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Social and Economic Consequences of Pulmonary Tuberculosis – Perspectives of Patients, Their Families, the Community, and Health Care Providers Who Care for TB Patients in Mbeya and Songwe Regions, Tanzania,

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SOCIAL AND ECONOMIC CONSEQUENCES OF PULMONARY TUBERCULOSIS – PERSPECTIVES OF PATIENTS, THEIR FAMILIES, THE COMMUNITY, AND HEALTH CARE PROVIDERS WHO CARE FOR TB PATIENTS IN MBEYA AND SONGWE REGIONS, TANZANIA



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and Dr. Aneesa Moolla

A dissertation submitted to the Faculty of Health Sciences in fulfilment of the requirements for the degree of Doctor of Philosophy (PhD) in the field of Public Health. University of Witwatersrand, Johannesburg, 2025

September 2025

DECLARATION

I declare that this dissertation is my own, unaided work. It is being submitted for the degree of Doctor of Philosophy at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at any other university.



_____

Stella Peter Kilima

29th day of September, 2025

DISCLOSURE

In the interest of transparency, I would like to disclose the use of Artificial Intelligence (AI) tools, specifically OpenAI's ChatGPT and Grammarly, in the development of this work. These AI tools assisted in refining and editing text, significantly enhancing the quality and efficiency of the writing process.

DEDICATION

This dissertation is dedicated to my beloved husband, Charles Haule, and my dear children, Charlotte, Charlene, and Brayden Haule. Your presence has made this long journey possible.

PUBLICATIONS

The following peer-reviewed publications are included in this dissertation.

1. Kilima SP, Hirasen K, Mubyazi GM, Moolla A, Ntinginya NE, Sabi I, Mwanyonga S, Evans D. Implications of pre-diagnosis costs incurred by patients and their families for tuberculosis-related health-seeking behaviours in Mbeya and Songwe regions, Tanzania. Submitted to *PLoS One*. *Under review*

2. Kilima SP, Mubyazi GM, Moolla A, Ntinginya NE, Sabi I, Simeon P. Understanding the implications of social and financial burdens of pulmonary tuberculosis on patients, survivors and their family caregivers on care seeking and treatment in Tanzania: Feedback from a qualitative study in Mbeya and Songwe regions. Tanzania Journal of Health Research, 2023;24(3):241–54. https://dx.doi.org/10.4314/thrb.v24i3-8

3. Kilima SP, Mubyazi GM, Moolla A, Ntinginya NE, Sabi I, Mwanyonga SP, Evans D. Perceived access to social support during and after TB treatment in Mbeya and Songwe regions, Tanzania: perspectives from TB patients and survivors set against health care providers. Frontiers in Health Services. 2024 Jul 11;4:1273739. https://doi.org/10.3389/frhs.2024.1273739

FORMATTING AND LANGUAGE

Following the Faculty of Health Sciences Guide, references are formatted in the Vancouver style and numbered sequentially within the text, using numbers in parentheses (e.g., (1)). Instead of listing references at the end of each chapter, a comprehensive list is included at the end of the dissertation.

The results chapters (i.e., Chapters 4–6) consist of two published articles and one submitted manuscript, presented as they were at the time of acceptance or submission. Although the text has been modified to meet the dissertation requirements, its structure follows the format specified by the respective journals.

PERMISSION TO PUBLISH

Two journal articles were included in this dissertation. The articles were published in open-access journals with a Creative Commons Attribution license and do not require additional permission to be reused or included in this dissertation. The remaining journal article is under review.

ABSTRACT

Tuberculosis (TB) is a significant health concern that profoundly affects individuals and communities, especially in low-income areas. The disease not only causes physical and psychological harm but also imposes heavy financial and economic burdens, especially on people with low incomes, who face limited access to healthcare facilities (HCFs). Pulmonary TB (PTB) is a highly contagious airborne disease that demands early diagnosis and prompt treatment to prevent severe complications and limit its spread. However, individuals in remote or rural areas face significant challenges in accessing timely care, further exacerbating the burdens associated with the disease.

This study aimed to enhance understanding of the social and economic impacts of PTB from the perspectives of PTB patients, their family representatives, PTB survivors, and healthcare Providers (HCPs) in the Mbeya and Songwe regions of Tanzania. Specifically, this study aim to describe financial burdens experienced by patients, their families, TB survivors and HCPs before and during PTB treatment. To explore the social and economic consequences of PTB as perceived by multiple stakeholders and investigate the coping strategies they employed with particular emphasis on the role of social support in managing illness and treatment.

This was a cross-sectional study nested in an observational longitudinal study called ‘The TB Sequel Project.’ It employed both qualitative and quantitative data to achieve its specific objectives. Quantitative data drawn from 261 laboratory-confirmed TB patients were used to address objective one. For objectives two and three, qualitative data were collected through key informant interviews with HCPs and in-depth interviews with patients and PTB survivors. All participants provided informed consent.

The study found that PTB patients and survivors in the study regions faced significant social and economic challenges, including stigma, financial hardship, and limited access to healthcare services. Psychological distress was frequently reported, particularly among patients lacking anticipated social support from their close relatives or broader community which sometimes hindered treatment adherence. The majority of TB patients spent most of their financial resources seeking care from inappropriate sources, such as traditional healers or unregulated drug vendors. Nearly three-quarters (72.8%) of participants reported delaying their visit to a health facility for more than four weeks after the onset of symptoms. These testimonies reaffirm existing evidence indicating that, although TB diagnosis and treatment in

Tanzania are provided free of charge, still many patients delay seeking medical attention due to pre-diagnosis costs, limited awareness of TB symptoms, and the pervasive stigma associated with TB and HIV. The implications of this delay in seeking care is significant because postponed care can lead to delayed diagnosis, increased disease transmission, worsening of clinical symptoms, and long-term health consequences. Furthermore, the delays not only undermines timely TB control efforts but also increase the risk of poor treatment outcomes and continue community transmission. TB Survivors similarly reported persistent challenges even after completing treatment, including economic hardship, ongoing stigma, and psychological distress. HCPs confirmed the prevalence delays in diagnosis and access to care, frequently attributing them to stigma, and financial constraints.

The findings suggest an urgent need for a holistic approach to PTB case management that incorporates social support, including both moral and financial ones, since they are important for encouraging the patients and the survivors. Also, multisectoral strategies involving commitments geared towards strengthening the existing healthcare infrastructure and expanding financial assistance programs are essential steps toward enhancing TB care and achieving the End TB Strategy 2035 goals.

Keywords: TB, social support, TB patients, TB Survivors, direct and indirect costs

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I am deeply grateful to Dr. Andrea Rachow and Dr. Nyanda Elias Ntinginya for selecting me as one of the beneficiaries of the TB Sequel project which is being funded by the German Ministry for Education and Research (BMBF; grant ID: 01KA1613) from 2016 to 2022.). The financial support provided through this project has been crucial to my PhD studies, offering both the necessary resources and the encouragement to continue. This support has facilitated my work and provided the strength and reassurance needed to persevere. I sincerely appreciate this opportunity.

Furthermore, I extend my gratitude to Dr. Issa Sabi for his invaluable advice and opinions during my fieldwork preparation and guidance on various aspects of my data collection plans, as well as during the actual data collection process. I also appreciate Dr. Joel Francis for his support and guidance. I also thank Mr. Kamban Hirasen for sharing his statistical expertise, which greatly enhanced the analysis of the TB Sequel dataset.

I am indebted to the School of Public Health at the University of Witwatersrand, Johannesburg, for granting me this wonderful opportunity to enroll as a PhD student in 2018.

Sincerely, I remain grateful to the Government of the United Republic of Tanzania for granting me paid study leave through the National Institute for Medical Research (NIMR), where I am employed, allowing me to pursue my PhD studies. The NIMR Management provided me with maximum cooperation and assistance whenever I needed it. Additionally, I

deeply appreciate the support from my co-workers at NIMR, both at the Mbeya Medical Research Centre (NIMR-MMRC) and at the Headquarters (NIMR-HQ) in Dar es Salaam.
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Finally, I extend my deepest gratitude to my family, including my husband, children, sisters, and brothers, who provided invaluable support, both collectively and individually, encouraging me to persevere and remain hopeful throughout my academic journey. I am profoundly thankful to my parents, Dr. Peter Kilima and Mary Nyenga, whose unwavering love and support made me feel an even stronger sense of belonging. They have been a constant source of blessings in my life, for which I am eternally grateful.

