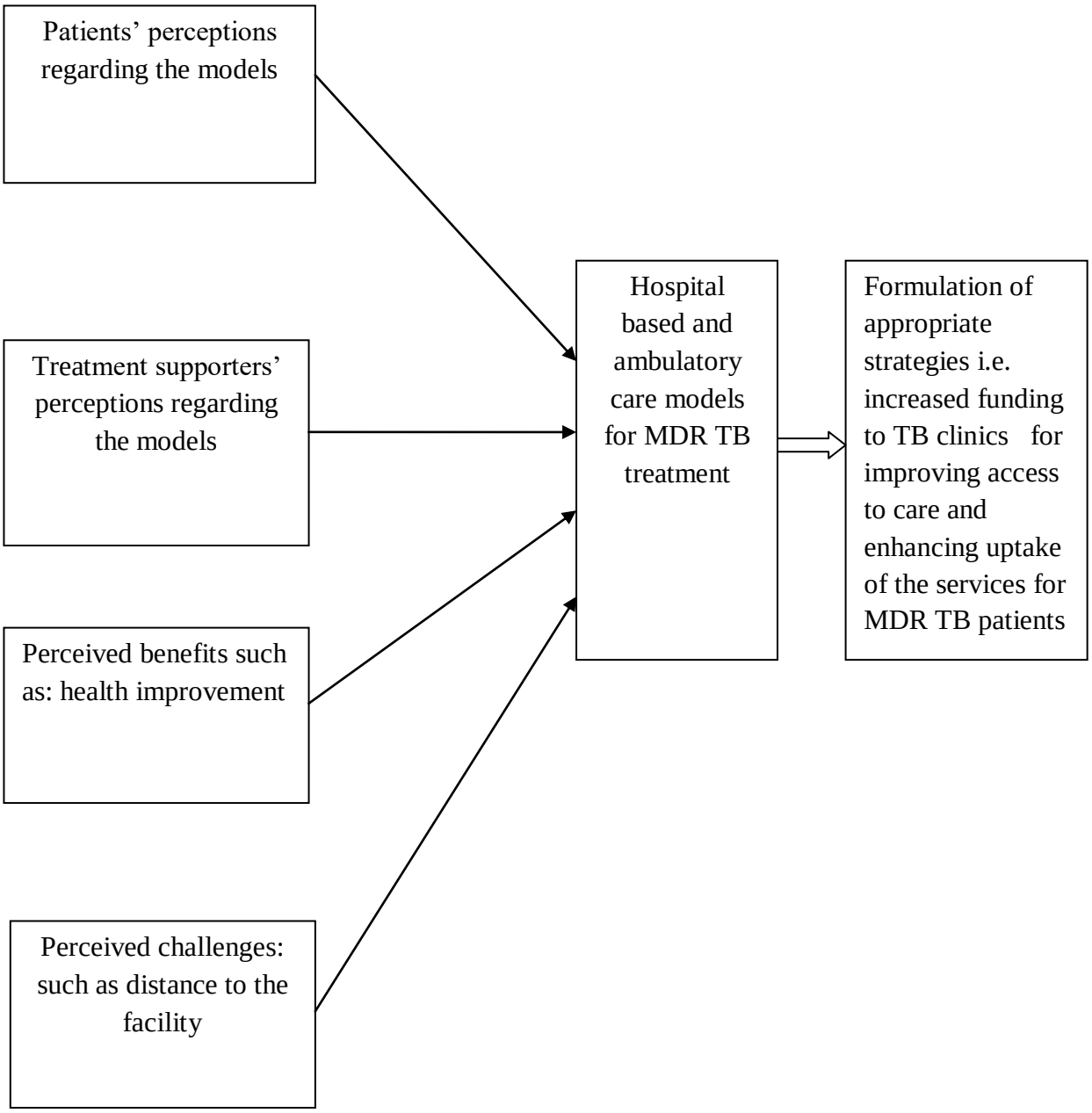


Figure 2: Conceptual Framework Illustrating MDR TB Patients' and Supporters' Perceptions about Receiving Treatment under Hospital-based and Ambulatory Care Models.

Source: Researcher's own formulation.

The focus of the conceptual framework is on perceptions and how such views will enhance uptake of the services for MDR TB patients. The four blocs – which are patients' perceptions, treatment supporters' perceptions, and perceived challenges towards MDR TB treatment to patients, if well addressed, will provide positive feedback with regards to these two models of TB care and improve in provision of care for MDR TB patients.

1.4 Significance of the study

This study is beneficial in several ways. Firstly, it explores the perceptions of patients and their supporters about MDR-TB treatment using the two models. Such investigation has largely been overlooked but it may prove crucial in planning further interventions aimed at combating the disease in the country. Secondly, the investigation into the perceptions of multi-drug resistant tuberculosis patients and their treatment supporters on receiving treatment under hospital-based and ambulatory care models will shed light into possible planning to ensure adherence for better treatment outcomes.

The findings of this study will help the Government, policy and decision makers in the Ministry of Health Community development, Gender, elderly and children (MoHCDGEC) through the National Tuberculosis and Leprosy Program (NTLP) to formulate appropriate strategies for successful programmatic management of MDRTB in the country.

1.5 Research Questions

1.5.1 Main research question

What are the perceptions of Multi-Drug Resistant Tuberculosis patients and their supporters about receiving treatment under hospital-based and ambulatory care models?

1.5.2 Specific research questions

1. What are the MDR-TB patients' perceptions on ambulatory care model and hospital-based model of care?
2. What are the MDR-TB treatment supporters' perceptions on ambulatory care model and hospital-based model?

3. What are the perceived benefits for MDR TB patients receiving treatment under hospital and ambulatory care models?
4. What are the perceived challenges encountered by Multi-Drug Resistant Tuberculosis patients receiving treatment under hospital based and ambulatory care

1.6 Objective

1.6.1 Broad Objective

To explore perceptions of multi-drug resistant tuberculosis (MDR-TB) patients and their supporters on receiving treatment under hospital-based and ambulatory care models.

1.6.2 Specific Objectives

1. To analyze patients' perceptions on ambulatory care model and hospital based model.
2. To describe treatment supporters' perceptions on ambulatory care model and hospital based model.
3. To identify perceived benefits for MDR TB patients receiving treatment under hospital and ambulatory care model.
4. To identify perceived challenges for MDR TB patients receiving treatment under hospital and ambulatory care model.

CHAPTER TWO

2.0 LITERATURE REVIEW

2.1 Introduction

This chapter constitutes a range of reviewed empirical literature on what others have done in the area of Multi Drug Resistant Tuberculosis. The chapter reviews issues related to patients' and their caretakers' experiences and perceptions in connection with hospital based and ambulatory based multi drug resistant TB services provided according to available literature.

2.2 Patients' Perception on Ambulatory Care Model and Hospital-based Model

2.2.1 Psychosocial Support for the TB patients

Most patients view the ambulatory care model as more conducive to recovery than the hospital-based model because it enables more psychosocial support given the closeness of family and friends and perceived connectedness in comparison with feelings of isolation and loneliness associated with hospital admission. It is further argued that patients who stay at home have greater possibilities of being visited by relatives and friends. Through such visits the patients are given moral support and encouragement to continue with the treatment (7).

Patients' perception of the ambulatory care model is seen as highly favorable to for three main reasons: it is regarded as more conducive to patient recovery, it enhances psychosocial support (influence treatment outcome), and it allows more free time for patients and caretakers to handle other activities. Patients interviewed mentioned the importance of being able to have free time for other activities and they thought of ambulatory treatment and care to be patient-centered, accessible, acceptable and feasible (7).

2.2.2 Treatment Outcome

In the province of KwaZulu-Natal, South Africa, Loveday *et al.*, (2015) reported that the ambulatory care model was considered more effective than the hospital-based model by most interviewed patients as evidenced by earlier treatment initiation, thus reducing patient default

and optimizing treatment outcomes. Therefore, higher successful treatment outcomes and lower default rates in ambulatory-based model may suggest that ambulatory care may address patients' needs more successfully for its allowing patients to stay home and affording them easier to access, convenient, as well as allowing family support. This experience is contrary to the centralized hospital-based MDR TB treatment approach where the same study reported a high default rate, and limited hospital bed capacity which leads to late treatment initiation with reports that in the year 2007, only 32% of MDR-TB patients accessed treatment in the province (6). This situation is experienced in other countries as well, including Tanzania.

A study done by Gerard *et al.,(*2017) titled Health system factors influencing Management of Multi Drug-Resistant Tuberculosis in four European Union countries which are Austria, Bulgaria, Spain, and the United Kingdom concluded that patient-centered approaches with strong inter-sectoral collaboration that address patients emotional and social needs; motivated and dedicated healthcare workers with sufficient mandate and means to support patients are the crucial important aspects for the successful treatment of MDR TB patients at their countries(13)

2.3 Treatment Supporter's Perceptions on Ambulatory Care Model and Hospital-based Model

A study done by Burtscher and colleagues (2016) on caregiver perceptions of Drug-Resistant Tuberculosis (MDR TB) treatment and came out with the result that the ambulatory patient-centered approach is more favorable than the centralized hospital-based as it aims at creating the most acceptable and comfortable environment for the patients, their families and caregivers themselves (14).

2.4. Perceived Benefits for MDR TB Patients Receiving Treatment under Hospital-based and Ambulatory Care Models

2.4.1 Engagement in other activities

Ambulatory care model provides free time for both the caretaker and the patient to engage in other activities such as performing small jobs and having social interactions, a study done by Horter *et al.,* (2014) in Uganda (7). Under the hospitalization model a patient cannot have that chance of engaging in other activities because she/he will be in a specialized hospital, cannot go to work or perform other activities compared to when the patient was home.

2.4.2. Breadwinner of the Family and MDR TB Treatment

According to Smart (2010) in his study on decentralized, patient-centered models of delivering treatment and palliative care for people with M/XDR-TB, it was concluded that patients prefer ambulatory care model so that they can remain at home with their families. This is particularly the case if the patient is the breadwinner of the family. Under hospital-based approach of MDR TB treatment, parent(s) and breadwinner(s) generally are taken away from their families, sometimes leaving no one to care for their children. This isolation/ separation of MDR TB patients from their homes creates enormous challenges to children and their parents (patient), while under the ambulatory care model the patient will remain home with his or her family (15).

2.5 Challenges Faced by MDR TB Patients Receiving Treatment under Hospital and Ambulatory Care Models

2.5.1 Barrier to Accessing Care

Horter *et al.,* (2014) report that in Uganda patients mentioned the barriers of accessing treatment in the facility-based ambulatory care model whereby a patient and his or her treatment supporter have to travel daily for treatment countering such challenges including distance, direct and indirect costs (e.g. transport costs). Living costs while in ambulatory and distance from home to the treatment facility were also mentioned as adding indirect costs because of the inability of the patient or caretaker to work. These barriers were seen as being

particularly prohibitive of treatment access because most MDR TB patients come from poor economic backgrounds; they are unable to raise the money to enable them to travel daily to the TB facility for treatment. If the patients were admitted in a centralized hospital, all of these barriers would not have been faced because in those hospitals everything is provided by the government for free.

2.5.2. Isolation, Rejection, Stigma and Discrimination

MDR TB patients are faced with various levels of isolation and rejection from families and communities. The stigma could go as far as leading to loss of employment, reduced education opportunities, vulnerability to disability, divorce or spoiled marriage prospects and isolation at home that forbids sharing food, utensils or sleeping space. Stigma attached to TB is caused by the severity of the illness, fear of infection and myths about its transmission, prejudice, lack of access to services, ignorance, irresponsible media reporting, and by the disease being confused with Human Immunodeficiency Virus (HIV) which is associated with perceived sexual misconduct.

According to Tadesse *et al.,* (2016) on the study "on stigma against TB patients" in Addis Ababa, Ethiopia, apart from community members and family stigma at home, there is also a self-stigma that was observed among TB patients in Ethiopia. TB patients in the country would cut off themselves from dealing with others preferring isolation to avoid being stigmatized. Moreover, the same study reported that some patients under the ambulatory care model mentioned that they did not experience any form of isolation from family members while a few patients being treated under the hospital-based model reported experiencing suffering besides the burden of the disease. He complained about separation from family; he eats alone, sleeps alone and lives alone, as nobody came close to him. Moreover, his friends and family have totally avoided him since he was admitted at the hospital (16).