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LIST OF ABBREVIATIONS

ADDO	Accredited Drug Dispensing Outlets
AIDS	Acquired Immunodeficiency Syndrome
BCG	Bacille Calmette-Guérin
CBOs	Community Based Organizations
CHWs	Community Health Workers
CRF	Case Report Forms
CSO	Civil Society Organization
DTLC	District Tuberculosis and Leprosy Coordinator
EPTB	Extra-pulmonary tuberculosis
HCF	Health Care Facilities
HFs	Health Facilities
HIV	Human Immunodeficiency Virus
LMIC	Low and Middle-Income Countries
MDR	Multidrug-resistant
MoH	Ministry of Health
MoHSW	Ministry of Health and Social Welfare
NGO	Non-Governmental Organization
NIMR	National Institute for Medical Research
NTLP	National Tuberculosis and Leprosy Programme
PLHIV	People Living with HIV
PTB	Pulmonary Tuberculosis
RTLC	Regional Tuberculosis and Leprosy Coordinator
SDGs	Sustainable Development Goals
SDH	Social Determinants of Health
TB	Tuberculosis

UHC	Universal Health Coverage
WHO	World Health Organization
ZRH	Zonal Referral Hospital

CHAPTER 1

INTRODUCTION

Tuberculosis (TB) remains one of the world's deadliest infectious diseases (1), ranking second to COVID-19 in recent years, in terms of mortality caused by single infectious agent (2,3). Despite decades of evidence-based global interventions, TB especially PTB continue to disproportionately burden public health systems, particularly in low and middle-income countries (LMIC) (4). This study explores the broader socio-economic and emotional effects of PTB, particularly within the Tanzanian regions of Mbeya and Songwe, where significant gaps persist in understanding the lived experiences of patients, caregivers and healthcare providers.

According to the latest WHO Global TB report (2024), the global TB incidence rate in 2023 was estimated at 134 cases per 100,000 population (95% uncertainty interval:125-145), reflecting a slight increase of approximately 0.2% from 2022, primarily due to global population growth. TB-related mortality continued to decline, with an estimated 1.25 million deaths in 2023 approximately 1.09 million among HIV negative individuals and 161,000 among those co-infected with HIV. This represents a modest reduction from the 1.32 million deaths reported in 2022 and builds on the progress made since the peak mortality period during the COVID-19 pandemic (2020-2022) (5).

TB is primarily categorized into pulmonary TB (PTB) and extra-pulmonary tuberculosis (EPTB) (6,7). PTB, the most prevalent form, is caused by *Mycobacterium tuberculosis* (*M.tb*), a pathogen that primarily infects the lungs but can also spread to other organs such as, the kidney, brain or spine (8,9). EPTB forms like TB meningitis and disseminated TB including TB sepsis, are considered more severe and life-threatening due to their severity and complications, and potential for rapid clinical deterioration (10,11). Globally it is estimated that 5–10% of people infected with *M.tb.* are likely to develop active TB disease during their lifetime (2). In its latent form, TB remains dormant and non-contagious, but when reactivated, it becomes infectious and symptomatic (2,12). The symptoms of active TB include a persistent cough lasting more than three weeks, which may produce mucus (phlegm) or mucus mixed with blood, along with symptoms such as fatigue, fever, night sweats, chest pain, loss of appetite and weight loss (12).

PTB is highly infectious, as *M. tb.* can spread through airborne droplets when an infected individual coughs, sneezes, or speak and others inhale the bacteria (13,14). Evidence shows that untreated, sputum-positive PTB patients can infect an average of 10 to 15 people per year (9). Prompt diagnosis and initiation of treatment are essential to prevent transmission and reducing the risk of serious health outcome, including death (15). Evidence reveals that the risk of widespread pathogen transmission is significantly elevated in community settings where this reality is either unknown or unacknowledged. Furthermore, even in cases where community members recognize the reported transmission risks, a lack of awareness about TB symptoms presents an additional challenge. The limited awareness of the reported health risks may lead to delays in seeking essential healthcare services, including timely diagnosis and prompt initiation of treatment at the appropriate HCFs (5).

Despite the availability of TB effective treatment, many patients experience diagnosis and treatment delays, especially in resource- limited settings. These are often caused by poor awareness of TB symptoms (5), geographical barriers to HCFs and inadequate infrastructure (13,16,17). Even after treatment initiation, a proportion of patients discontinue therapy and become lost to follow-up (LTFU), which compromises disease control efforts (15). LTFU remain a major contributor of PTB related morbidity, mortality, and continued transmission, especially in LMICs. Between 2012 and 2019, the global rate of LTFU remain around 6% and this trend has continued in recent years (18,19).

Failure to initiate TB treatment early or to adhere to the full recommended regimen significantly increases the risk of prolonged illness, ongoing transmission and most critically the development of drug-resistant TB (20). Drug resistance often arises when anti-TB medications are misused, whether through incorrect prescriptions, substandard drug quality, or premature discontinuation by patients (5) One of the most severe outcomes of non-adherence is multidrug-resistant TB (MDR-TB), caused by Mycobacterium tuberculosis strains resistant to isoniazid and rifampicin, the two most effective first-line drugs. MDR-TB requires longer, more toxic, and more expensive treatment regimens, and is associated with a higher risk of treatment failure and mortality (5,21). This form of TB continues to pose a serious global public health and health security threat. Despite the introduction of shorter all oral regimens such as Bedaquiline + Pretomanid + Linezolid+ Moxifloxacin (BPaLM/BPaL)

which is now WHO recommends for MDR/RR-TB patients, access to these treatment remains limited with only 40% of MDR -TB cases initiated on treatment globally in 2023 (5,21).

Preventing MDR-TB through early diagnosis and strict treatment adherence remain the most effective and cost-effective strategy. For drug-susceptible TB, WHO has recommended a 6-month regimen consisting of four drugs: rifampin, isoniazid, pyrazinamide, and ethambutol during intensive phase, followed by isoniazid and rifampin during the continuation phase (2, 5). Adherence to the current WHO-recommended treatment protocol for a 4-6 month course of anti-TB drugs offers the potential to save the lives of approximately 85% of affected individuals (2,13). The prescribed treatment for PTB consists of two distinct phases; namely, the intensive and continuous ones. In the intensive phase, patients are generally given all four mentioned drugs. After two months, pyrazinamide is typically discontinued, while isoniazid and rifampin are continued as daily therapy for an additional four months (2). However, if a patient's results remain culture-positive after two months, the treatment may need to be extended. The purpose of the intensive phase is to eliminate most bacteria and rapidly prevent the development of drug resistance.

Clinical research evidence demonstrates that PTB patients, strict adherence to their medication regimen is essential to prevent the development of MDR-TB (2). It simultaneously spares the patient and their family from bearing unnecessary, additional, and catastrophic financial and economic burdens (13,22,23). Moreover, the entire healthcare facility, the broader healthcare system, and the health sector can achieve significant financial and economic savings by avoiding costs associated with the hospitalization of numerous patients. Additionally, this helps prevent the transmission of the pathogen to others (24). However, it's crucial to emphasize that all of these consequences can be avoided if patients are able to access timely and appropriate treatment for PTB.

In the worst-case scenario, failure to commence treatment early and to adhere to the recommended dosage can result in more severe outcomes for the lungs and other organs, thereby complicating the treatment process and increasing the risk of death (25). Those who survive the disease may suffer from long-term psychological impacts due to stigma and isolation, including anxiety, depression, and social isolation (26). TB-related stigma often

prevents individuals from seeking or continuing care, further perpetuating the cycle of illness and poverty (26).

Research has demonstrated that, despite decades of global evidence-based interventions, PTB remains a significant public health challenge. Even though PTB is treatable and curable with proper diagnosis and prompt treatment using standard regimens, the disease continues to disproportionately burden public health. Despite robust global evidence linking poverty and low socio-economic status (SES) to an increased risk of PTB infection and its associated health and social consequences, millions of people in LMICs, particularly in Africa and southern Asia, remain vulnerable (27,28). These regions face persistent challenges such as poverty, malnutrition, limited access to healthcare, and overcrowded living conditions all of which are major social determinants of TB (27–30). This is largely due to inadequate, targeted interventions to break them out of this poverty trap (31). Every person is at risk if exposed to TB pathogens, but the most at-risk population groups are those living in extreme poverty (29,30). The vulnerability of PTB is linked to living as migrants in socially and healthcare-under-served settings. Homelessness increases risk since individuals often lack basic social amenities, including access to essential healthcare unless there is sufficient and timely social support and HCFs (32,33).

Additional risk factors include HIV co-infection, malnutrition, diabetes, indoor air pollution, alcohol abuse, tobacco use and immunosuppressive therapy (34,35). These comorbidities increase the risk of TB infection and progression to active disease. TB also severely disrupts the livelihoods of patients and their families by impairing work capacity and productivity (8,25,36). Many patients are unable to work during severe illness, while others experience reduced efficiency, leading to income loss (36). While many countries provide free TB treatment (8), diagnostic services such as imaging and follow-up tests may incur out-of-pocket costs [36]. For low-income households, these expenses can be catastrophic. Health insurance coverage of financial protection schemes are essential to improve access and ensure adherence, aligning with the goals of universal health coverage (UHC) (24,38).

Learning from the real-world experience regarding the financial, economic, and social costs of PTB faced by individual patients and their households or families, as well as by service providers, is key to addressing this public health threat. The lessons learned, if properly and

timely used to inform policy and program authorities, along with practical recommendations, can significantly contribute to accelerating the best practices outlined in the global (and subsequently the Regional and Specific National) End-TB Strategy. This perspective forms the core of the present dissertation, which systematically presents and discusses a study conducted in two regions of Tanzania, namely: Mbeya and Songwe. The study focuses on exploring PTB patients' experiences in relation to care-seeking behaviours, the social support they received both before and after their diagnosis, and the financial and economic burdens they incurred while seeking PTB-related care during their illness. These costs often hindered their ability to participate effectively in income generation or in other means of subsistence. Additionally, the study examined how caretakers of these patients perceived the burden of PTB, focusing on the financial, economic, and social costs involved in caring for PTB patients. Frontline healthcare providers (HCPs) were also given the opportunity to explain the PTB-related costs from their perspective and that of the healthcare system in which they were employed. This approach widened the chance for getting the feedback that has been analyzed to broaden the understanding of PTB's social and economic consequences from the perspectives of stakeholders representing different groups of the community, and these are the PTB patients, their household or family representatives, TB survivors, and healthcare providers in the study regions.