In Uganda, stigma towards MDR-TB patients was observed, but the stigma perceived or enacted was not due to the MDR-TB itself but rather its association with HIV symptoms that were perceived as being similar for both conditions (7). Patients reported experiencing considerable stigma and discrimination on account of their disease, especially on the

ambulatory care model. The obvious cause of discrimination is the community fear of being infected. In hospital-based model, stigma and discrimination were not observed as the wards were filled by MDR TB patients of same status only. Moreover, the lack of adequate knowledge about the cause, spread, and treatment of the disease leads to increased apprehension of stigmatization, and patients become averse to securing proper treatment (17).

According to WHO (2014), the hospital-based model of care for MDR TB patients requires proper infection control measures in place to reduce to a minimum the risk of nosocomial transmission to staff and other patients. In many low-resourced areas, infection control measures are poor or even absent. Hence, working in a hospital or being hospitalized in these settings can be a significant risk factor for MDR-TB infection and other infectious diseases.
Furthermore, hospitals should also provide or enable access to all social support services needed by patients, including adequate food, a proper heating system in cool areas and fans or cooling systems in hot climate (10). This is however recognized as a challenge in poor resource countries. However, a national wide cohort study in Nigeria concluded that infection control measures were taken seriously in the hospital wards, including environmental and administrative measures to prevent nosocomial transmission. In general, there were ventilators in all the wards and staff used N95 respirators whenever they came into contact with the patients irrespective of the culture status. As a results, there were no nosocomial transmission reported at the hospital (18). With good treatment outcomes reported, high treatment adherence rates among patients and the absence of hospital infection, the hospital-based care of MDR TB treatment is well functioning in Nigeria.

2.5.3 Transmission of Diseases to the Community

Horter *et al.,* (2014) further explain that community members were asked about their fear of contracting MDR TB for staying with patients under ambulatory care treatment plan. None of the interviewed community members showed or expressed such of being infected with the diseases for simply staying with MDR TB patients attending clinic for treatment (7).

In concluding this chapter, it can be observed that the surveyed literature shows that that there is inadequate information, particularly in Tanzania, regarding patients' and their caretakers' perceptions about transmission of MDR TB at households where patients reside.

CHAPTER THREE

3.0 METHODOLOGY

3.1 Introduction

This chapter presents the methods that were used in conducting this study. It features the study design, study area, study participants, selection of study of participants, data collection methods, data collection plan, trustworthiness of the study, data analysis plan, ethical considerations and study limitations.

3.2 Study Area

3.2.1 Dar es Salaam

Dar es Salaam is Tanzania's largest city as well as the most important business center. The city consists of five administrative districts (commonly known as municipalities): Kinondoni, Ilala, Temeke, Kigamboni and Ubungo. It has a total population of 4,364,541 with an annual population growth of 5.6% (NBS 2013). The study was conducted in Dar es Salaam in its three (3) municipalities which are Ilala – Prison dispensary, Temeke- Mbagala rangi tatu hospital, and Ubungo – Sinza hospital

3.3.2 Kibong'oto National Tuberculosis Hospital (KIDH)

KIDH is a specialized hospital for TB and MDR TB which is located in Siha district in Kilimanjaro region. Kibong'oto was chosen because it is the only facility in the whole country where the researcher managed to obtain comprehensive information of MDR TB patients who are hospitalized for long periods of time. The relatives of the patients who were interviewed for this study were those who visited their relative with MDR TB at KIDH. Kibong'oto Hospital is the only facility in the country that MDR TB patients are hospitalized for about eight months for intensive care (19).

On the other hand, Dar es Salaam municipalities were chosen because they have consistently registered a high number of new smear positive cases (due to high prevalence of MDR TB

patients) and Dar es Salaam is among the first administrative areas to implement ambulatory care services in the country. (12).

3.3 Study Design

A cross sectional design using qualitative methods of data collection and analysis was applied in the study. This approach was considered suitable for this study because it explores how people interpret their experiences, how they construct their worlds, and what meaning they attribute to their experiences (20). This qualitative method is considered to be well suited for locating the meanings that people place on the events, process and structure of their lives and their perceptions, presuppositions and assumptions. Therefore, in this study, the researcher explored perceptions of MDR TB patients and their treatment supporters on how they perceived treatment under hospital based and ambulatory care models.

3.4 Study Population

The study population involved MDR TB patients at Kibong'oto Hospital together with MDR TB patients who have been enrolled under ambulatory services found in Dar es Salaam municipalities and their treatment supporters in Dar es Salaam and KIDH.

3.5 Sample Size and sampling methods

3.5.1 Sample Size

A total of 36 patients and relatives (supporters) were interviewed, 17 men and 19 women their ages ranges from (14) fourteen and (70) seventy years of age. Purposive sampling was used to select study participants in the selected Dar es Salaam municipalities as follows: MRDT TB Patients and their supporters were selected because they are in administrative areas to implement ambulatory care services in the country. The region was also chosen because of its having the highest numbers of annual MDR TB cases detected and enrolled for treatment.

The Kibong'oto Infectious Disease Hospital was also selected because is the only facility in the country enrolling MDR TB patients. Participants from the hospital took into consideration

such factors including sex/gender (males and females), occupation, age (older and younger patients from various regions), as well as time spent at the hospital (newly admitted versus 8 months of hospitalization and old patients).

3.5.2 Sampling Techniques

Purposive sampling technique was used to recruit study participants in Ilala, Temeke and Ubungo municipalities whereby the RTLC introduced the researcher to the patients and their treatment supporters, and thereafter the appointment for interview was set. All participants were informed about the purpose of the study and informed consent to participate was obtained from each participant before being interviewed. The researcher first interviewed the patients and followed by their treatment supporters. The interview was done at the health facility and two (2) to three (3) respondents were interviewed per day

Study participants at Kibong'oto Infectious Disease Hospital were purposefully selected whereby patients eligible to participate in the study were those who had stayed between one (1) and eight (8) months regardless of their sex, age, occupation, older and region of origin. These patients gave the researcher their lived experiences under hospitalization model of MDR-TB care and treatment.

Lastly, the KIDH coordinator introduced the researcher to the patients' relatives visiting their patients during the time of data collection. Interview with the treatment supporters were conducted on the same day to hear their opinions about the hospitalization model of MDR TB treatment.

3.6 Data Collection Tools

Semi structured interview guides were used to obtain information from the respondents. The guides contained open-ended questions based on the research questions, objectives of the study and information gained from literature. A tape recorder and handwritten field notes were used to capture information during the interviews which took an average of 40 minutes each. The interview guides were developed in English and translated into Kiswahili to facilitate communication during interviews.

3.7 Recruitment and Training of Research Assistants

Two (2) research assistants who are degree holders in social sciences were recruited and trained for x days. They were all females since it was not possible to get male during the time of research. Factors that were considered for the recruitment include familiarity in conducting qualitative research and good communication skills. Research assistants were oriented for one day on the objectives of the study. They were familiarized with the interview guide, maintaining confidentiality, the use different research tools, including the use of tape recorder, and documentation of the information given during the interview.

3.8 Pretest of Data Collection Tools

Pretesting of data collection tools i.e. semi structured interview guide was done at Tambukareli in Temeke Municipality for the ambulatory care model and Sinza Hospital in Ubungo Municipality for hospital-based care model. A total of 16 participants were recruited for piloting. They consisted of 4 patients (3 men and 1 woman) and 4 relatives (2 men and 2 women) representing ambulatory care since the relatives accompanied their patients to the facility; and 4 patients (2 men and 2 women) and 4 relatives (2 men and 2 women) at Sinza hospital representing hospital based. The average time spent for interviewing one respondent was 40 minutes and a total of 6 days were used to pretest the tool. The results from the pretest study provided a clear indication on the responses to the questions; hence they helped to improve the interview guide.

3.9 Data Collection Procedures

Data was collected using qualitative approach. The principal investigator (PI) and two research assistants collected data from patients and their relatives from three Dar es Salaam Municipalities of Ilala, Kinondoni and Temeke, and the principal investigator and one research assistant collected data from Kibong'oto Hospital in Kilimanjaro. The PI was responsible for guiding the discussion while one research assistant was responsible for taking notes, including all non-verbal signs and the other research assistant was responsible for ensuring the tape recorder was functioning well. Each selected study participant was introduced to the research

team. All participants were informed about the aim of the study. Each participant was asked for his or her consent before conducting the interview. Data collection lasted for 35 days.

3.10 Data Trustworthiness

The aim of trustworthiness in a qualitative inquiry is to support the argument that the inquiry's findings are 'worth paying attention to. The trustworthiness of this study was assured based on three dimensions: dependability, credibility and conformability (Polit and Beck, 2012).

Credibility*:* Is the ability of the study to capture what the researcher really aims at studying. This has been achieved by providing rich information about the study. In this study, credibility was ensured through rigorous use of the interview guide ensuring that the questions were properly posed and participants accurately described their experiences. Suitable participants were identified and the researcher adequately explained to each interviewee the essence of the study. The researchers also built enough rapport with the study participants in order to increase their willingness to participate and give the requested information. The interviews were recorded and field notes were taken to ensure that there is no any missing information from the study participants.

Dependability: Refers to the stability of data even if the work is to be repeated in the same context, with the same methods and the same participants. In this study, dependability was ensured through consistent application of the methods of data collection across all study participants to ensure uniformity. Consistency and uniformity were also ensured in data analysis.

Conformability: This ensures as far as possible that the work's findings emanate from the experiences and ideas of the participants rather than the characteristics and preferences of the researcher. In ensuring conformability in this study, the researcher documented carefully and truthfully (with the aid of tape recorders) all the experiences described by the research subjects. Quotes from the informants have been extensively provided to show objectively the responses of the study participants.

3.11 Data Management

Data generated from the interviews were checked and re-checked so as to ensure quality and consistency. All recorded data during the interviews were coded and analyzed according to the emerging themes. The researcher read and re read the transcripts so as to be familiar with the content represented by the informants. The codes were explored to deduce important information and then the interpretation of the findings followed. The management of data was done at a high level of confidentiality as nobody who was not directly involved in the study had access to the collected data. Digital audio recorder and other data are safely kept whereby access is limited to the principal investigator alone.

3.12 Data Analysis

Data were analysed using thematic approach. Thematic decomposition analysis is a specific form of thematic discourse analysis which identifies patterns (themes, stories) within data and theorises language as constitute of meanings and meaning as social (Stenner, 1993). The thematic analytical approach was employed to analyse qualitative data. The following process was followed during data analysis: data recorded during the field was transcribed verbally in written form to make the researcher familiarise with the data and grasp the general idea. Then, the Principal Investigator and Research Assistants created a *Start List* and *Initial Nodes* (codes). Data reduction was done. The nodes helped to identify the features of the data that appeared to be interesting and to find meaningful data. The meaningful data helped in the sorting of themes focusing on broad patterns in the data and combining coded data with the proposed themes. After identification of the themes, the Principal Investigator read and reviewed the coded data so as to know if they had appeared to form a coherent pattern which helped to address key issues in the report (21).

3.13 Ethical Consideration

In this study, the researcher sought ethical clearance from the Muhimbili University of Health and Allied Sciences (MUHAS) Ethical Review Committee in order to obtain the permission to conduct the study. Permission to conduct the study was sought from the office of District

Administrative Secretary of Ilala, Temeke and Kinondoni Municipalities where the Ukonga Prison Dispensary, Sinza Hospital, Mbagala Rangi Tatu Hospital and Tambukareli Dispensary (the implementing health facilities) are situated.

Permission to conduct the study was also sought at Kibong'oto Infectious Disease Hospital. All participants were informed about the purpose of this study and an informed consent to participate was obtained from all participants before being interviewed (written and verbal) and for a 14 year old patient participant consent was sought from the parent (the father of the patient) Required measures to maintain the rights of human subjects in social research – including right to privacy and confidentiality and right to prevention from any type of harm – were carefully considered.

3.15 Dissemination of the Research Findings

The results of this work will be published in academic journals as per KNCV-Challenge TB sponsorship requirements. Publishing this work will help to bring findings to the Government, decision and policy makers in the Ministry of Health, Community Development, Gender, Elderly and Children through National Tuberculosis and Leprosy Program (NTLP) as well as other partners, including KNCV. This dissertation will also be presented at health-related conferences, such as the International Union for TB and other national health conferences. It will also be available at the Muhimbili University of Health and Allied Sciences (MUHAS).

CHAPTER FOUR

4.0 RESULTS

4.1 Introduction

This chapter presents the study findings based on the lived experiences of the patients and treatment supporters concerning their treatment of multi-drug resistant tuberculosis disease (MDR TB). The chapter is divided into six sections. The first section presents introduction, the second section is on socio demographic information of the study participants, the third section presents patients' perceptions on ambulatory care model and hospital based model of MDR-TB treatment. The fourth section addresses the treatment supporters' perceptions on the ambulatory care model and hospital based model. The firth section covers the perceived benefits for MDR TB patients receiving treatment under hospital and ambulatory care models. The last section presents the results on the perceived challenges for MDR TB patients receiving treatment under hospital and ambulatory care models. Each main theme is divided into sub-themes.

4.2 Socio Demographic Information of the Study Participants

Thirty-six (36) participants were invited into this study whereby. Their ages ranged from fourteen (14) to seventy (70) years. Participants aged less than eighteen years had their parents consenting on their behalf. Respondents belonged to different educational levels as presented in the table below**.**

Table1: Demographic Information of Study Participants

Participants' age	
Minimum age	Maximum
14	70
Sex	
Patients (22)	
15 Male	7 Female
Relatives (14)	
6 Male	8 Female
Participants educational background	
Primary education	32
Secondary education	02
College (Diploma & Degree)	02
HIV status	
2 patients were both MDR TB and HIV +	
Total	36

Source: Field data, 2017

4.3 Patients' Perceptions about Ambulatory Care Model and Hospital-based Model

This study was designed to explore perceptions of Multi-Drug Resistant Tuberculosis (MDR TB) patients on receiving treatment under hospital-based and ambulatory care models. The study has found that there have been diverse perceptions from patients receiving treatment under the ambulatory and the hospital care models as follows: -

4.3.1 Patients and Relatives Awareness of the Models

In both the Kibong'oto Infectious Diseases Hospital (KIDH) and Dar es Salaam Municipalities, respondents were asked to explain their awareness regarding the model of

treatment under which they are enrolled. In Dar es Salaam, patients were aware of both models: That is, before the ambulatory model was introduced, patients were taken to Kibong'oto hospital for treatment immediately after they were diagnosed MDR TB. In KIDH, patients were aware of both models of MDR TB care, although the most known to them is hospitalization.

*"I was the first person to be initiated with this service while coming from home. Before that, they told me to get prepared to go to Moshi(KIDH) where other patients were being hospitalized, but then they told me to wait as doctors from Moshi(KIDH) were coming to Dar es Salaam. So, I started treatment here." (*Ambulatory Patient Respondent from Sinza Hospital)

Another ambulatory patient commented:

"I know about the ambulatory model because after they told me that I have MDR TB, they told me I can get the treatment services here at the facility without going to Kibong'oto. " (Patient Respondent from Temeke- Mbagala Rangi Tatu Hospital)

A patient from KIDH added:

"I was being treated at Mkuranga Hospital for normal TB for six months and there was no improvement. I was still sick and then they tested me again and found that I have MDR TB. After the second diagnosis, they told me I can get treated either at Mbagala Hospital or at KIDH. I decided to come to KIDH because I thought of so many things, like distance from Mkuranga to Mbagala, bus fare, and I was worried to infect my family." (Patient Respondent from KIDH)

Patients' relatives from Dar es Salaam Municipalities whose patients were initiated in ambulatory care model of MDR TB treatment demonstrated that they were aware of these models in which their patients are being initiated for treatment. The same observation was made among relatives of patients admitted at KIDH as they showed awareness of both models

although the hospitalization model was the most known to them and is the one they found more appropriate than the ambulatory model.

"They told us that our patient will be staying at home while receiving treatment; although previously patients like ours used to be sent to Kibong'oto for treatment." (Patient's Relative Respondent from Sinza Hospital)

Another ambulatory relative insisted:

*"I was given information about the models of MDR TB care after my husband was diagnosed with MDR TB. We were given health education on MDR TB and the models of treatment we chose was hospitalization." (*Patient's Relative Respondent from KIDH)

The above arguments indicate that patients from both KIDH and Dar es Salaam Municipality MDR TB treatment facilities are aware of these two models. However, nine (9) patients respondents were leaning toward the hospital-based model whereby patients were taken to KIDH

Patients' relatives from Dar es Salaam Municipalities were also aware of the ambulatory model as they were introduced to it by the healthcare workers upon their patients being diagnosed with MDR TB. Respondents from KIDH did not have enough knowledge about the ambulatory MDR TB care model because their relatives with MDR-TB were directly hospitalized.

4.3.2 Care and Treatment

Findings show that there are differences in the level of care and treatment among patients who receive treatment under the ambulatory and the hospital care models of multi-drugs resistant tuberculosis disease. In one hospital, a patient explained that they have enough time to discuss their progress and treatment with healthcare service providers. Healthcare service providers also had the opportunity to monitor patient progress and institute suitable measures for patients whose conditions showed signs of deterioration.

"Healthcare providers are very much concerned about our health; we are being tested for sputum at the end of the month to know if we have converted to smear negative. Once you are converted to smear negative, you are shifted to another ward which makes us to feel more secure." (Hospitalized Male Respondent from KIDH)

Another ambulatory patient from Dar es Salaam explained that they have been receiving good services from healthcare workers but they have little time to talk with them. Once they report at the treatment facility they receive injection and go back home. There is not even time to rest. One patient had the following to say:

"At least after injection they should give us a bed rest. In the beginning, we were given a place to rest, but as days went by the number of patients increased, and now we are no longer given a place to rest. As soon as you are injected, off you go." **(**Patient Respondent from Sinza Hospital)

Under the ambulatory care model, MDR TB patients meet with healthcare providers during their clinic appointments or when they are taken back to the hospital for help in case of emergency. The patients receive treatment in the form of injection. This brings unwanted dizziness and heaviness for some patients and hence a rest is required before departing to their homes. All of the three visited facilities (the initiation ambulatory facilities) do not have room for rest purposes.

4.3.3 Opportunity to Learn about Drug Use

Respondents from KIDH said that they have enough time to learn more about drug use because they are close to the healthcare service providers all the time. In case of any drug reaction, they can report instantly to the healthcare workers so that immediate measures can be taken. Patients also learn from each other; they know about drug reaction. As they stay together, they see each other's progress. One respondent said that:

"We have seen our fellow patient who came here normal, but as the days pass by, they experience side effects like deafness, numbness of hands. Our healthcare experts have

*explained to us that, the situation is caused by drug side effects." (*Hospitalized Male Patient Respondent from KIDH)

During data collection process, the researcher observed that patients under the hospital-based model receive counseling more frequently during treatment. They know how to protect themselves from acquiring new infections; they wear mask all the time and they know how to take their pills (how many with their combinations), hence their chances to heal are also high.

This experience differs from the ambulatory care model in which patients go to healthcare facilities for medications and return home immediately thereafter. Therefore, MDR TB patients receiving treatment under the ambulatory model have inadequate information concerning drug usage and adverse effects.

"It is hard for the patient. We are happy only because it is home, but to say the truth, I wish I could be admitted. You can find that the first up to the fourth month patients are not familiar with the medication. Once you receive injection you will start to feel awful and you have to go home. I think there should be a ward for admitting patients for at least two (2) or three (3) months." (Patient from Sinza Hospital)

MDR TB patients need to know the drugs they are using and their side effects as this will reduce fear as well as facilitate drugs adherence. In order to minimize drug side effects, the patients need to be tested monthly and results should be communicated to them. This should go alongside the provision of continuous health education.

4.3.4 Stigma

Respondents from Dar es Salaam explained that they get good support from family members and relatives. This is especially for those who are married. They are thankful for the support they receive from their partners. However, other respondents complained that they are stigmatized by their relatives, attributing it to their fear of sharing the information about having MDR TB.

"My wife is the one who knows about my situation; we did not tell our relatives what am suffering from. Although they know that am sick and they come to pay me a visit, they do not know what exactly I am suffering from! Others say I am HIV positive." (Patient Respondent from Prison Dispensary)

In addition, two participants under ambulatory care model reported on self-stigma. They reported isolating themselves from other people for the fear that they will infect their family and people around them.

"*I am now staying alone. I sent my family, my wife and daughter away for the fear that I will infect them. But when I get cured, I will bring them back."* (Patient Respondent from Temeke-

Mbagala Rangi Tatu Hospital)

Another ambulatory patient added:

"I divorced my wife not because I do not love her, but I am afraid I will infect her and she is too young." (Patient respondent from Temeke- Mbagala rangi tatu hospital)

Moreover, one ambulatory patient reported being stigmatized by a healthcare worker:

" do you see that nurse! She is the one that stigmatized me. She did not even come near me. I was alone back then; if she enters in this room I will get out/." (Patient Respondent from Temeke- Mbagala Rangi Tatu Hospital)

Patients under the hospital-based model explained that they do not experience stigma because they are more isolated from the general society and some of them do have relatives who visit them. The patients mentioned that healthcare service providers are taking good care of them without stigmatizing them.

"We receive good services from nurses. They come on time and when you call them they come without missing. They even bath the patients and change their clothes; they keep doing that until the patients stands up on their feet. It is unconditional love." (Younger Patient from KIDH).

Moreover, other hospitalized patients reported being stigmatized while at home, which is why they have decided to come to the hospital where they believe they will live comfortably and free from stigma.

"I was stigmatized and discriminated against by my relatives from my mother's side. Hence, my grandmother from my father's side took me to live with him in Mbeya. But later on, I decided to come and get treatment in the hospital." (Patient Respondent from KIDH)

Study findings indicate that patients who receive treatment through the ambulatory care model are more likely to experience more stigma because of their being in contact with other people in the community who do not understand the disease. Society members also hold different believes and myths about TB and MDRTB

4.3.5 Availability of Basic Needs

Respondents from Dar es Salaam were found to have varying attainment levels of basic needs: two patients managed to get all of the needs such as food, clothing and shelter; one patient owns his own company, so he was able to get all the needs; and another one has family members who support her for everything she needed. Respondents explained that if you have someone who takes care of everything you become comfortable to the extent that you even sometimes forget that you are sick.

"I thank God; I have my own general enterprise company even though it is now managed by my younger brother. Things are not the same, but I ca not complain because it still supports me with my basic needs." (Patient Respondent from Prison Dispensary)

Another ambulatory patient insisted:

"...My parents are in Arusha and I am staying here with my relatives, but they all support me. Sometimes I give up and start to cry thinking of my condition but they cheer me up. My parents sent me some money to help with my basic needs. With additional help from my relatives whom I stay with, I am satisfied." (Patient Respondent Sinza Hospital)

However, one respondent had opposing views on how to fulfill one's basic needs because of the cost involved. This is of concern among patients that are also the breadwinners of their families. After falling sick, things would change as one would now needs support from other members of the family.

"we have to eat well since the drugs are very strong. But the food cost a lot of money. Even the relatives who are supporting us can be tired of helping. But at least if you stay there, you can get anything to eat." (Patient Respondent from Temeke Mbagala Rangi Tatu Hospital)

Another ambulatory patient added:

"*I do not have any money, but my two daughters have husbands and they always help me out. I think that at some point what the government has done is good because in three months they gave us a total of TZS 150,000/. But they do not know about our clothing and where we live, which they should also think about too. Also, I do not like the environment here because they are ignoring us most of the time. They do not have any dignity towards us; I do not think if they even realize how many people are in this project and that there are no chairs here for us to sit"."* (Patient Respondent from Prison Dispensary)

A patient respondent from KIDH commented on the condition of basic need while in hospital:

"I cannot complain about the food. First, I am happy being at the hospital where I get all of my basic needs. The food is especially good compared to the one I manage to get at home. The only improvement should be on cooking the stiff porridge; it has a lot of lumps." (Older Patient Respondent from KIDH)

Study findings also show that due to inability of most patients and their relatives to secure basic needs such as food, shelter and clothes, majority of the interviewed patients preferred the hospital care model than the ambulatory care model. The situation is different for those who receive treatment under the hospital care model because they are sure of being provided with food, hospital clothing and other basic needs even if it is not according to one's preference.

4.3.6Socio-economic Status of Patient Respondents

The researcher has discovered from respondents that majority of MDR TB patients are associated with poor adherence of first line TB medications. However, for TB infection to develop to MDR TB is not necessarily due to failure of first line drugs. The fact of the matter is that MDR TB patients are also associated with poor socio-economic status in terms of poor housing, poor nutrition and poor working environment which is likely to contribute to the incidence of TB disease. Patients under the hospital-based care model are forced to close all their businesses so as to attend treatment at designated facilities. Consequently, essential household expenses for food, rent and other basic requirement cannot be met, irrespective of the fact that the hospital care model of multi-drug resistant tuberculosis (MDR TB) has been of great help as most of the treatment costs are being covered by the government.