To guide the analysis, the study is grounded in Cohen and Wills's Stress and Social Support Theory developed in 1985, which argues that individuals with limited social support are more vulnerable to stress and its health consequences. In the context of PTB, lack of emotional, informational and financial support from families, communities, and healthcare providers can exacerbate the illness experience and delay recovery (39,40). To achieve positive outcomes, PTB patients must receive appropriate support, in order to improving outcome and reduce the broader social and economic impacts This can be done by including information, companionship, as well as financial and emotional assistance (32,40).

Therefore, this study seeks to deepen understanding of how PTB affects individuals and communities beyond clinical outcomes. Despite the availability of free TB treatment in many countries, including Tanzania, limited attention has been given the broader socio-economic and emotional impacts of PTB on patients, their families, healthcare providers, and communities. Existing literature focuses largely on clinical and epidemiological aspects, with

fewer studies addressing the real-life experiences of those affected in low-resource settings. To fill this gap, the study examines the socio-economic consequences of PTB and the coping strategies used by patients and survivors in Mbeya and Songwe regions. The findings aim to generate context-specific evidence to support more holistic, patient-centered TB interventions aligned with the Global End TB Strategy.

ORGANIZATION OF THE DISSERTATION

Chapter One: This chapter highlights the existing research gap, sets the contextual background, and delves into the theoretical issues surrounding TB illness and its socioeconomic impact in Tanzania. Furthermore, the chapter provides a definition of the disease, outlines its impact, and expounds upon the methodology employed for data collection. It also examines the use of stress and social support theory, shedding light on its implications for patients with PTB. The chapter ends by leveraging the perspectives of patients, TB survivors, and HCPs.

Chapter Two: This chapter extensively explores the academic literature, delving into the epidemiology of TB to lay a comprehensive foundation for the dissertation. The literature review dissects scholarly works and arguments on TB, focusing on how they align with the Global End TB strategy. Moreover, this section offers a comprehensive understanding of the current conversation regarding TB, investigating its extensive social and economic impacts in Tanzania and worldwide. This chapter also explores the theoretical and conceptual framework, illustrating the connections between TB and the costs it imposes on society. TB not only affects patients physically but also takes a toll on their social and economic well-being, underscoring the need for social support to alleviate the associated challenges.

Chapter Three: This chapter, describe the methodology employed in this research, providing an analysis informed by my experiences in the study regions. It explores my dual role as both an observer and active participant in the research process. The chapter details how both the quantitative and the qualitative data collection methods were employed in an attempt to gather the data during the exploration process on the issues specified according to the stated study objectives. It justifies how the application of mixed methods provides great benefits in the

investigation on issues that are unobvious to be recorded statistically or by direct observation, for example, the implicit drivers for a timely or delayed seeking of PTB treatment and care, meanwhile, a triangulation of results obtained from the application of mixed methods for data collection and data analysis discussed justifiably.

Chapter Four: This chapter explores the pre-diagnosis costs borne by TB patients and their families. The findings indicate that approximately 72% (nearly three-quarters) of the interviewed PTB patients reported seeking care from formal HCFs more than four weeks after the onset of symptoms. Alarmingly, some individuals disclosed delays of up to a year before seeking care. The majority initially resorted to self-medication until their health deteriorated to the point where they sought hospital diagnosis. This behaviour poses a significant risk to the broader community, as research indicates that a single individual with TB can potentially transmit the disease to 10-15 people in close contact annually [9].

Chapter Five: This section explains the implications of PTB's social and financial burdens to patients, survivors, and caregivers. Through qualitative data collection methods, respondents provided detailed accounts of the challenges they faced when obtaining funds for transportation and meals, as well as time spent seeking care at formal HCFs. Patients reported that managing TB alongside other conditions like diabetes, hypertension, and other infectious diseases significantly increased the amount of time and money required for treatment. Additionally, they highlighted the social repercussions, such as stigma, social isolation, and the association of TB symptoms with witchcraft. These factors contributed to delays in seeking treatment and led to additional health and financial burdens.

Chapter Six: This chapter explains the experiences of patients and survivors regarding social support during and after treatment. It highlights the high demand for psychosocial, financial, and material support throughout the treatment process and in the post-treatment period. Most TB patients and survivors report an absence of support from their relatives or the broader community. As a result, they faced considerable challenges, particularly when required to pay out-of-pocket for transportation while seeking care. Survivors shared experiences of being denied support even by their close relatives. It is important to recognize that survivors of TB require support in order to recover what they may have lost during their illness. Some individuals may experience lingering effects that make it difficult for them to fully engage in

certain activities. They also reported experiencing social isolation due to the belief that they could transmit PTB infections. Additionally, limited psychological support at the TB clinics they visited was a common concern. The experiences of TB clinic staff closely aligned with nearly all the accounts shared by their clients

Chapter Seven: This chapter presents the study's findings through an integrated narrative, providing an overall perspective of the research, from its methodology to its findings and conclusions.

Chapter Eight: This is an overall conclusion that summarizes the whole discussion of my study, its contribution to the End TB strategy, and identifies further research areas. This dissertation concludes that effectively eradicating TB is a challenging task that requires substantial social support to mitigate the social and economic consequences. To address this, it is proposed that the government should establish a system that provides financial assistance to TB patients who adhere to their treatment regimens. This support could serve as a vital buffer against the adverse impact of TB on individuals and communities. Also, this chapter provides a discussion on the policy implications and recommendations.

CHAPTER 2

LITERATURE REVIEW

2.1.1 Epidemiology and Disease Overview

This chapter explores TB's general aetiology and epidemiology, thoroughly understanding its global and local impact, focusing on Tanzania. It highlights the significant association between TB and HIV, the psychological and social dimensions of the disease, and the challenges in its management and treatment. Furthermore, this section examines TB's economic and social repercussions, highlighting the pressing need for cost-effective strategies, strengthened social support systems, and innovative approaches to mitigate the disease's impact. Understanding these aspects is vital for developing interventions that address the clinical management of TB and its broader societal implications.

2.1.2.1 TB: General Aetiology and Epidemiology of the Disease

TB is an infectious disease caused by a pathogen scientifically called *Mycobacterium tuberculosis* (*M.tb)*. Although the disease affects mostly the lungs, it can also impact other parts of the body (41,42). TB often affects men more than women during their prime working years, typically between the ages of 15 and 59 (43). It is estimated that a quarter of the world's population has been infected with TB bacteria, with approximately 5-10% eventually developing symptoms and progressing to active TB. It is important to highlights that individuals infected with TB bacteria who have not developed illness cannot transmit the disease to others (23,44). TB is a serious condition that can be fatal if left untreated. However, it is also preventable and curable. Treatment usually consists of a course of antibiotics taken over six months. In Tanzania, infants and young children receive the Bacille Calmette-Guérin (BCG) vaccine to protect against TB (45). Although the BCG vaccine is effective in preventing TB in infants and young children; however, its effectiveness in preventing TB infection in adults is limited (23,42–45).

2.1.2.2 Global Picture of TB

TB is both preventable and curable; however, in 2022, it ranked as the world's second leading cause of death from a single infectious agent, following the coronavirus disease (COVID-19) (18). TB affects about 10.6 million people worldwide, of which 5.8 million are men and 3.5 are women, including 1.3 million children (23). Unfortunately, 3.1 million cases remained undiagnosed or unreported (1,12). The WHO's 2023 report indicates that in 2022, most TB cases were reported in Southeast Asia, and this accounted for 46% of global cases. Africa accounted for 23% of cases recorded, followed by the Western Pacific region with 18% (23). While the TB epidemic impacts all regions worldwide, its burden is disproportionately concentrated in 30 countries, which accounted for approximately 87% of the estimated global incidence of TB cases in 2022 (46).

Moreover, although some countries have significantly reduced their TB burden, by achieving a notable reduction of fewer than 10 cases and less than one death per 100,000 people annually a remarkable milestone (47). These successes are not uniformly distributed, and progress remains fragile particularly in the face of health system shocks such as COVID-19 pandemic. The pandemic not only disrupted TB diagnosis and treatment services but likely contributed to an estimated a half a million additional TB related deaths between 2020 and 2022, suggesting a reversal of hard-won gains. In addition, many countries have recently demonstrated strong political commitment to ending the TB epidemic. In 2023, an estimated 1.25 million deaths were caused by TB globally, marking a slight decrease from the 1.32 million deaths reported in 2022 (23,48). While the global number of TB-related deaths decreased by 19% from 2015 to 2022 (49), the fact that 3.1 million cases remained undiagnosed or unreported in 2023 signals persistent gaps in case detection and surveillance. This highlights the ongoing challenge of strengthening systems, addressing stigma, and improving health seeking behaviours.

Significant progress has been made in reducing TB-related deaths with 47 countries achieving a reduction of at least 35% (23). Implementing timely, affordable, cost-effective, and socially acceptable policies, tools, and interventions is essential to achieving the sustainable development goal of eliminating tuberculosis by 2030 (18). Furthermore, WHO launched the End TB Strategy 2016-2035, urging all WHO and United Nations (UN) member countries to develop or adopt policies and programs aimed at reducing TB-related deaths by 95% and reducing the number of TB patients by 90%. The strategy also sought to eliminate the excessive financial burden on families affected by TB (13). During the WHO 2023 assembly,

the importance of all participants sharing a common understanding of the issue and the path forward was emphasized. Countries were encouraged to ensure that their policies and programs supported innovative initiatives, including affordable, efficient, and compelling new technologies, while also considering the feasibility and acceptability within their specific contexts (50–52).

2.1.2.3 Overview of the LMICs

TB is a disease that can occur anywhere in the world, but it mainly affects people in LMICs (53). Studies have shown that over 80% of annual TB cases and deaths worldwide are reported in LMICs. In these countries, mechanisms for finding TB cases exist but are often ineffective due to various obstacles. These obstacles contribute to the national health information systems not being adequately prepared, thus relying on individual case reporting rather than active outreach programs (54). Active case detection is a new approach to TB screening that holds considerable promise for rapidly identifying cases within underserved healthcare settings. This approach is particularly suitable for targeting high-risk groups, including homeless individuals, miners, and those living in remote or isolated areas (2).

Controlling TB has become more expensive, and there is a growing need for financial and human resources to address this issue effectively (55). Reports on the epidemiology of TB suggest that the burden of the disease varies across continents and countries (55). In African countries, the high prevalence of HIV/AIDS exacerbates the TB situation (55]) In sub-Saharan Africa, the TB burden is connected to undiagnosed and delayed diagnoses, along with challenges in accessing high-quality care (56). These factors result in an elevated risk of mortality, prolonged suffering, and significant financial hardship. In East Africa, a person can be identified as having TB when they report to a HCF after experiencing a cough for two weeks (56). Although the literatures indicates that TB case detection in East Africa region has reached approximately 40%, this remains insufficient to meet the required WHO End TB strategy target which aim for 50% reduction in TB incidence by 2025 (56,57). TB incidence rate in the East Africa region is 183/100,000 population in Tanzania, 223/100,000 population in Kenya, and 198/100000 population in Uganda (57,58). While the number of TB cases notified per 100,000 population was 165 in Tanzania, 237 in Kenya and 213 in Uganda (59,60). These consistently high incidence rates show that the TB screening process among contacts may not be conducted as thoroughly as required (61,62). Despite national efforts, effective implementation of TB screening continues to face challenges in these settings, with

millions of TB cases remain undiagnosed or unreported annually. Contributing factors include limited health seeking behaviour, persistent stigma, financial constraints and gaps in public health infrastructure (1,62). In these countries, the disparity between estimated incidence and notified cases highlights weaknesses in case detection efforts (62,63). According to WHO 2023, many LMICs, including those in East Africa, experience significant diagnostic gaps due to limited access to quality-assured screening tools and inconsistent integration of TB screening into routine primary healthcare services (1). These limitations contribute to the persistence of undetected and untreated TB cases, thereby perpetuating TB transmission and mortality in the region (64)

Furthermore, the majority of TB cases occur in the LMICs setting, where health system are often under resourced and patients are more likely to experience catastrophic costs due to limited social protection (65). These setting share common challenges such as weak health infrastructure, delayed diagnosis and heavy reliance on out -of-pocket payment as most individuals lack health insurance coverage (66). Social support becomes especially vital in such contexts, underscoring the need to explore how individuals and households cope under these constraints. The economic burden of living with pulmonary TB, whether seeking care or not, highlights the strong link between vulnerability to TB and socioeconomic status (27,67,68). In both low- and high-income settings, poverty is significantly associated with delays or failure to seek care at formal health facilities (68). Individuals experiencing financial hardship often face challenges accessing TB-related care, and those with limited awareness of the disease are more susceptible to delayed diagnosis and adverse outcomes. Additionally, patients frequently incur high out-of-pocket costs when seeking care from distant health facilities, especially when already facing financial distress (69).

In both categories, there is a significant association between living in poverty and the delay or failure to contact the conventional HCFs for care and treatment. Individuals experiencing serious financial hardships face difficulties in seeking TB-related care, while those with limited knowledge about the symptoms and consequences of the disease are more susceptible impact to TB survivors: to PTB infection and suffer more severely from negative consequences compared to those who are better off and more knowledgeable (70,71). It is further noted that PTB is associated with high costs for patients needing to visit HCF located far away, often while in a state of financial shortage. Additionally, failing to adhere to the scheduled treatment increases the risk of developing MDR-TB, which requires more complex and costly treatment and may lead to long-term or permanent physical or mental disabilities,

or both (72,73). Strengthening health systems, implementing active case detection, and increasing resource investments are essential to reducing TB's impact and improving outcomes, especially for high-risk and underserved populations.

2.1.2.4 The Association between TB and HIV

TB is classified as an opportunistic infection that occurs more frequently in people with weakened immune systems. HIV is known to weaken the immune system, which raises the risk of TB in people living with HIV (PLHIV). Research shows that individuals co-infected with both TB and HIV face a greater economic burden than those affected by either TB or HIV alone (52,74). Individuals with comorbidities benefit from integrated clinics, as they reduce the frequency of health facility visits. The participants reported facing catastrophic costs as a result of managing both TB and HIV (75). The literature demonstrates a strong correlation between TB and HIV, suggesting that individuals with HIV are more likely to develop TB. Adhering to recommended disease control services is crucial for effective TB management (18,76). Numerous epidemiological studies have confirmed the high prevalence and incidence rates of HIV and TB in various countries (77). Therefore, HIV and TB create a double burden, not only for the patient but also for their families, society, the country, and the world at large (78). The co-existence of TB and other infectious diseases has further complicated efforts to control TB (79).

The prevalence and incidence rates of both TB and HIV vary by region and district, as well as among different socio-demographic and economic groups (80). similar trends observed in most developing countries (80). To address the low TB screening rates among PLHIV, the Tanzanian government has strengthened TB screening efforts by ensuring the availability of diagnostic tools and providing intensified mentorship on the effective use of these machines for case detection among PLHIV (81). Furthermore, to prevent the progression of latent TB infection into active disease TB among at-risk household contacts, especially children and HIV patients, a preventive treatment known as TB preventive Therapy (TPT) is provided (82,83). The TPT dosage for adults is 300mg daily and 10mg daily for children, both six months; TPT is given once in a lifetime, and a no-repeat cycle is needed (83).

In the literature, the relationship between TB and HIV is explored not only from a biological perspective where HIV induced immunosuppression increases vulnerability to TB but also

through a socio-economic lens, which reveals the compounded impact on already disadvantaged population (84). This dual burden disproportionately affects individuals with limited financial resources, unstable housing, or poor access to healthcare, making it not only a medical issue but also a structural and social one (85). For instance, while integrated clinics for TB and HIV have been shown to reduce health facility visits and ease treatment access, the implementation of such services remain uneven, particularly in resource constrained settings (85,86).

Moreover, research highlights those individuals co-infected with TB and HIV face significantly greater financial strain, often resulting in catastrophic healthcare expenditures that deepen poverty and social marginalization (87). These findings suggest that without addressing the broader social determinants such as poverty, stigma, and health system inequities the biomedical response alone may be insufficient. Therefore, more context-specific interventions are needed that account for both the clinical and socio-economic dimensions of co-infection, particularly in high-burden, low-income settings. This underscores the importance of integrated, equity-focused approaches in both policy and program design. Therefore, integrated strategies must be urgently implemented to manage comorbidities associated with both diseases and to simplify TB management (88). Additionally, various strategies and interventions are being introduced and implemented to alleviate the burden of TB (89). Some of these strategies aims to control other diseases that impact TB, such as HIV and AIDS.

2.1.2.5 TB Situation in Tanzania

Global TB Reports indicate that Tanzania is one of the LMICs with a high TB prevalence (9), and listed among the 30 countries most heavily affected by the disease (23,38). However, there has been recent positive progress: Tanzania's national average TB incidence rate has decreased by 32%, (40%) dropping from 306/100,000 in 2015 to 183/100,000 population in 2021 (57,90). While these improvements are often highlighted as signs of success, they obscure critical disparities across and within regions that limit equitable progress. A more disaggregated analysis reveals substantial heterogeneity. In 2021, for example, the overall number of TB notifications increased by 2.1% compared to the previous year, reaching 87,415 cases (57). However, this marginal increase raises questions, if it reflects genuine improvement in case of detection, or merely a partial recovery from underreporting during

previously disruptions such as COVID-19. Additionally, the number of TB-related deaths in Tanzania has decreased by 68%, from 58,000 in 2015 to 18,400 in 2023 (57,90).

However, there are still variations among and within the regions. In the Mbeya region the TB notification rate is estimated to be 143 /100,000 population, while in Songwe, it is 80 cases per 100,000 (91,92). The regional notification rates vary widely, these contrasts raise critical concern about reginal inequalities in health access, surveillance capacity and case finding. Over the years, trends in notification cases of TB in Tanzania have been changing. These figures indicate that more strategic measures are needed to reduce the TB burden, if not its permanent eradication (18).