"Before I came here I was farming at Makete; but now I left my wife who will be taking care of the farm. Things will not be the same when it was the two of us." (Patient Respondent from KIDH)

Another hospitalized patient added:

"I have a wife, two children and my mother. My father is already dead. That means I have left four people at home who are depending on me. I think I have lost so many things since I was brought here because I had to close my business."(Patient Respondent from KIDH).

Another respondent from Dar es Salaam added:

"I am a driver, but for now I have stopped working until I become smear negative and until I regain strength. For now my wife is selling cloths in order to support the family." (Patient Respondent from Sinza Hospital)

The study findings show that respondents were engaged in income generating activities before becoming sick except for one respondent. They were belonged to different occupations such as being electricians, fishermen, businessmen, farmers, jewelry makers, drivers and much more,

but things have changed and they are now dependent on their families and friends for everything. Due to this dependence, there is increasing burden to families and communities

4.3.7 Misconceptions about the Hospital Care Model

Respondents from Dar es Salaam four (4) out of twenty two (22) commented that they would prefer to be admitted to the hospital, but due to the misconceptions they have heard from other people they have reservations about the hospital model of MDR TB care and treatment. Some of the misconceptions are that patients are not provided with food, they cook for themselves, they are not allowed to go anywhere which is equal to being in prison. Since the location of the hospital (Kibong'oto) is very far, especially for patients from outside the Kilimanjaro region, patients lose hope, lose connection with their families

"If that is the case I better die, because I cannot go there. How will I go to the place I do not know; and what they will do to me; and it is also very far." (Patient Respondent from Temeke-Mbagala Rangi Tatu)

The argument above shows that patients receive wrong information about the hospital-based model of MDR TB care and treatment; they are being given information which is not true. The wrong information makes other patients to choose the ambulatory care model even if the situation at home is not favorable for them to receive treatment under ambulatory care. The information they receive from other KIDH patients who are early discharged under early discharge criteria, so the health care workers need to provide patients with correct information

4.4 Treatment Supporters' Perceptions on Ambulatory Care Model and the Hospital-based Model

The study aimed at describing treatment supporters' perceptions on ambulatory care model and hospital-based model on treatment of MDR TB. The supporters were asked about their perceptions regarding the model that their patients have been receiving care, they responded differently: -

4.4.1 Family Support

Participants from Dar es Salaam responded that they are more comfortable when they are involved in the process of taking care of their patients. They feel it is a good way of showing them love and support. They further mentioned that it is a family responsibility to provide care and support to the patient. They fear if the patient will be under the hospital-based care model they will not have a close relative to care for him/her.

"I think it is good because from the beginning they told him he was supposed to go to Moshi (KIDH) but then, they left him here. I am grateful that he is here. I have to force him to eat. Now I was wondering if he was in Moshi (KIDH) who could insist on him to eat as we are doing it now as his family." (Relative Respondent from Temeke-Mbagala Rangi Tatu Hospital)

Another ambulatory relative added:

"It is good that she is staying at home because sometimes she is just crying and I am there to give her hope and courage." (Relative from Sinza Hospital)

Moreover, one relative from KIDH prefers to have her patient at home but she was told by the healthcare providers that the patient will get cured early upon staying in the hospital. Because the relatives wanted him to get cured, they decided to send him to the hospital.

One relative respondent from KIDH had this to say:

"I would like to stay at home with my husband but I have been told that he will get cured when he stays in Moshi (KIDH). I miss him; I just talk to him over the phone and he told me he is doing okay. I cannot just pray for his recovery." (Relative of Respondent from KIDH)

4.4.2 Socio Economic Status of Relative Respondents

Relatives of patient respondents from Dar es Salaam said that before becoming sick, their patients were able to generate income through different engagements and occupations.

However, due to illness the patients are unable to continue with work. As a result, the development and well-being of the household eventually becomes compromised.

"My husband cannot work from the time he developed the illness. So, I collect rent from our tenants and I have started business of selling cloths." (Patient's Relative Respondent from Sinza Hospital)

Another ambulatory relative added:

"He was working as a bus conductor, but now he cannot work. He and his wife are depending on me." (Patient's Relative Respondent from Prison dispensary)

When patients become sick they need support from the family. In such situations, the relative cost of living becomes very high because there are expenses for food, transport, rent and other basic social requirements which have to be catered for.

4.4.3 Relatives' Misconceptions about Hospital Care Model

Participants who are relatives of patients admitted to the Kibong'oto Infectious Disease Hospital (KIDH) said that they are not well informed about the hospital care model of MDR TB treatment. They think that it is a place that patients are going to be stranded with no help for those who need assistance, especially those who cannot eat by themselves. Due to this unfounded belief, they think that the health condition of their patients might deteriorate due to taking of the pills without eating.

"also, patients do not like to go to Kibong'oto because of the rumors circulating about the experiences with hospitalization there. Healthcare workers should provide important information on what kind of care and treatment a patient would receive at KIDH, and all other important information about the place." (Patient's Relative Respondent).

From the study findings, it shows that relatives of the hospitalized MDR TB patients support the idea that their patients should stay at home (i.e. the ambulatory model). This is triggered by lack of proper information about management of their patients while at the hospital. Such

decisions are moreover informed by the long travel / distance from regions of origin to the hospital location, such as KIDH which is located in Kilimanjaro.

4.5 Perceived Benefits for MDR TB Patients Receiving Treatment under Hospital and Ambulatory Care Models

The study also intended to identify the perceived benefits for MDR TB patients receiving treatment under hospital and ambulatory care models. The respondents were asked to explain the benefits of the models under which they were being treated.

4.5.1 Close Follow-up on Treatment by Family Members

Study findings revealed that five (5) out of eleven (11) relatives respondents prefer to stay close to the patient believing that they could assist them in their treatment and make sure they follow all the required treatment measures. They hold the assumption that when a patient receives treatment under the hospital-based care model there is no one who can closely monitor the patient's progress. For instance, if a patient is not interested in eating there is no one to insist him or her to eat.

*"I think it is good because from the beginning they told him he could potentially go to Moshi(KIDH), and he did not like it because he does not know anyone in Moshi(KIDH) who could help him out. I am grateful that he is here. I have to insist him to eat. I was wondering when he is alone who could push him to eat if not us, his family." (*Temeke- Mbagala Rangi Tatu Relative Respondent)

Study findings show that most families prefer closely monitoring their patient's progress, and this can frequently be ensured in the ambulatory care model of MDR TB treatment.

"Yes, because it helps him and strengthens his health and it is easy to reach here rather than that center in Moshi (KIDH)." (Prison Dispensary Patient's Relative Respondent)

And ambulatory patient added:

"There are advantages like staying with relatives. As for those who went to Moshi(KIDH), they said that they just had to stay inside; they did not get a chance to go anywhere else. But for us, we have the chance of meeting any one and going anywhere." (Patient Respondent from Sinza Hospital)

4.5.2 Health Improvement

Patient respondents from KIDH appreciated the kind of treatment and care they receive from the hospital. They are thankful on how their health improves and the food they are given despite the limited choices. The patients mentioned that healthcare workers provide good care to them and ensure that they never miss their drug schedule.

"I thank God for receiving treatment, medicine and food, although is stiff porridge and beans only. It is only stiff porridge and beans; there are no food choices, like fish, and we are taking a variety of very strong medications." (Patient Respondent from KIDH)

Another patient added:

"There is a benefit of being admitted here because I receive treatment and am sure I will recover and go back in my daily activities and be able to produce as how I used before. (Patient Respondent from KIDH)

Patients placed under the hospital care model count themselves as very lucky people as they are sure of the treatment they receive and easy access to other services. However, ambulatory care patients can also register improvements in their health despite encountering challenges such as skipping meals due to economic hardships at the family level.

"Nobody expected that I would recover. You can ask nurse Leah for proof. There was no hope for me. But now, as you can see… I thank God I have recovered despite the challenge of affording to buy food at home." (Patient respondent from Temeke-Mbagala Rangi Tatu Hospital)

4.5.3 Availability of Medicines, Supplies and Reagents

Respondents from both KIDH and Dar es Salaam Municipalities reported being supplied with enough medications. However, they reported that sometimes the facilities lack some reagents for laboratory testing. Patients with MDR TB require regular testing of their health, especially the functioning of the liver, renal functioning, as well as audometry (hearing) due to the history of adverse drug reactions affecting these organs among MDR TB patients.

*"due to lack off reagents, we are not tested as required, although we have never missed any medications." (*Patient Respondent from Temeke- Mbagala Rangi Tatu Hospital)

Moreover, study findings show that patients never miss taking their medicines although the facilities sometimes run out of reagents for laboratory tests. It was also discovered that the patients give reasonable cooperation during treatment due to the health education they receive from healthcare service providers.

4.5.4 Patients Needing Special Attention

Relatives of patient respondents from KIDH said that they preferred to stay with their patients at home, but some of the patients were reported to have more than one ailment. Some patients have HIV/AIDS and MDR TB, a situation that further complicates the manner of handling their needs. Under such circumstances, the relatives had no other options than to allow their patients to stay at the hospital.

*"The situation could turn out to be worse apart from all the good care and hope she receives from the family. At the hospital, she is receiving treatment and close follow up from healthcare professionals who watch over her progress much closer." (*Patient's Relative Respondent KIDH)

Study findings also show that there are patients who need special attention due to their illness conditions. They need to be admitted despite the fact that they could get hope of recovery by seeing their relatives around. These kinds of patients require close monitoring of their progress by trained healthcare professionals.

Moreover, patients who are not critically ill need to be well informed about caring for themselves, about ways of protecting others from the infection, and about good use of the medicine, all of which can be provided under both the hospital and the ambulatory care models at all times.

4.6 Perceived Challenges for MDR TB Patients Receiving Treatment under the Hospital and the Ambulatory Care Models

A number of challenges were reported during interviews with treatment supporters and MDR TB patients receiving treatment under the hospital-based and the ambulatory care model**.**

4.6.1 Transport Cost

MDR TB patient respondents under the ambulatory care model in Dar es Salaam need to travel to the facility for treatment and back on a daily basis. However, majority of them are the heads of the households on whom their family and relatives have been depending upon. When these persons become sick, it translates into their households to experience increased economic hardships.

"The other challenge is that we are not financially well. So, when we run out of money we may ask our children who are financially struggling, too, because the work they depend on does not give them with enough money." (Patient Respondent from Prison Dispensary)

The results from this inquiry show that MDR TB patients receiving treatment under the ambulatory care model face transport challenges in the process of accessing treatment. Due to their poor health condition, some of them can hardly walk by themselves. They need support every time they want to attend their clinic appointments. Their bodies have become weak due to prolonged use of strong medications that have weakened their ability to move. Addressing such challenges, one patient's relative respondent said the following:

"Yes, I take a tricycle which costs almost 8,000/= TZS, per trip every day because he claims his legs feel heavy. Sometimes when I am not around, his children normally brought him here." (Patient's Relative Respondent, Prison Dispensary)

The transport challenge came mainly from patients placed under the ambulatory care model than from patients receiving treatment the hospital care model as attested by the following statement made by one of the interviewed respondents.

"I think they should look consider increasing the amount of stipend they provide. After every 3 months, they provide 150,000/=TZS which is not enough. Or, at least they should provide every month dividing that amount by three months. Yes, they should give us 50,000 every month also they should find us a place to rest for sometime after receiving injection." (Patient Respondent Prison Dispensary)

Another ambulatory patient made the following:

"It is good to come here from home. I live in Tabata. The advantage I see is the great change on my health. There is the transport challenge that I face when coming to the hospital from home every day. Long distance, traffic jam, and high costs in terms of bus fare. (Patient Respondent Prison Dispensary).

The transport challenge has been experienced by respondents in both models although it is in different ways. The relatives of hospitalized patients from other regions complain about high transport costs when they visit their patients at the Kibong'oto Hospital in Moshi (KIDH), Kilimanjaro. On the other hand, patients under ambulatory care MDR TB treatment model experience the transport challenge on a daily basis upon visiting the healthcare facilities for medication and follow up.

"I have been here for six months and my relatives are not able to pay me a visit. Musoma is very far from here; they cannot afford to travel from that far just to greet me. They will use that money to do other things." (Patient Respondent KIDH)

Another hospitalized patient from KIDH added that:

"Currently, I am staying far from my family. I ask myself several questions: why this? They cannot see me apart from hearing my voice through the phone. But I cannot see how they progress. I feel lonely, and from here to Makete is very far. They cannot afford bus fare to

come visit me. At the same, time I don't know for how long I will be alive. People who suffer from this kind of disease normally die without any notification." (Patient respondent from KIDH)

4.6.2 Distance to the Health Facility

Participants from Dar es Salaam mentioned that the distance from home to the facility is a challenge to most patients who stay far away from the healthcare facilities. The distance will require a patient to take a motorcycle or a public transportto report for treatment. This is not the case in the hospitalization model as all patients are staying in the hospital for treatment until they fully recover or they are early discharged according to the applicable hospital procedures.