Therefore, such variability raised critical concerns about the reliability of national averages as an accurate indicator of progress. While reduction in TB incidence and mortality at the national level are commendable, these aggregate figures may conceal substantial pocket of undetected transmission, particularly in underserved or hard to reach areas. Notably, it is estimated that 36% of TB cases in Tanzania remains undiagnosed or unreported each year (93), highlighting the extent to which national average can mask deep regional disparities and underlying systemic weaknesses. This diagnostic gap represents a significant challenge to achieving the End TB Strategy targets and directly aligns with the present study's focus on social and economic costs of TB among TB patients and survivors.

2.1.3 Clinical and Psychological Aspects

2.1.3.1 TB and Psychological Problems

The impact of TB extends beyond physical health to include psychologically, social, and economic dimensions. Poor mental health particularly depression and anxiety is increasingly recognized as a co-morbidity in individuals with chronic physical conditions like TB. Studies estimate that the notably rates of depression and anxiety are estimated to be at least double in TB patients compared to those without TB (94). Studies indicated that depression is more prevalent among individuals with MDR-TB (52%) compared to those with drug-susceptible TB (45%), and this correlates significantly with the severity and duration of the illness (95). This suggests a clear need to integrate mental health considerations into TB management. Furthermore, these mental health challenges stem not only from the treatment itself but also

from broader factors such as income loss, disrupted social roles, stigma and hopelessness (96,97).

Additionally, while depression and anxiety may improve during treatment, untreated mental illness can severely undermine treatment adherence and outcomes, reduce functional ability and lower quality of life, and impose significant economic burdens (34–36). This highlights the importance of early mental health screening and psychosocial support for patients, families, and communities as integral component of effective TB care.

2.1.3.2 TB and its impact to TB survivors

Multiple studies show that even among patients who complete treatment, up to 50% report ongoing health problems, especially related to post-TB lung disease (PTLD), including chronic respiratory symptoms and impaired pulmonary function (98). For example, data from global estimates suggest that over 150 million TB survivors may be living with such sequelae (98). These chronic issues are not only medically under-recognized but also socially and economically disruptive (99).

TB survivors often experience a double burden: persistent physical morbidity and unaddressed social vulnerabilities. Survivors may struggle with loss of income, workplace exclusion, persistent stigma, and psychological distress (99,100). Evidence from Tanzania and other low-resource settings shows that many patients are discharged from care systems without any structured post-treatment support, despite facing enduring hardship. Such fragmentation in care continuity reflects a larger systemic gap in TB programming where outcomes are narrowly defined by bacteriological cure rather than long-term well-being (100,101).

Critically, the literature also highlights that this neglect of the post-TB phase undermines the goals of person-centred care and the WHO's End TB Strategy. It challenges the assumption that successful treatment equates to full recovery. Scholars such as Wingfield et al. (2014) and Kallon et al. (2022) argue that the transition from "patient" to "survivor" marks a new phase of vulnerability, in which individuals often lack the financial, psychosocial, and medical support required to rebuild their lives (102).

Moreover, the social determinants of health that contribute to TB onset of poverty, food insecurity, stigma often persist or worsen after treatment. The intersectionality of these factors (e.g., being poor, chronically ill, and socially excluded) makes TB survivors uniquely susceptible to falling back into the cycle of disease, unemployment, and social marginalization (103). The revised literature review critically questions why current TB programs pay little attention to this phase. It identifies a key research gap: the lack of structured models for post-TB care and social reintegration, especially in resource-constrained settings like rural Tanzania. Several authors call for systematic follow-up of TB survivors, integration of social protection schemes, and long-term monitoring of physical and mental health outcomes.

It is important to recognize that social and financial barriers do not end at treatment completion but instead influence the longer-term trajectory of TB survivors' health and well-being. The framework also supports a person-centred approach to TB care that includes rehabilitative, psychosocial, and socioeconomic support, thereby making it more relevant to current global health priorities.

2.1.3.3. Coping Strategies Employed Among the Patients and Survivors in the context of the PTB Management Challenges

As PTB patients and TB survivors face stigma and discrimination from both their families and the broader society, accessing empathetic attitudes, material support, or positive handling care to help them cope with the disease becomes increasingly rare (104). Economic studies indicate that families or households falling in the low socioeconomic status (SES) category, mainly with reference to financial income ownership, are the ones bearing the most significant burden of TB-related financial costs (105). This raises a significant challenge to the success of ending TB, highlighting the need for coordinated efforts to address it effectively. These patients and their family members are often forced to postpone spending on essential needs, such as school fees, basic consumables like food, and utility bills for electricity and water. This underscores how TB as a disease that perpetuates poverty, pushing affected households deeper into financial hardship and significantly diminishing their quality of life (QoL) (106,107).

At the family or household level, when the breadwinner falls ill and is unable to participate in economic production activities, it affects the livelihood of everyone in the household (108). This loss of income is a direct cost that strains the family's resources. Accessing TB care, whether at a hospital or health center, can be challenging if the point of care is far from the patient's residence. The travel time and associated financial costs add to the burden, a situation commonly experienced by those residing in rural areas or in the peripheral urban settings of large cities (109,110).

Misinterpreting some TB symptoms as being HIV-related often delays timely TB care, and resulting in avoidable costs (111). TB experts emphasize that effectively halting the spread of the disease requires coordinated strategies across multiple disciplines and sectors (52). Strategic mechanisms are crucial to support PTB patients and survivors, shielding them from the severe economic impacts of the disease. Without such mechanisms, individuals may borrow money with interest from lenders (112) or, in the absence of lenders, sell valuable assets at significantly low prices to meet urgent medical expenses. It is common for patients or their families to sell land, houses, livestock, farm produce, or other valuable possessions (113,114). These economic challenges compel patients and families to make critical decisions about resource allocation, care-seeking timing, and where to access care (72,119).

The role of social support is well documented, but this support is neither uniformly available nor equally effective. Systematic studies have shown that social support is important in patients' health and acts as a mediator between self-efficacy and various outcomes, including depressive mood, stigma, and economic barriers (115). The level of support received can significantly influence an individual’s health behaviours and, ultimately, morbidity and mortality outcomes. Four types of support are particularly important for TB patients and survivors, but insufficient without interrogating who has access to such networks and why others do not (116). Furthermore, healthcare providers roles in delivering such support are often undermined by staff shortage, burnout, and insufficient training in psychosocial care. This necessitates a critical examination of health systems’ capacity and willingness to humanize TB care beyond drug regime.

2.1.4 Social and Economic Impact

2.1.4.1 Social and Economic Burden of TB

Research indicates that approximately 50% of TB patients and their relatives experience considerable social and financial burdens during the treatment-seeking process (117). These burdens include direct medical costs and indirect expenses such as loss of income, amounting to around 30% of their annual household income (118). The End TB strategy aims to eliminate these high costs associated with TB treatment (49). This highlights a major obstacle to accessing and completing TB treatment. Overcoming this challenge necessitates progress toward universal health coverage (UHC) and the implementation of effective social protection measures (47,119).

The results of the data analysed based on both the qualitative and quantitative confirm that the onset and experience of TB (particularly PTB) financially and economically burdened individuals with the lowest income (120,121). Even when conventional medical services are available for free or at highly subsidized user fee payment at formal HCFs (105), a considerable number of people remain hindered by travel time and the money spent on transportation. This significantly impacts the economic well-being of patients and their families (122). PTB often forces individuals living with it to cease many of their daily economic production activities (110,123). For those who depend on these activities for their livelihood, this interruption leads to financial strains (103). Therefore, the initial financial costs associated with seeking care and getting a TB diagnosis can be highly burdensome for individuals from financially constrained households. Besides the money paid for transport and the time lost while travelling, there are additional costs such as registration fees at the contacted HCFs and the user fees for diagnostic and medical consultation services prior to treatment initiation (37,123).

Furthermore, experience shows that TB-related costs are not necessarily borne solely by the patients themselves. These costs may also fall on the patients' home-based caretakers, who serve as their primary social supporters. Such supporters often find themselves responsible for settling medical bills at the contacted HCF, especially for children or elderly patients unable to manage on their own (124,125). Apart from the direct financial OOP expenses for transport to visits HCFs, caretakers may need to purchase meals and soft drinks for patients. They also

face opportunity costs, including lost income and leisure time, due to travel and waiting periods (38). In some cases, family members incur additional costs for accommodation when required to stay overnight away from home while accompanying patients at health facilities (30,124,126).

The specific TB care model influences the different cost categories in place, such as the reliance on hospitalization versus outpatient care and the frequency of required health facility visits (110,127). For example, in Tanzania, during the intensive phase (0-2 months) of treatment, patients must collect their medication weekly, which can be very costly for those residing far from healthcare facilities. The distribution of costs also varies across countries, but it is evident that even in countries with policies offering free TB treatment and care, like Tanzania, households affected by TB still bear direct medical costs (126). National TB programs and the Ministry of Health must prioritize minimizing the direct medical costs to TB patients and their families. Moreover, the literature demonstrates the importance of eliminating non-medical costs and addressing income losses. Non-medical expenses, such as transportation, nutritional supplements, food, and other related expenses, collectively known as "direct non-medical costs," constitute a significant portion of the total expenditures in certain countries, notably 64% in Kenya, 60% in Uganda, and 51% in Tanzania (128).