"I wish I could stay at the hospital until I get cured. The long travel distance is a problem, and also is bus fare. But if I could manage to get fare, I would not miss my medication, because there are days that I missed my medication due to not having money for bus fare." (Patient Respondent Temeke -Mbagala Rangi Tatu Hospital)

Also, the patient's relative had the same concerns regarding travel distance and bus fare to the facility when she pointed out that they live far away from the healthcare facility where the patient receives treatment.

*"It is better if he can stay at the hospital until he feels better because we are facing a big challenge in getting daily bus fare and food." (*Patient's Relative Respondent from Temeke-Mbagala Rangi Tatu Hospital)

4.6.3 Limited Food Choices

Eight out of ten study participants under the hospitalized model expressed dissatisfaction with the food they eat at the hospital. They mentioned lack of food variety as being the main problem since they are given the same type of food every day. The interviewed patients were of the opinion that if they could have many food choices, like what they have at home, the situation would have been much better. They showed preference for a wide range of choices,

but due to the limited budget the hospital receives from the government it cannot entertain all the needs of the patients.

"Stiff porridge with beans; they are pushing us to eat because of the economic situation. If we could be well financially, we could change and eat other kinds of food. There are some of us who have money, who can manage to buy milk. Some people who can afford it cook for themselves despite facing health impacts from the flame that comes out of the stoves." (Patient Respondent from KIDH)

Eight out of eleven interviewed patients under the ambulatory care model of MDR TB treatment reported facing the same dietary challenges due to economic hardships and they asked for support from the government.

"We are thankful for the transport support that we receive from the government. However, they have to think also about food and other needs. We can no longer produce due to illness but we need balance diet that can help our body to resist the toughness of the dosage we are taking." (Patient Respondent from Sinza Hospital)

4.6.4 Unfavorable Environment and Infrastructure

All Patients respondents from all of the three facilities visited in Dar es Salaam reported that, there is no place for them to rest for sometime after injections and in case they need to wait for the service there is also no suitable place to accommodate them. Therefore, the patients found themselves hanging around or sleep on grass because there is no waiting lounge or resting area.

"At the injection room, there is a bench and a folded mattress only, the building generally is not good before that we were being treated at the rest room but now the number of patient is increasing they have decided to use this building though it's not official" (Patient from Prison dispensary)

Another ambulatory patient added:

"The environment is not good as you can see for yourself; there is no appropriate waiting area especially for the patients who are seriously ill. People have to sleep on the grass. Normally, we arrive at 8am or 9am and wait up until 10:15am. Then, we go back home. But if we could have been given waiting areas to rest when someone feels weak or dizzy due to drugs, that would have been better." (Patient Respondent from Sinza Hospital)

Also, there has been reported poor planning and organization in all of the facilities visited whereby new and old patients are kept in the same area. This triggers the fear of acquiring new infection among patients with improved health. All of the three (3) visited healthcare facilities did not have enough space to accommodate all patients who went for treatment. This experience has been a challenge to most patients receiving treatment under the ambulatory care model of multi-drug resistant tuberculosis.

"They should separate us because you can find that new patients and those who have been under treatment for six months are all kept in the same space. Some might come with dangerous infections and contaminate us. They should be kept far from us until they get treatment." (Patient Respondent from Sinza Hospital).

On the other hand, patients who receive treatment under the hospital-based care model complain about aging infrastructure, equipment and supplies such as beds, clothes and the buildings which have not been renovated for quite some time. Therefore, they face some difficulties when accessing the services. One of the patients made the following comment at the Kibong'oto Infectious Diseases Hospital (KIDH):

"We are happy that we get treatment here at the hospital but the buildings are old they need renovation or they can shift us to the new buildings because they are there and no patients are in" (Patient respondent from KIDH)

It was also found that patients who receive treatment under the hospital care model had relatively better treatment environment despite the aging infrastructure and supplies. On the contrary, MDR TB patients placed under the ambulatory model experience poor treatment environment characterized by lack of space for resting and other purposes.

4.6.5 Inadequate Medication and Supplies

This challenge was reported by respondents from Sinza Hospital whereby all the interviewed patients mentioned the problem of intermittent shortages of medicine and other supplies such as syringes and gloves. Consequently, patients sometimes have to buy the items themselves. Laboratory tests results are also a challenge whereby patients claimed that specimen would be taken from them but they would not be given their results. Problems in medical supplies and the lack of transparency in the patients' laboratory test results will likely worsen the patients' health conditions.

"They should increase their drug stock as there is scarcity of medicine. Sometimes we have to buy syringes and saline solution bottles. Also, we should be given our test results frequently because most of the time they take samples from us but they do not give us our results. They say that if you see silence that means you are doing fine." (Patient from Sinza Hospital)

Another ambulatory patient added:

"Every month we are tested for renal function and liver function but they stay long with the results. There was a certain time after a test it was found that I had a problem in my liver and I delayed getting the results. If I could know that early enough I could drink enough water, milk and take more fruits to reverse the situation." (Patient Respondent Sinza Hospital)

The researcher has found that lack of supplies and delayed laboratory results cause patients not to be well informed of their health progress on time. It would be good that these patients are tested for adverse drug reactions. Early and timely detection of a a particular health problem could help healthcare professionals to address the situation and curb its further development into any disability such as deafness, or renal and liver failure.

4.6.6 Inadequate Staffs

Patients from one facility were complaining of waiting too long for treatment attributing the delay inadequate number of staffs. One nurse would serve the first line TB patients who are

usually served first followed by MDR TB patients. This would keep MDR TB patients waiting for up to one and a half hours despite their reporting early to the clinic.

"They should increase the number of healthcare service providers so that when we come here we get the services and go home early before the overhead sun." (Patient from Sinza Hospital)

Patients under hospital care model did not report shortage of staffs, patients are being treated on time no delays, even though they need additional staffs for better provision of the service.

4.6.7 Transmission of Disease

Majority of respondents for this study said it openly that at home there is a high chance of disease transmission because relatives and caretakers usually do not follow the advice given by healthcare service providers. Caretakers are told not to share room with the patient during the early stage of treatment, staying outside as much as possible so that to reduce infection Moreover, ambulatory care model provides a wide range of interaction between patients, relatives and other family members who could be exposed to TB transmission if they do not take safety precautions offered by healthcare professionals.

"I told them not to use the utensils I used but they do not listen to me. We have been told by the healthcare service providers not to share these things because they will contract the disease." (Patient Respondent Temeke-Mbagala Rangi Tatu Hospital)

This experience was significantly different from the hospital-based model of MDR TB care as patients were being assigned to wards according to their conversion status, thereby reducing the chances for disease transmission to non-infected individuals and cross-infection among the patients themselves.

An interviewed patient from Kibong'oto responded:

*"When I came here I was admitted to that ward, but as we speak I have been shifted to this ward because my status is not the same as those I was staying with before. So, in here if you progress well you are shifted to the next category." (*Patient Respondent from KIDH)

Another respondent from KIDH reported the risk of getting skin infection due to sharing of toilets in the wards. The patient did not have doubts about MDR TB patients spreading infection to others as reported by patients in the ambulatory care model.

"Please, I beg you to talk with the hospital management so that they can insist on proper toilet use so that we can avoid skin infection. This is because most patients do not know how to use these modern toilets." (Patient Respondent from KIDH)

CHAPTER FIVE

5.0 DISCUSSION

5.1 Overview

This chapter presents the discussion of the findings based on the lived experiences of the MDR TB patients' and their supporters' on receiving treatment. The chapter is divided into seven (7) parts. The first section is overview, the second section addresses patients' perceptions on ambulatory care model and hospital based model. The third section addresses treatment supporters' perceptions on ambulatory care model and hospital based model. The fourth section covers the perceived benefits for MDR TB patients receiving treatment under hospital and ambulatory care models, and the firth section expounds on the perceived challenges for MDR TB patients receiving treatment under hospital and ambulatory care models. The sixth section is public health implication and the last section is policy implication

5.2 Patients' Perceptions about Ambulatory Care Model and Hospital-based Model

The findings of the study showed that relatives and patients are aware of the models of providing care to MDR TB patients. However, more knowledge is needed on how to protect them-selves and protect others against the disease. This is especially applicable to those patients placed on ambulatory care model as this model proves to be new to them. In this way, the infection transmission to other family members and community at large will be controlled.

Study findings revealed that in the hospitalization model, patients had more time to share with others their experiences of the treatment and care they receive. Moreover, healthcare workers have a better opportunity to monitor patients' progress and take suitable measures in case a patient's health is deteriorating. These health care workers have more experience in caring MDR TB patients. These findings are similar to the study that investigated Multi-Drug Tuberculosis Resistance in Europe conducted by Christopher *et al.,(*2014) which discovered that in-patients with MDR TB are frequently cared for by physicians who are primarily

specialized in the management of TB/ MDR TB, and that they are regularly counseled and are aware of Infection Prevention and Control (IPC) mechanism (22).

Study findings revealed that stigma and discrimination is prevailing to the community, especially under the ambulatory care model, as patients reported being stigmatized by their friends, close relatives and even healthcare workers. The patients who did not experience stigma are the ones that did not disclose their health status for the fear of being stigmatized and discriminated. This has an implication on the success of the management of the patient and infection control in general. An example is a patient who feels shy to wear a TB protective gear, thus risking the transmission of infection to others. This is similar to the study conducted by Horter *et al.*, (2014) in Uganda reports that MDR TB patients are isolated by their families and friends due to the unfounded fear of TB transmission among non-infected individuals (7).

In addition to that, a study on hospitalized care for MDR-TB in Nigeria, where patients were interviewed and reported being stigmatized by close relatives for the fear of being infected with the disease. Moreover, there were reported cases of patients isolating themselves from their children, partners, and coworkers. Other patients did not disclose their MDR TB status for the fear of being stigmatized by their communities. In the same study, patients also reported being stigmatized by healthcare workers. Some healthcare worker rarely entered their wards or held a conversation with them due to the fear of being infected with MDR-TB. This fragmented interaction hindered service delivery and contributed to deleterious health outcomes in some instances (23). However, patients interviewed for this study at the Kibong,oto Infectious Disease Hospital did not mention having encountered any instances of stigma by healthcare workers.

Patients under the hospital-based model are assured of being provided with their daily basic needs – including food and shelter – provided by the hospital through funding from government and support from development partners. Although the patients cannot order food of their choice, and contrary their counterparts under ambulatory care where they sometimes lack food and other uncertainties due to economic hardships in most households.

The findings are further corroborated by a study by researchers Tadese and colleagues (2016) in Ethiopia which made the same observations regarding the deficiencies in the ambulatory care model whereby it was found that patients were not in a position to work due to illness and were faced with financial hardship as a result. The study also reported that other patients were isolated by their families due to the fear of being infected with tuberculosis, a situation that made it difficult for them to receive adequate help (16).

From this study finding, the researcher discovered that ambulatory care patients had misconception concerning the hospital-based model. The patients reported that in the hospital patients are not free, they live as if they are in a prison hence majority of them prefer ambulatory care model, they had no experience with hospital care model but relied on information they receive from the public and other patients. These findings are similar to the results of a study done by Bieh *et al.,* (2017) titled "Hospitalized care for MDR-TB in Port Harcourt, Nigeria" in which hospitalized patients likened their admission to the hospital to being imprisoned. (23).

5.3 Treatment Supporters' Perceptions on Ambulatory Care Model and Hospital-based Model

This study findings show that relatives prefer to stay home with their patients believing that they can assist them in all aspects, including offering psychosocial support throughout their sickness instead of staying away from them. This is good as they maintain family bonds allowing the relatives to provide good care to their patients unlike when the patient is away from them making them unable to monitor the recovery progress. They also believe that if a patient is admitted to a hospital they will not have a close follow-up compared to when the patient stays at home where one can get a chance of engaging in other light activities.