TB can be attributed to potential rejection by community members, family, and friends and the loss of employment, resulting in a state of dependency (129). Additionally, TB may result in social stigma, as evidenced by various studies focused on the causes of stigma and discrimination related to the disease (130-132). These studies reveal that both patients and their families tend to distance themselves from society, exacerbating the social impact of the disease (67). Moreover, children from TB-affected families experience significant disadvantages, ranging from school absenteeism and dropouts to decreased caregiving at home and being obligated to care for TB patients (133). Patients require social support to cope with the disease, adhere to treatment, and resume their normal daily lives.

2.1.4.1 Underestimated Economic and Social Costs of TB

As noted above TB is widely recognized as a disease that primarily affects the poor, although there are exceptions where even the rich are affected (134). To ensure equitable access to TB services, there is a focus on serving the poorest and most vulnerable groups. Many countries

have policies that recommend providing essential health services free of charge (135). Despite strong political will and the National TB Programme's commitment to offering free TB diagnosis and treatment to all patients registered in formal healthcare facilities, TB continues a disproportionate burden on the poorest populations (74,112,136). This paradox reflects deeper systemic barriers that free healthcare alone cannot resolve. According WHO team of experts, TB patient often lose 3-4 months of productive time and up to 30% of their annual household income (118,137), contributing to an estimated US$12 billion in losses annually in low income communities (138).These losses are not limited to direct medical costs, but also include out-of-pocket expenses to both formal and informal service providers (139). Also paid through health insurance or social welfare support (112,140,141).

Evidence on the economic impact of the pre-TB treatment phase remains limited. Many patients spend a significant amount of time seeking treatment for TB symptoms because of a lack of awareness (138,142). In the midst of sickness, some patients move from one provider to another, leading to delayed treatment and worsening of their condition(143). Furthermore, the financial costs, productivity losses, and psychological consequences for patients and their families have not been thoroughly explored. To better understand the impact of TB, experts recommend investigating the direct and indirect economic and social costs, and the coping strategies employed by patients, survivors, and their caregivers (113)

This study reveals that the low socioeconomic status of TB patients and survivors can contribute to inadequate treatment outcomes due to their health-seeking behaviours. Therefore, implementing multi-sectoral approaches and socio-economic enablers is essential to optimize TB care. Educating communities about TB symptoms is crucial, as efforts to track patients to prevent them from moving between multiple providers. It is also essential to develop a tool that educates community members about TB symptoms through community health workers and health service providers, including drug store sellers. Social support for TB patients is crucial and can come from their friends, family members, and neighbours. Strengthening social support is necessary to ensure treatment adherence and early diagnosis, which are key to achieving the End TB Strategy 2035 in Tanzania.

2.1.5 Health System Response

2.1.5.1 TB Care and Strategies to Enhance Treatment Outcomes

Tuberculosis (TB) care encompasses a holistic approach to diagnosing, treating, and managing the disease while addressing factors that impact treatment adherence and outcomes (144,145). In Tanzania, a limited number of HCFs are equipped with essential TB diagnostic tools include microscopy, culture and drug susceptibility testing (DST) and GeneXpert MTB/RIF or GeneXpert Ultra (144). Therefore, seeking treatment promptly is crucial to minimize the negative effects of TB, including social stigma, depression, inability to work, and in severe cases, death (146,147).

Although TB services are freely provided in Tanzania, research indicates that patients frequently delay seeking recommended healthcare (56,148). This hesitation is partly due to the burden of both direct and indirect costs (110,149). The available literature reveals that pre-treatment diagnostics can involve significant costs, such as travel to and from the healthcare facility for those living far away, initial consultation fees, and food while waiting in the hospital. TB-related costs are found to increase if the patient is also suffering from comorbidities, such as HIV (2,150). To enhance TB treatment outcomes, there is a need to improve access to diagnostic tools, especially in rural and underserved areas, along with timely and appropriate treatment. Furthermore, patients require comprehensive medical, psychological, and social support throughout their treatment journey to ensure adherence.

In 2020, Tanzania reported treatment outcomes for 84,232 new and relapse TB cases, marking an achievement of a case-holding rate of 99.7% (57). This high rate was due to the use of a case-based electronic system and active community involvement in TB management. The use of these strategies facilitated early case detection and an improvement in TB treatment adherence. The overall treatment success rate for reported new and relapse TB cases was 96%. The remaining proportion (4%) reflected unfavorable outcomes, including 2,772 patients (3.3%) who died of the disease during their treatment period, 779 (0.92%) who were LTFU while, 69 cases (0.08%) had experienced a treatment failure (151). However, the studies conducted in 2021 show limited access to HCFs in rural areas. Also, some of the available facilities were found to lack the basic TB diagnosis equipment, besides a shortage of professional and skilled HCPs (152-154).

The above-identified deficiencies suggested that, in order to have sustainable efforts to improve TB management, there is a need for the authorities concerned to be informed of the underlying social financial, and structural factors that contribute to delayed individuals, both confirmed and suspected of being infected with *M. tb*, from seeking timely and appropriate healthcare (155). Also, there is a need to account for individual financial challenges, particularly those related to geography (151). This includes people who live in rural/remote areas, which mostly face limited transport; some individuals have to walk long distances to reach health facilities, which can delay access to medical care and increase the risk of spreading the infection to others in the community. Additionally, Social disparities such as gender, income, and social economic status can further deter individuals from seeking necessary care (156). The government needs to ensure equitable access of TB management and control to achieve the End TB strategy (153). Although Tanzania reported a high treatment success rate (96%) and demonstrated impressive case retention through electronic systems and community engagement, critical gaps remain unaddressed particularly the inequitable distribution of diagnostic tools, healthcare infrastructure, and skilled personnel in rural areas.

2.1.5.2 Barriers to the achievement of PTB service provision.

In reviewing the literature, it was noted that despite some of the success achieved so far in TB service provision, there are several challenges still being confronted. Among these challenges are the inadequate knowledge and uptake of the available TB interventions or services, partly due to limited community access to information about these services (110). This issue is further compounded by systemic deficiencies that contribute to the non-delivery or suboptimal delivery of the intended services to those in need. Strategies to increase TB screening in the community have been considered and partly implemented, although not yet with full population and community coverage (110). Tanzania has consistently planned to enhance TB testing and screening as part of its national End TB strategy (110). To achieve this, several practical measures have been taken, including public and community health education and sensitization about TB, its nature, prevention, detection, and eventually treatment for those diagnosed with the disease (157).

This study highlights the impact of social and financial factors on TB among TB patients, TB survivors and their families. Financial constraints emerge as a major barrier to timely access to TB diagnosis and treatment. Such delays not only contribute to the progression of the disease and more severe health outcomes but increase the risk of ongoing transmission within communities and elevate mortality rates (157). The consequences are costly to the patients and their families, who bear the brunt of the financial and emotional strain. Stigma plays a significant role in this dynamic, with many patients delaying care due to fear of discrimination or lack of awareness about TB symptoms. In some cases, patients turn to traditional healers, further delaying access to appropriate medical treatment.

The stigma and discrimination associated with TB are pervasive, affecting individuals at the personal, community, and societal levels. This stigma and limited access to HCFs, especially in rural areas exacerbate treatment delays (158). In these regions where many TB patients reside, access to care is often a significant challenge, leading to prolonged suffering and increased transmission risks. The experiences shared by TB patients and survivors, corroborated by TB clinic staff, reflect the substantial challenges faced by those affected by TB. These challenges are both medical and deeply social and economic, underscoring the need for a more holistic approach to TB care. This approach should address the stigma, improve access to HCFs, and provide the necessary psychosocial and financial support to ensure that patients can seek timely and effective treatment. Only then can the cycle of delayed care, prolonged suffering, and increased transmission be broken, leading to better health outcomes for patients in Tanzania.

In summary, the delayed health-seeking observed among TB patients in Mbeya and Songwe not only exacerbates the physical and psychological toll of the disease but also deepens the socio-economic challenges faced by individuals and their families. The financial burden associated with delayed treatment contributes to prolonged suffering, increased risk of disability, and a negative impact on the overall economic condition of patients. These challenges highlight the urgent need for interventions aimed at reducing delays in seeking care by enhancing access to appropriate and timely healthcare services while mitigating the financial hardships faced by TB patients, survivors, and their families.

This study's focus on the socio-economic impacts and access to TB care is directly relevant to the WHO End TB Strategy's objectives of reducing TB incidence by 90%, TB deaths by 95% and eliminating catastrophic costs for TB-affected households by 2035. Achieving these

targets, particularly eliminating catastrophic costs, requires comprehensive interventions that address both clinical and socio-economic factors affecting TB patients. Without targeted interventions, such as, financial support, improved access to care, and integrated mental health services, it will be impossible to eliminate catastrophic costs for TB-affected households by 2035. This highlights the critical need for multi-faceted approaches to TB management and care.