This finding is contrary to the study titled "documenting best practices psycho-socio-economic support for TB patients", a study done by KNCV Tuberculosis Foundation *et al*., 2014. The researchers explained that patients received psychosocial support from psychologists composed of TB nurses and social workers. The experts provided individual support to

patients including explaining to them the importance of treatment adherence in both models. The above observation differs from the findings of our study because psychosocial support to MDR TB patients was reportedly provided by relatives under ambulatory care, a situation that seems lacking under the hospitalization model. In accordance with the TB treatment procedures, it is best that MDR TB patients receive psychosocial support in both models of care in efforts to address issues such as depression among patients (24) since most MDR TB patients have reported experiencing major physical and emotional suffering.

Data from this study also show that relatives of the patients face enormous economic hardships while nursing their loved ones. After being detected with tuberculosis, the patients cannot engage in production. In the midst of the said challenges, the patients will also need assistance from their struggling relatives in securing food, bus fare, rent and other necessities. Therefore, in most cases MDR TB patients become a burden to their relatives in both models. Despite the hospitalization model being of great help to the patients since the government assumes responsibility for all MDR TB patients admitted to Kibong'oto, the patients leave behind their responsibilities to their economically struggling relatives while seeking treatment at the facility. This particular finding agrees with a study on socio-economic challenges among Pakistan MDR TB patients in southern Punjab where it was found that both patients and their supporters experienced enormous economic hardships. As a result, the direct and indirect costs associated with MDR TB treatment appear to be a key concern to them (25).

5.4 Perceived benefits for MDR TB Patients Receiving Treatment under Hospital and Ambulatory Care Models

This study finding also revealed that relatives prefer to stay with their patients at home (ambulatory) so that they can offer enough support including psychosocial support and to closely monitor patient's recovery. This is contrary to patients being in the hospital where their relatives are not able to see or help their loved ones. Moreover, in the ambulatory care model, patients have the time to engage in other lighter activities and have interactions with various people including the relatives that come to visit them. This experience is unlike the one in the hospital where patients are rarely visited by friends and relatives. This finding is in

line with the observations made by Decentralization Framework (2015) which recommended that MDR TB patients could be managed under ambulatory care so as to reduce hospital admission and allow their communities to actively engage in caring for their sick ones (11)

Furthermore, this study finding showed that patients under the hospitalization model are more familiar with how to care for themselves without infecting others especially after they participate in several counseling sessions which help them to overcome depression. This experience differs considerably from the encountered one in the ambulatory care model.

MDR TB patients in the ambulatory model may receive counseling and treatment while attending the TB clinic but they would not apply the safety measures as explained by the healthcare provider providers afterwards. This is sometimes triggered by the fear of being sidelined by their communities, thus potential spreading MDR-TB. This research outcome aligns with the results from a study which sought to understand case management of MDR-TB patients in Europe by researchers Christopher and colleagues (2014) which discovered that in-patients with MDR TB are aware of Infection Prevention and Control mechanism (IPC) (22).

5.5 The Perceived Challenges for MDR TB Patients Receiving Treatment under Hospital and Ambulatory Care Models

The findings from this study showed that patients in the ambulatory care model face the challenge of daily traveling from home to the facility. The situation becomes further complicated for some patients who live far away from the healthcare facilities (initiation sites). Due to long travel/distance and poor travel logistics, sometimes patients happen to miss their clinical appointments. The missed appointments at TB clinics could lead to drug adherence problems which may give rise to further transmission of MDR-TB and expose the patients to the risk of developing Extensively Drug Resistant TB (XDR-TB). This situation is not the case in the hospitalization model. This situation has been acknowledged by the World Health Organization (WHO) in its recent TB management manual in which it explains that long daily travel can be a reason for defaulting treatment (WHO, 2014). It is therefore recommended that when the patient receives clinic-based treatment, rapid access to Direct Observed Therapy

(DOT) should be ensured to allow a quick departure from the facility. This practice will reduce the exposure to potential sources of TB and other infections (26).

MDR TB patients in the hospitalization model are facing the challenge of limited food choice, with the dominant food of all times being stiff porridge with beans. The MDR TB patients sometimes prefer different food varieties which the hospitals cannot afford to provided due to limited budget. This is also a problem to patients under the ambulatory care model whereby their families cannot afford to provide them their desired type of food due to economic hardships experienced at the household level. This is contrary to the study titled "treating Drug-Resistant TB" a study conducted on South Africa, Kenya, Swaziland e.t.c. by Frontières and his colleagues (2011) report that the patients are observed and helped throughout treatment. The kind of social support given to the patients include both incentives (such as money or household food parcels) and enablers (assistance with transport, and nutritional support for patients). In the republic of Georgia, for example, patients receive both material and financial support to rehabilitate their houses for infection control, whilst in Armenia, patients are provided with food parcels and allowances for heating and transport, (27). This European experience in caring for TB patients differs considerably from the findings of this study as patients, especially those under ambulatory care, who do not receive food support. Rather, the patients enrolled in ambulatory MDR TB care in Tanzania are only given stipends for transport provided by KNCV TB foundation.

In another study conducted among hospitalized TB patients in Nigeria in 2016, participants voiced their complaints about the food they were given in the hospital. The patients presented their group's recommended food menu to the authorities to resolve their disapproval of the type and quality of the food served in the facility (23). Patient dissatisfaction over food was also among the concerns mentioned by most patients who participated in this study at the Kibong'oto Hospital.

The study also discovered that patients under the ambulatory care model are being given services under unfriendly environments. The new model is being introduced but the facilities remain the same as there is no enough space to accommodate the patients. Moreover, MDR TB patients are mixed with other patients despite their belonging to different conversion status. In such environments, there is a need to institute a risk reduction program which would address administrative and environmental challenges with the aim of reducing and stopping TB infections from spreading. Moreover, risk assessment should be conducted regularly within TB clinics providing ambulatory care to TB patients to determine the infection risk levels and take appropriate actions to address any challenges. This might not be the case in hospitalization model of TB treatment whereby patients are assigned to stay in wards according to their conversion status, but still health care providers need to protect and monitor infections to hospitalized patients

In both models, the problem of inadequate supplies was also a challenge discovered when conducting the study. It was observed that patients were sometimes asked to buy their own syringes for injection and gloves despite most of them coming from poor socio-economic backgrounds.

In the hospital-based model, patients also reported facing the problem of inadequate supplies (i.e. machines breakdown, lack of reagents). During the time of data collection, the researcher received information that the machines were not functioning for almost 4 months. Hospitalized MDR TB patients receive better treatment as they do not face delays in getting attended because of the availability of adequate staff at the Kibong'oto Hospital. This observation partly agrees with the findings in Christopher et al., (2014) study in which the number of MRD TB patients in one of the countries observed increased tremendously which resulting in the country's healthcare facilities to experience the absence of MDR-TB drugs, a situation that resulted in high death rates and loss of follow-up (28).

In a study on "Health system factors influencing management of Multi Drug-Resistant Tuberculosis in four European Union countries" by researchers Gerard and colleagues (2017) none of the respondents in the four researched countries reported challenges with availability

of laboratory consumables for treatment of MDR-TB (29). The European experience differs from the findings of this study whereby incidents of inadequate drug supplies and machine breakdown were reported in all facilities. Lack of supplies cause enormous challenges such as worsening the patient health condition. As a consequence, other patients developed loss of hearing due to adverse drug reactions.

Another reference study titled "systematically reviewing the effectiveness of hospital and ambulatory models of MDR TB treatment" by Basil and colleagues (2013) mentioned limited funding as the major challenge compromising patients' access to treatment in most settings under the hospital-based model of TB care. The findings of this review suggest that in the absence of medical or social justification for hospitalization, all MDR-TB patients could be effectively treated on an ambulatory basis. However, the researcher argued that managing patients under ambulatory care is good although household poverty affecting most families make it difficult for patients and their relatives and this may hinder them from accessing the treatment services as required by the guideline.

Study findings have also uncovered the challenge of inadequate staff in most TB care and treatment facilities whereby patients are subjected to long waiting periods during treatment. This is especially the case in the ambulatory care model, but it does exist in hospital-based model also.

Data from this inquiry also revealed that patients under the ambulatory care model face transport challenge in the process of accessing treatment. The researcher was informed that there are patients who can barely walk due to body weakness caused by MDR-TB disease. These patients need a motorcycle or a bicycle which can prove hard for their families to afford due to poverty.

Therefore, the daily transportation costs required for patients to report to the TB treatment facility for treatment is just another burden compromising the quality of care received by most MDR TB patients under ambulatory care. In the hospitalization model, patients may encounter

lesser challenges compared to their counterparts placed under the ambulatory care plan; although they relinquish access to their loved ones and work.

These results are similar to findings of a study by researchers Horter and colleagues (2014) in Uganda where patients mentioned transport difficulties as barriers to accessing treatment in the ambulatory care model which requires patients and their supporters to visit healthcare facilities on a daily basis for treatment. These include distance, affordability, transport costs, and living costs. These barriers were considered as prohibiting patients from accessing treatment because of household poverty making them unable to raise funds to visit healthcare facilities for daily treatment. If the patients are admitted in a centralized hospital, all of these barriers would not have been problems since the government provides everything (7).

Relatives of the TB patients interviewed for this study expressed their fear of being infected with the disease for staying with the patients at home where they share space, as most of them have smaller houses to live. Therefore, more health education is needed to the families and the community at large on how to live with TB patients in order to stop the infection from spreading while avoiding stigma directed toward TB patients. This observation however does not apply to the hospital-based of MDR TB treatment since patients are placed in wards according to their conversion status in order to avoid the danger of transmission of the disease.

Moreover, this particular research finding goes contrary to the Horter *et al.*, (2014) study whereby no patient or family respondents mentioned fears or association of treatment at home with the heightened risk of secondary transmission of MDR-TB (7).

5.6 Public Health Implications

This study provides evidence that both MDR TB treatment models are of crucial importance in combating the disease in Tanzania. Improvements in drug supply, staff availability and space in most healthcare facilities are called for given the deficiencies observed during data collection for this study. This is especially meant to ensure better provision of services for MDR patients under ambulatory model of TB care and treatment. For the patients relatives

and community at large they should offer support to their sick ones and ensure that they finish the treatment as recommended by health care providers (as per guideline)

5.7 Policy Implications

Models of MDR-TB Care (ambulatory/hospitalization)

The World Health Organization recommends that patients with MDR-TB should be treated mainly under the ambulatory model of TB care due to limited resources to cater for the needs of hospitalized patients in most developing countries (WHO, 2014). This recommendation is made based on very weak evidence of successfully treating such cause using the stay-at-home approach (30).

According to the study done by Basil and colleagues (2013), the two models of TB care and treatment elicit no statistically significant differences in their treatment outcomes. This finding may be used to support the WHO preference for ambulatory care in treating MDR-TB cases only that infection control measures are seriously considered both at home and at healthcare facilities. Moreover, the clinical condition of patients, availability of treatment support to facilitate adherence to treatment, and the provision of backup facility services for patients who require hospitalization should also be put in place in order to optimize the MDR-TB treatment outcomes (31).

Therefore, the two models of TB care need to complement each other to ensure better treatment outcomes to MDR-TB patients in the country.

CHAPTER SIX

6.0 CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

The study sought to explore perceptions of Multi Drug Resistant Tuberculosis patients and their supporters on hospital-based and ambulatory care treatment models. The study revealed that both models have their own benefits and challenges as far as patients' and supporters' perceptions are concerned. These two models need to be combined: there is a need to continue with the hospital-based care model for critically ill patients as they cannot be ambulated, while abled patients with families that can support them can preferably be considered for ambulatory care. The models complement each other and prove to be helpful to patients in various aspects. However, the ambulatory care model requires more efforts by medical and non-medical stakeholders in order for it to achieve the desired results. I.e. health education to both patients and relatives on how to protect and prevent other people from the disease, increased budget to TB department (provision of transport stipends to the patients)

6.2 Recommendations

From the study findings and analysis, the following recommendations are made:

1. **Health Education**

In order to address the challenges associated with stigma, health education on TB transmission becomes an imperative to the relatives, healthcare workers and the community at large so that they know how to live with TB patients without discriminating them, so the government through the Ministry of Health Community Development Gender Elderly and Children should launch a comprehensive health education campaigns regarding MDR TB to raise community awareness of the disease. This MDR TB community awareness campaigns could embrace the HIV/AIDS awareness efforts both in content coverage and magnitude. Such efforts will create and increase the people's awareness of the disease, its transmission and prevention, as well as help to reduce stigma experienced by the patients. The awareness campaign should be aimed

at passengers at bus stands carrying content such as ‘Open the Window'. It could make use of media channels, including radio, where talk show tackling health topics including MDR-TB can be aired in order to reach a larger public in both rural and urban areas

. Community TB education will help patients not to fear about exposing their health status to others knowing that the community will not isolate them. Stigmatizing these patients may increase the chances for the spread of the disease.