2.1.6 Policy Implication and Response

In terms of policy response, Tanzania has demonstrated high political commitment to global TB goals. The country endorsed the 2017 Moscow Declaration and later reaffirmed its position during the 2018 UN High level meeting on TB (159,160). Most recently in 2023, Tanzania adopted the Multisectoral Accountability Framework (MAF) to formalize the commitments to TB elimination by 2030 (152,160). In the meeting, 23 ministries pledged their commitment to the framework by signing the MAF TB (160). This initiative is designed to extend TB prevention and treatment services to vulnerable populations such as prisoners, miners, healthcare providers, refugees, and others who face heightened TB risk (152,160). The framework is expected to support national efforts to end TB by 2030, including addressing structural barriers that contribute to TB stigma and discrimination (152).

Although these actions reflect an ambitious and commendable vision, the translation from policy to implementation remain uneven. For example, while 23 ministries signed onto MAF TB Framework the worry remain about how effectively these commitments are translated into tangible service delivery improvements, particularly in the high burden and hard to reach regions like Mbeya and Songwe. The MAF outlines intentions to prioritize high-risk groups such as prisoners, miners, healthcare providers, and refugees (81). However, the operational capacity to consistently reach these groups, monitor outcomes, and scale relevant interventions remains unclear. Moreover, structural barriers such as stigma, poverty, and health system fragmentation continue to impede access to timely TB care.

Tanzania has continued working towards improving access to TB services and reducing the number of unreported cases (93). The country has implemented community involvement initiatives to achieve this. Among the targeted stakeholders are Non-Governmental Organization (NGOs) and Civil Society Organizations (CSOs), which are involved in wider

community engagement through the 'ENGAGE TB' program, represent a more grassroots effort to close the gap. Through these various strategies and techniques have been adopted, such as using mobile phones (mHealth) to educate people about TB symptoms and enable self-screening. Also the involvement of CSOs, Community Health Workers (CHWs), TB survivors, community leaders, religious leaders, traditional practitioners and accredited drug dispensing outlets (ADDOs) to educate community members about TB (93). By using the community engagement Tanzania has sought to increase awareness and improve early detection at household level (161) However, evidence of effectiveness and sustainability of these interventions is limited, particularly in rural area with inadequate infrastructure and low digital penetration.

Despite considerable global efforts to control tuberculosis, its burden remains disproportionately high in low- and middle-income countries, where structural inequalities, health system limitations, and socio-economic vulnerabilities persist. In high-burden settings such as Tanzania, the interplay between clinical, psychological, and social challenges necessitates a comprehensive understanding of patient experiences and systemic barriers to effective TB care. This study seeks to explore the social and economic burden of TB, and to evaluate the coping strategies employed by TB patients, survivors and their families. These insights are intended to inform more responsive, equitable, and patient-centered TB policies and interventions. To guide this inquiry, the study adopts Cohen and Wills' Stress, Social Support, and Buffering Theory, which posits that social support can buffer the negative effects of stress during periods of illness. This theoretical lens facilitates an exploration of how different forms of support such as emotional, informational, and material can help TB patients and survivors in navigating the psychosocial and systemic challenges of treatment and recovery, particularly in the context of stigma, poverty, and service delivery gaps.

2.2 Theoretical Framework

Many theories were taken from the available literature, contributing to the development of this study's objectives. Various theorists were identified who, either directly or indirectly supported the recognition of the role of social determinants in disease control strategies. Notably, the article was written by Cohen and Wills (1985) (162) was found particularly interesting as it provides a theoretical framework for researchers interested in studying the role of social support in shaping an individual's health and overall well-being. This article has

added value to the other views of other literature I reviewed on the same topic, including those claiming the existence of a relationship between social support and patients' adherence to TB-related treatment and care (32,39,163), as well as other types of care beyond TB (115,164). Additionally, the conception of this study was reinforced by my awareness of established evidence on the relationship between living in poverty or marginalized conditions and increased susceptibility to TB infection, and the more severe physical and psychological health outcomes (165). The relationship between poverty and TB is cyclical, as analysts have demonstrated: poverty increases the risk of TB, and TB, in turn, exacerbates poverty, creating significant challenges for affected individuals to overcome (166,167). Exploring such relationships in the context of Tanzania is particularly relevant, with a focus on the two study regions selected for the reasons outlined in the overall methodology section below. These regions are also discussed in two previously published articles (168,169) and one unpublished but under review by a journal (Chapter Four).

From an economic perspective, studies indicate that individuals exposed to TB infection are at risk of contracting the disease, irrespective of their income or socioeconomic status (170); substantial empirical evidence indicates that those who are economically disadvantaged and marginalized are particularly vulnerable to TB (171). This suggests that TB programs should prioritize interventions targeting these vulnerable groups (171). Therefore, it is essential to conduct research that documents the social and economic effects of the disease from a social science perspective. The study aims to use social science methodology to investigate existing theories and examine the cause-and-effect relationships. To assess and analyse the issues of interest, the study adopts Cohen and Wills' Stress, Social Support, and Buffering Theory.

The evidence confirms that long-term illness can lead to health and economic challenges for families (172). According to Cohen and Will (1985), individuals facing severe or long-term illnesses can significantly alter family dynamics, especially when the demands of caregiving conflict with the developmental milestones associated with specific stages of the family life cycle. Additionally**,** the theory demonstrated that individuals with a strong support system of spouses, friends, and family members experience better health outcomes compared to those with limited social contacts (173). The theory emphasizes that social support is crucial to overall well-being and is closely linked to psychological and physical health. The presence of a supportive social network within the community has been found to benefit patients and other community members by contributing to positive health outcomes. Research also indicates that individuals with low levels of social support have an increased risk of mortality.

The absence of support and appropriate coping strategies can exacerbate the situation for individuals affected by tuberculosis. Patients and TB survivors may require emotional companionship, information (regarding care and treatment of the disease), and material support (173). The current study aims to explore PTB's social and economic implications, specifically emphasizing the support provided by family, community, and healthcare providers. This study demonstrates the various forms of support that family members, healthcare providers, and neighbours offer to individuals suffering from PTB.

Individuals with PTB frequently incur substantial direct and indirect financial costs related to treatment and other associated expenses. To reduce the social and financial burden of TB, it is essential to provide comprehensive support to patients and their families. This support should encompass access to information, assistance with timely transportation to healthcare facilities, and financial aid for those in need (173). Social support plays a crucial role in helping to alleviate stress and mitigating the adverse effects of challenging situations. It can help reduce the impact of stressful events, minimize negative reactions, and address any maladaptive behaviours that may arise in response to these events (173).

2.2.1 Conceptual Framework

Under this framework, two hypotheses were tested: (1) Social and financial barriers delay timely TB care-seeking behaviour, leading to poorer health outcomes, including prolonged illness, higher transmission rates, and increased mortality among TB patients. (2) Inadequate social support before, during and after TB treatment can negatively impact care-seeking behaviour, treatment adherence, and recovery. This can increase the likelihood of treatment failure, relapse, and psychological distress.

Among the extensive literature, both in the form of published articles and textbooks, describing the relationship between social conditions and the prevalence of various diseases, as written by Link and Phelan (1995) (174) titled "*Social Conditions as Fundamental Causes of Disease."* This article examines how social conditions influence the prevalence of different diseases, which inspired me to develop the research idea that led to the writing of this dissertation. Other scholars advocate for continued research to enhance our understanding of the social, financial, and economic impact of TB on patients, survivors, and their families, as well as how these groups cope with challenges posed by the disease (169). Analysts recommend studies that focus on factors affecting individuals' ability to access the

recommended services in resource-constrained communities and healthcare facilities, particularly in rural areas. Challenges in these areas include limited availability or affordability of transportation and restricted access to information on TB control and available services. Additionally, cultural values, such as negative beliefs and norms, can hinder some people from seeking timely TB-related care at conventional health facilities, presenting significant barriers to accessing necessary care (170,175,176).

Furthermore, a deeper interest in investigating the social determinants of health (SDH) and their influence on TB prevention, treatment, and control strategies in Tanzania was inspired by the literature that was reviewed. Such literature consists of the suggestions made by various authors pointing out how these determinants have a complex and cross-cutting relationship with the prevalence of specific diseases (177). Rather than being confined to intrapersonal or limited interpersonal sources, most determinants are, in reality, cross-cutting. In other words, they often originate with an individual but eventually extend their effect to others, sometimes crossing borders (178–180). This understanding motivated me to pursue the chosen research topic with the dual goals of earning a PhD and contributing to the global, regional, and national End-TB Strategy. The aim was to generate systematic evidence related to the real-world social and economic determinants of health in the context of real implementation of scientifically recommended interventions supported by existing national policies and programs that have been identified as a priority in Tanzania (181). and globally (8).

It is suspected that some individuals, even when at risk for TB or directly affected by it, may either be unaware of their status or, if aware, may not take appropriate action (182). This could be due to negligence or because they face barriers beyond their control, such as financial and social constraints. As a result, they may need to visit multiple providers outside of HCFs before receiving proper treatment. Delayed healthcare seeking can result in higher medical expenses for individuals and their families, suboptimal treatment outcomes, recurrent TB infections, loss of follow-up appointments, and, in the worst cases, death. The financial and social consequences of TB are unavoidable for patients, survivors, and their relatives (20). My interest also extends to what happens to individuals after they have been medically confirmed to no longer carry the tuberculosis bacterium. Specifically, I had been enthused in understanding how the QoL of each individual patient or survivor of the disease was affected

by the presence or absence of necessary social support since not everyone could be able to meet all the basic needs alone during a financial hardship moment (183).