2. **Establishing Zonal Centers for MDR TB**

The Government and other donors funding TB and MDR TB i.e. KNCV should consider creating zonal centers for ambulatory MDR TB patients during the first one to two months of intensive phase they can stay at the center. This will reduce the risk of infection to other people. After that, the patients can be allowed to go home and continue with clinic calls since they will not be highly infectious compared to their conversion status at the initiation period. Additionally, the government should also consider establishing more ambulatory MDR TB sites to save patients from traveling long distance to access treatment.

3. **Improvement of Healthcare Facility Infrastructures**

The Government and other stakeholders should find ways of expanding the infrastructure in the facilities. The present infrastructures, such waiting areas, are not enough. Patients are being mixed in TB clinics, which could pose the danger of spreading the infection to other people and cross-infecting, other patients with different conversion status. New MDR TB patients and those who have already converted to smear negative must stay separately so as to avoid infections among themselves.

4. **Recruitment of committed Health Staffs**

The government through Ministry of Health should recruit enough and committed healthcare staffs so as to improve provision of healthcare services to MDR TB patients. This is especially the case for patients receiving treatment under ambulatory as there is the need to ensure that patients do not spend unnecessarily long waiting times to receive treatment.

5. Availability of Supplies and Equipment

The government and other partners in health, KNCV, MDH should ensure the supply of enough medical supplies and equipment so that MDR TB patients can receive treated uninterrupted. Reliable and uninterrupted early treatment is required to guarantee early recovery which would allow patients to return to production.

6. Minimize financial Difficulties

Patients under ambulatory care face financial difficulties which hinder their access to food and other necessities. Moreover, such patients find it hard to afford rent and transport costs to the clinic. The researcher recommends that the government should increase budget to the Ministry of Health Community Development Gender Elderly and Children where by a special allocated budget should go to TB department (establishing a special fund for TB) so that the fund will assist the people who are highly in need and they lack support from the family as it is now done by KNCV –TB Challenge under which MDR TB patients are provided with a stipend to help reduce the economic hardships they experience.

7. Improvements of Patients' Diet

There is a need to provide patients under the hospital-based model of MDR TB with a treatment balanced meal so as to speed up their healing while receiving treatment at the designated centers. The government should work on mobilizing resources from various stakeholders, including organizations such as the World Food Program (WFP), to be able to provide the required support to both hospitalized patients and patients placed under the ambulatory model of TB care and treatment. Moreover the researcher recommends that at the International TB day which is held on 24 March every year there efforts should be made to mobilize resources for helping the MDR TB patients with the challenges they faced

8. Further Research

There is a need for further research into strategies to reduce stigma and discrimination toward MDR TB patients by relatives, friends and the community at large.

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APPENDICES

Appendix I A : Consent Form English Version

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES(MUHAS)

DIRECTORATE OF RESEARCH AND PUBLICATIONS.

TITLE OF THE STUDY: EXPLORING PERCEPTION OF MULTI-DRUG RESISTANT TUBERCULOSIS PATIENTS AND THEIR RELATIVES/ TREATMENT SUPPORTERS ON RECEIVING TREATMENT UNDER HOSPITAL BASED AND AMBULATORY CARE MODEL IN DAR ES SALAAM MUNICIPALITIES AND KIBONG'OTO

ID NO……

Consent to Participate in the Study

Greeting! My name is Lucia Njovu from MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES, MA-HPM Candidate. I am conducting a study with the objectives of exploring perception of multi-drug resistant tuberculosis patients and their treatment supporters on receiving treatment under hospital based and ambulatory care model in Dar es Salaam municipalities and Kibong'oto Infectious Disease Hospital

Purpose of the Study

The purpose of the study is to collect information on perception of multi-drug resistant tuberculosis patients and their relatives/ treatment supporters on receiving treatment under hospital based and ambulatory care model in Dar es Salaam municipalities and Kibong'oto Infectious Disease Hospital.

The result of this study will help policy and decision makers in the Ministry of Health Community development, Gender, elderly and children (MoHCDGEC) through National Tuberculosis and Leprosy Programme (NTLP) to improve access to care for patients with multi-drug resistant tuberculosis (MDRTB), to know the perceptions of patients and their supporters on models so as to address challenges that will be identified by formulating strategies of improving services.

Participation requirement

If you agree to participate in this study you will be required to answer questions exploring perception of multi-drug resistant tuberculosis patients and their relatives/ treatment supporters on receiving treatment under hospital based and ambulatory care model in Dar es Salaam municipalities and Kibong'oto

Confidentiality

I assure you that all the information collected from you will be kept confidential. Only people working in this research study will have access to the information. We will be compiling a report which will contain responses from the people interviewed without any reference to individuals. We will not put your name or other identifying information on the records of the information you provide.

Benefits

The information you provide will help in providing recommendations mainly to policy and decision makers in the Ministry of Health Community Development, Gender, Elderly and Children through National Tuberculosis and Leprosy Programme (NTLP) as well as other implementing partners and stakeholders to know the perceptions of patients and relatives on models and to address the challenges that will be identified

Potential Risks

I assure you that no risk will arise from participating in this study and that your contribution is highly valuable.

Rights to withdraw and alternatives

Taking part in this study is completely your choice. If you choose not to participate in the study or if you decide to stop participating in the study you will not get any harm. You can stop participating in this study at any time, even if you have already given your consent.

Refusal to participate or withdrawal from the study will not involve penalty or loss of any benefits to which you are otherwise entitled.

Contacts

If you ever have questions about this study, you should contact the principal investigator, Lucia Njovu, Muhimbili University of Health and Allied Sciences (MUHAS), P.O. Box 65001, Dar es Salaam, Mobile phone no: 0717577897.

If you ever have questions about your rights as a participant, you may contact Dr. Joyce Masalu, Chairperson of the Senate Research and Publications Committee, P. O. Box 65001, Dar es Salaam. Tel: 2150302-6 and Dr. M. Mwangu. Tel :(+255713 253513) who is the supervisor of this study

I _____have read/listened to the contents in this form. I agree to participate in this study.

Signature of the respondent _____

Signature of Principal Investigator _____

Date of Signed consent _____

Appendix IB: Ridhaa ya kushiriki katika utafiti-Kiswahili Version.

CHUO CHA SAYANSI NA TIBA MUHIMBILI

KURUGENZI YA UTAFITI NA MACHAPISHO.

UTAFITI JUU YA MTAZAMO WA WAGONJWA WA KIFUA KIKUU SUGU WANAO TIBIWA WAKIWA MAJUMBANI/WAKITOKEA MAJUMBANI AU WANAOLAZWA HOSPITALI PAMOJA NA NDUGU ZAO, UTAFITI UTAFANYIKA DAR ES SALAAM NA KIBONG'OTO HOSPITALI YA MAGONJWA YA KUAMBUKIZA

FOMU YA RIDHAA

NAMBARI YA UTAMBULISHO_____

Ridhaa ya kushiriki kwenye utafiti

Habari! Jina langu ni Lucia Njovu, natoka katika Chuo Kikuu cha Sayansi na Tiba Muhimbili, mwanafunzi wa shahada ya uzamili katika sera za Afya na Uongozi. Ninafanya utafiti wenye lengo kuu la kujua mtazamo wa wagonjwa wenye kifua kikuu sugu wanaopata tiba wakiwa wamelazwa na wanaopata huduma wakiwa wanatokea majumbani kwao.

Lengo la utafiti

Madhumuni ya utafiti hu ni kukusanya taarifa kwa wagonjwa na ndugu zao (ndugu wa karibu) juu ya mtazamo wao kwa huduma wanazopata, wakitokea nyumbani au kulazwa hospitali, utafiti huu utafanyika Dar es Salaam katika manispaa za Ilala, Temeke na Ubungo na Kibong'oto hospitali iliyopo Kilimanjaro

Ushiriki

Endapo utakubali kushiriki katika utafiti huu utatakiwa kujibu maswali yote yanayohusu mtazamo wako juu ya huduma za kifua kikuu kwa wagonjwa wa kulazwa (Kibong'oto) na kwa wanaotibiwa kutokea nyumbani (Ilala, Temeke na Ubungo)

Usiri

Taarifa zitakazokusanywa kutoka kwako zitakua ni za siri na zitatumika kwa ajili ya utafiti tu, watu wanaofanya kazi katika utafiti huu tu ndiyo wanaweza kuziona taarifa hizi. Hatutaweka jina lako au taarifa yoyote ya utambulisho kwenye kumbukumbu za taarifa utakazotupa.

Faida za kushiriki katika utafiti

Taarifa utakazotupatia zitasaidia kutoa mapendekezo kwa watoa maamuzi na watunga sera za afya nchini kupitia Wizara ya afya, wazee, jinsia na watotot pamoja na wadau mbaimbali katika kuweka mikakati na utekelezaji wa njia bora za kuwapa huduma za Afya kwa wagonjwa wenye kifua kikuu sugu.

Athari

Nakuhakikishia kwamba sitarajii kama kuna athari yoyote inayoweza kutokea kwasababu ya kushiriki katika utafiti huu na ushiriki wako ni wa muhimu sana.

Haki ya kujitoa na mambo mbadala

Ushiriki wako katika utafiti huu ni wa hiari na endapo utaamua kutoshiriki au kusimamisha kushiriki hutopata madhara yoyote. Unawea kusimamisha kushiriki katika utafiti huu kwa muda wowote hata kama ulisharidhia kushiriki. Kutoshiriki au kujitoa katika utafiti huu hakutasababisha madhara yoyote, adhabu yoyote au kufanya usipate faida yoyote unayotakiwa kupata.

Mawasiliano

Endapo utakuwa na swali lolote kuhusu utafiti huu unaweza kuwasiliana na mtafiti mkuu Lucia Njovu, Chuo Kikuu cha Muhimbili, S.L.P 65001, Dar es Salaam, number ya simu 0717577897.

Kama utakuwa na maswali yoyote kuhusu ushiriki wako unaweza kupiga simu kwa mwenyekiti wa kamati ya chuo ya utafiti na machapisho Dr. Joyce Masalu, simu namba 2150302-6 na S.L.P 65001, Dar es Salaam, na Dr. M. Mwangu, simu namba (+255713 253513) ambaye ni msimamizi wa huu utafiti.

Mimi.....nimesoma/nimesikiliza yaliyomo katika hii fomu na nimekubali kushiriki katika utafiti huu.

Sahihi ya mshiriki _____

sahihi ya mhojaji _____

Tarehe ya kuweka sahihi _____

Appendix IIA: **Interview Guide - English Version**

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES (MUHAS)
DIRECTORATE OF RESEARCH AND PUBLICATIONS

TITLE OF THE STUDY: EXPLORING PERCEPTION OF MULTI-DRUG RESISTANT TUBERCULOSIS PATIENTS AND THEIR TREATMENT SUPPORTERS ON RECEIVING TREATMENT UNDER HOSPITAL BASED AND AMBULATORY CARE MODEL IN DAR ES SALAAM MUNICIPALITIES AND KIBONG'OTO INFECTIOUS DISEASE HOSPITAL

IDENTIFICATION

NAME OF THE FACILITY ……..
Serial No.…….
Date; ……
Age ……years
Sex……
Education Level ……..
Job Title …….

INSTRUCTIONS TO INTERVIEWER

1. The interview will be conducted in Privacy.
2. Introduce yourself and assign number to interviewee.
3. The interview will take approximately one hour
4. The interview should be clearly tape recorded and notes will also be taken to compliment recorded interviews

QUESTIONS TO INPATIENTS (HOSPITALIZED) – INTERVIEW GUIDE

1. What were you doing for a living?
2. Do you have people who were depending on you for provision of basic needs? If yes who is taking care of them while you are in hospital?
3. When were you diagnosed and started treatment?
4. Are you experiencing discrimination by your fellow patients or health care provider? If yes how?

   Probe if the discrimination is from health care worker, fellow patient e.t.c
5. How do you feel being away from the people that you were used to be with? Do you get any support from your relatives or close friend since you have been hospitalized? Did they visit you?
6. Would you kindly tell me, do you have any fear of getting other disease transmission from the hospital? If yes or no

   Probe on: -

Health education on Infection Prevention and control (IPC), where did you get the information from? (From health care worker, community health care, others)

1. What is your opinion on hospital based model? Are you comfortable being at hospital? Is the environment favorable for you to live here?

   Probe about:

   Provision of food, cooperation from the family and what about ambulatory care model?
2. What do you think are perceived benefit of this model? Mention them.
3. What do you think are the main challenges of being hospitalized?
4. What is your suggestion to overcome those challenges?

QUESTIONS TO RELATIVES OF INPATIENT (HOSPITALIZED)

1. Have you ever heard about hospital care model for MDR TB patients? Also ask about ambulatory care model
2. Have you ever receive health education on MDR TB and hospital model of care
3. Probe on where did you get knowledge?
4. Probe on the knowledge of MDR TB and models (Do you know how to prevent yourself from the disease? Are you aware of Infection Prevention and Control?)
5. What was your patient doing before suffering from MDR TB?
6. Does he/she have surrounding people who were depending on him/her?

   Probe on

   - Wife/husband
   - Children
   - Relatives

   Who is taking care for them?

1. Have you heard about discrimination of MDR TB patients? Did your patient experience discrimination? Under what circumstances MDR TB patients could be discriminated?

   Probe if it happens from any member of the family (husband/wife, children, others)
2. What is your opinion about hospital model of care?
3. What do you think are perceived benefit of this model?
4. What do you think are the main challenges of your patient being hospitalized?
5. What is your suggestion to overcome those challenges?

QUESTIONS TO OUTPATIENT (AMBULATORY)

1. What are you doing for a living?
2. Since you are receiving services at outpatient basis are you still able to provide basic services to the family? Do you get a chance of engaging in your normal activities? e.g. farming, job
3. When were you diagnosed and started treatment?

4. Are you experiencing discrimination by health care provider? If yes how? Probe if the discrimination is from health care worker, fellow patient, treatment supporter e.t.c
5. Are you comfortable being at home? Do you think the environment is favorable for you?
6. How do you feel to be with your family? What support do you get from them?
7. Would you kindly tell me, do you have any fear of transmitting the disease to your family? If yes or no.

-Probe on

Health education on Infection Prevention and control (IPC), where did you get the information from (From health care worker, community health care, others)

8. What is your opinion on ambulatory care model?

-How do you feel going daily to the clinic with your supporter for treatment? What about the distance to the facility, bus fare for you and your patient?

-Will you be able to get bus fare for the whole period of treatment i.e. 8 months treatment, what is your opinion about hospitalization model?

9. What do you think are perceived benefit of this model? (ambulatory)
10. What do you think are the main challenges of being treated coming from home?
11. What is your suggestion to overcome those challenges?

QUESTIONS TO RELATIVE OF OUTPATIENT (AMBULATORY CARE MODEL)

1. Have you ever heard about ambulatory care model? Also ask about hospitalization model
2. Have you ever receive health education on MDR TB and ambulatory model of care

   Probe on where did you get knowledge?

   Probe on the knowledge of MDR TB and models (Do you know how to prevent yourself from the disease? Are you aware of Infection Prevention and Control?)
3. What was your patient doing before suffering from MDR TB?

4. Does he/she have surrounding people who were depending on him/her?

   Probe on

   - Wife/husband
   - Children
   - Relatives

   Is she/ he able to provide the basic needs as before?

5. Is your patient experiencing discrimination? Have you heard about discrimination of MDR TB patients? Under what circumstances MDR TB patients could be discriminated?

   Probe if it happens from any member of the family (close relative friends, husband/wife)

6. Would you kindly tell me, do you have any fear of acquiring the disease as you are caring your patient? If yes or no,

   Probe on health education on Infection Prevention and control (IPC), what do you know about IPC, where did you get the information from? (From health care worker, community health care, others)

7. What is your opinion on ambulatory care model?

   -How do you feel going daily to the clinic with your patient for treatment? What about the distance to the facility, bus fare for you and your patient?

   -Will you be able to get bus fare for the whole period of treatment i.e.8 month's treatment?

8. What do you think are perceived benefit of this model?
9. What do you think are the main challenges of being hospitalized?
10. What are your suggestions to overcome those challenges?

Appendix II B: Muongozo wa Mahojiano

CHUO KIKUU CHA SAYANSI YA TIBA MUHIMBILI

IDARA YA UTAFITI NA UCHAPISHAJI

UTAFITI JUU YA MTAZAMO WA WAGONJWA WA KIFUA KIKUU SUGU WANAO TIBIWA WAKIWA MAJUMBANI/WAKITOKEA MAJUMBANI AU WANAOLAZWA HOSPITALI PAMOJA NA NDUGU ZAO, UTAFITI UTAFANYIKA DAR ES SALAAM NA KIBONG'OTO HOSPITALI YA MAGONJWA YA KUAMBUKIZA

UTAMBULISHO

Jina la Kiambajengo……

Nambari ya dodoso……..…

Tarehe ……..……

Umri(miaka)…….……

Jinsia…….……

Kiwango cha Elimu …….……..

Cheo ……

MAELEKEZO KWA MTAFITI

1. Mahojiano yafanyike katika usiri.
2. Jitambulishe na toa namba ya utambulisho kwa mhojiwa.
3. Mahojiano yatachukua takribani saa moja
4. Mahojiano yote yanapaswa kurekodiwa kwenye mkanda kumbukumbu na kuandikwa kwenye kitabu.

Maswali kwa mgonjwa aliyelazwa

1. Ulikuwa unafanya nini kwa ajili ya kujiingizia kipato?
2. Ulipimwa lini kifua kikuu sugu na lini ulianza matibabu?
3. Una watu wanaokutegemea? Kama ndio, nani anawahudumia kwasasa wakati umelazwa?
4. Umewahi kuhisi kunyanyapaliwa na wagonjwa wenzio au mtoa huduma za afya? kama ndio kivipi unanyanyapaliwa?
5. Unajisikiaje kuwa mbali na nyumbani na watu uliowazoea? Unapata msaada wowote
6. kutoka kwa ndugu zako au marafiki wa karibu tangu ulipolazwa? Wanakutembelea?
7. Tafadhari, unaweza kuniambia kama unaogopa kupata maambukizi mengine yapatikanayo hospitali? Kama ndio, mmepewa elimu ya kujikinga na maambukizi? Kama ndio elimu hiyo ulipewa na nani? (mtoa huduma za afya, muelimishaji jamii, mwingine taja)
8. Nini maoni yako juu ya kupata huduma za kifua kikuuu sugu ukiwa umelazwa? Una furaha kupata huduma hapa hospitali? Mazingira ni mazuri hapa?

   Uliza zaidi kuhusu:

   Upatikanaji wa chakula, kutembelewa na ndugu zake na kama anapata ushirikiano na familia na vipi kuhusu kupata huduma za kifua kikuu sugu ukiwa unatokea nyumbani?(lengo ni kujua kama anazijua huduma zote mbili)
9. Unafikiri zipi ni faida za kupewa huduma ukiwa umelazwa? Zitaje
10. Unafikiri zipi ni changamoto za kupata huduma ukiwa umelazwa? zitaje
11. Nini maoni yako juu ya utatuzi wa changamoto hizi?

Maswali kwa ndugu wa mgonjwa aliyelazwa

1. Umewahi kusikia kuhusu huduma ya kulazwa kwa wagonjwa wa kifua kikuu sugu? Na je umewahi kusikia kuhusu huduma hizi kutolewa kwa mgonjwa akitokea nyumbani?
2. Umewahi kupata elimu ya afya juu ya kifua kikuu sugu na huduma ya kulazwa kwa wagonjwa tajwa? Kama umewahi kupata elimu hiyo ulipewa na nani? Uliambiwa jinsi ya kujikinga na ugonjwa huo?
3. Mgonjwa wako alikuwa anafanya shughuli gani za kujiingizia kipato kabla ya kulazwa?
4. Ana watu wanao mtegemea? Kama mke/mume. Watoto na ndugu wengine? Nani anawahudumia kwa sasa?
5. Umeshawahi kusikia juu ya kunyanyapaliwa kwa wagonjwa wa kifua kikuu sugu? Mgonjwa wako amewahi kunyanyapaliwa? Kama ndio amenyanyapaliwa na watu gani? (Mgonjwa mwenzie, mtoa huduma za afya)
6. Nini maoni yako kuhusu huduma za kulazwa kwa wagonjwa wa kifua kikuu sugu?
7. Unafikiri nini faida za kupata huduma za kifua kikuu sugu mgonjwa akiwa amelazwa? zitaje
8. Unafikiri zipi ni changamoto za kupata huduma za kifua kikuu sugu kwa mgonjwa akiwa amelazwa? zitaje
9. Nini maoni yako juu ya utatuzi wa changamoto hizi?

Maswali kwa mgonjwa anayetokea nyumbani

1. Unafanya shughuli gani kujiingizia kipato?
2. Kwasababu unapata huduma za kifua kikuu sugu ukitokea nyumbani, bado unaweza kutoa huduma kwa familia yako kama zamani ulivyokuwa hauumwi? Unapata nafasi ya kufanya shughuli nyingine? Kama kulima na nyinginezo?
3. Ulipimwa lini kifua kikuu sugu na lini ulianza matibabu?
4. Umewahi kuhisi kunyanyapaliwa na mtoa huduma za afya, mgonjwa mwenzio au msaidizi wako? kama ndio kivipi?

5. Unafuraha kutibiwa ukitokea nyumbani? Unafikiri mazingira ni mazuri kwako?
6. Unajisikiaje kuwa na familia yako nyumbani wakati unaumwa? Unapata msaada wowote kutoka kwao?
7. Una hofu ya kuwaambukiza ugonjwa huu kwa familia yako? Kama ndio au hapana elezea

   Uliza zaidi juu ya: kama amepata huduma ya kujikinga na maambukizi na kama amepata amepewa na nani huduma hiyo (mtoa huduma za afya, muelimishaji jamii, mwingine taja)
8. Nini maoni yako juu ya huduma ya kutibiwa ukitokea nyumbani?

   -Unajisikiaje kwenda hospitali kila siku na msaidizi wako? Vipi kuhusu umbali kutoka nyumbani mpaka hospitali, nauli?

   -Utaweza kupata nauli kwa miezi yote nane ya kufuata huduma hospitali?

   - Unazungumziaje upatikanaji wa huduma hii ya kifua kikuu sugu ukiwa umelazwa? (lengo ni kujua kama anazijua huduma zote mbili)
9. Unafikiri zipi ni faida za kupewa huduma ukiwa unatokea nyumbani? Zitaje
10. Unafikiri zipi ni changamoto za kupata huduma ukiwa unatokea nyumbani? zitaje
12. Nini maoni yako juu ya utatuzi wa changamoto hizi?

Maswali kwa ndugu wa mgonjwa anaetibiwa akitokea nyumbani

1. Umewahi kusikia kuhusu huduma za kifua kikuu kwa mgonjwa atokeaye nyumbani? Na je umewahi kusikia kuhusu huduma hizi kutolewa kwa mgonjwa akiwa amelazwa?

2. Umewahi kupata elimu ya afya juu ya kifua kikuu sugu na huduma ya kutokea nyumbani kwa wagonjwa tajwa? Kama umewahi kupata elimu hiyo ulipewa na nani? Uliambiwa jinsi ya kujikinga na ugonjwa huo

3. Mgonjwa wako alikuwa anafanya shughuli gani za kujiingizia kipato kabla ya kuumwa kifua kikuu sugu?

4. Ana watu wanao mtegemea? Kama mke/mume. Watoto na ndugu wengine? Ana uwezo wa kuwahudumia kama zamani alipokuwa haumwi?

5. Umeshawahi kusikia juu ya kunyanyapaliwa kwa wagonjwa wa kifua kikuu sugu? Mgonjwa wako amewahi kunyanyapaliwa? Kama ndio amenyanyapaliwa na watu gani? (Ngudu wa karibu, mume/mke)

6. Tafadhari, unaweza kuniambia kama unaogopa kuambukizwa ugonjwa huu wakati unamuhudumia mgonjwa? Kama ndio au hapana, umepewa elimu ya kujikinga na maambukizi? Kama ndio elimu hiyo ulipewa na nani? (mtoa huduma za afya, muelimishaji jamii, mwingine taja)
7. Nini maoni yako kuhusu huduma kwa wagonjwa wa kifua kikuu sugu wakitokea nyumbani?

8. Unafikiri nini faida za kupata huduma za kifua kikuu sugu mgonjwa akiwa anatokea nyumbani? Zitaje

9. Unafikiri zipi ni changamoto za kupata huduma za kifua kikuu sugu kwa mgonjwa akiwa anatokea nyumbani? Zitaje

10. Nini maoni yako juu ya utatuzi wa changamoto hizi?