In summary, the framework illustrates how social and financial barriers, combined with inadequate social support, affect each stage of the TB continuum of care, from care-seeking to treatment and recovery, and how these interactions contribute to the cycle of poor health outcomes in TB patients. It provides a structured approach for investigating the hypothesized factors and their influence on the patient journey. The conceptual Framework, as presented below **(Figure 1)**, attempts to reflect on, in a summarized but pictorial manner, the thoughts behind the study reported in this document and the resultant discussions, conclusions, and recommendations. The respective framework aims to capture the potential SDH in relation to PTB care-seeking behavioural determinants (184), and the implications of any unexpected behaviours. PTB is a debilitating disease that can result in missed social and economic opportunities for patients, whether or not they receive treatment. The costs associated with dealing with the disease may force patients, including those who develop illnesses related to PTB, to seek financial support through borrowing from neighbours, relatives, or community members or even selling property to cover treatment expenses. These financial strains can lead to poverty, food insecurity, social exclusion, and other detrimental effects on their lives. To mitigate these consequences, patients need robust social support from their families and communities. Lack of support can increase stress and the risk of death, while adequate support can reduce depression and promote quicker recovery. Social support is crucial for encouraging timely visits to healthcare facilities, ensuring proper treatment, and preventing further community infections. Therefore, early treatment and strong social support are essential for minimizing the economic and social consequences of TB (185,186). **(Figure 2.1).** The conceptual framework illustrates how social and financial barriers, combined with inadequate social support, affect each stage of the TB care continuum from care-seeking to treatment and recovery and how these interactions contribute to the cycle of poor health outcomes in TB patients. It provides a structured approach for investigating the hypothesized factors and their influence on the patient journey.

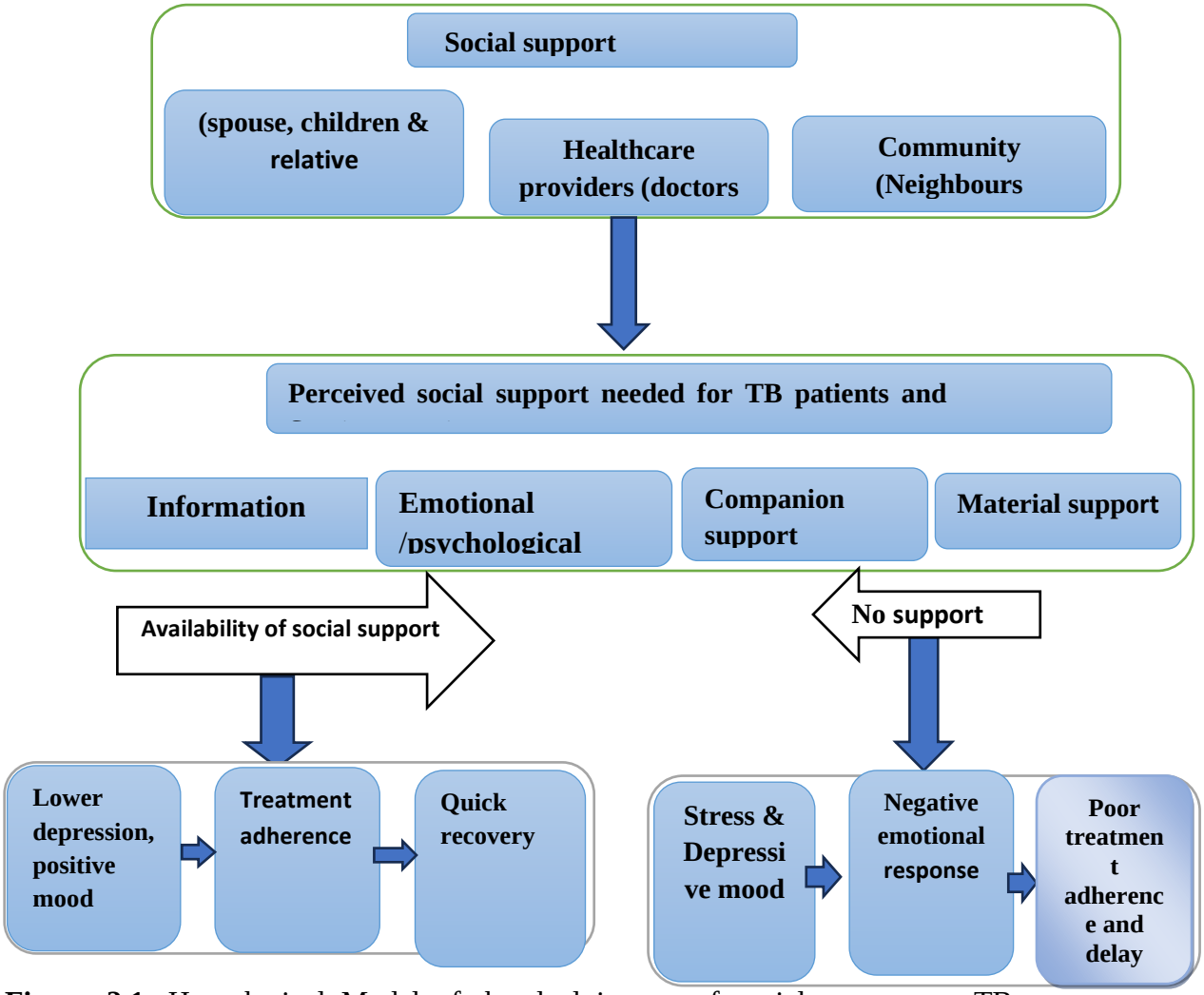

Figure 2.1. Hypothetical Model of the dual impact of social support on TB outcome for patients and survivors

2.2.2 Statement of the Problem

From both economic and social perspectives, infectious diseases' micro and macro burdens were extensively discussed, drawing on both systematic evidence and anecdotal insights within existing conceptual and theoretical frameworks. Regarding PTB, not all economic and social benefits of its effective prevention, proper treatment, and overall control measures could be directly or explicitly measured. While explicit costs – such as those incurred for care-seeking, access to medical services, and medications – were calculated, many implicit costs remain unmeasured despite their significant impact on patients, their families, and their communities (187). However, some benefits particularly those that were immense and cross-cutting across sectors often remained unmeasured and thus unrecognized. This underscores the need for policy and program-backed interventions to be designed and implemented using integrated, multidisciplinary approaches to achieve the desired success (188).

More than two decades have passed since the WHO recognized the role of SDH in preventing and controlling diseases, including communicable and infectious diseases like PTB. WHO comments that, while a thorough understanding of the biomedical aspects of infectious diseases, such as the medical epidemiology of TB is undeniably crucial, it is insufficient without systematic, evidence-based knowledge of these diseases' economic and social determinants. Such a type of knowledge is found essential in contributing to the enhancement of understanding of both disease prevalence and its burden, as well as the healthcare-seeking behaviours and utilization of available interventions or services (189). By focusing on the real-world impacts of SDH on TB care, this research contributes to the global effort to reduce TB incidence and mortality, particularly in high-burden countries like Tanzania.

Literature shows that, despite the global efforts to combat TB, the disease remains a significant public health challenge, especially in resource-limited settings such as Tanzania. In Tanzania, TB prevalence remains high as social and financial barriers, along with inadequate social support, significantly hinder the efficiency of TB prevention and treatment strategies. Many TB patients, especially those in rural and impoverished areas, face delays in seeking timely health care due to poverty, stigma, transportation, and limited access to healthcare services. These barriers not only lead to prolonged illness but also increase transmission rates and TB-related mortality. Even when patients begin treatment, the absence of strong social

support systems both during and after treatment further exacerbates poor treatment adherence, raises the likelihood of treatment failure and heightens psychological distress among patients (122). The lack of family, community, and healthcare support can trap patients in a vicious cycle of illness, treatment disruption, and social exclusion, resulting in negative health outcomes and a persistent burden of TB on both patients and their communities (122).

This current research was aimed at investigating how social determinants of health, particularly, financial barriers, influence care-seeking behaviors, treatment adherence, and recovery outcomes among TB patients. It was grounded in the premise that, understanding these complex interactions can yield valuable insights for developing effective interventions to address the social inequities that impede TB control efforts in Tanzania.

2.2.3 Study Justification

Despite global progress in TB prevention and control, TB remains a major public health concern in Tanzania, particularly in region with limited resources and persistence socio-economic vulnerabilities. While biomedical interventions have traditionally been central to TB interventions, there is growing recognition that structural and social determinants such as poverty, stigma, limited knowledge, and poor access to HCFs play a critical role in shaping TB outcome. However, there is a notable lack of empirical, context specific research examining the broader social and economic impact of TB on individual patients, survivors, households, and HCPs. This gap limits the development of comprehensive, patient-centred responses (190). This study seeks to address the gap by exploring how PTB affects patients, and their families in both economic and social terms, as well as how TB survivors in the Mbeya and Songwe regions cope with these challenges. In doing so, the research aims to generate insights that can inform effective TB policies and interventions, particularly in high-burden settings. Understanding these lived experiences is essential not only for improving treatment adherence and outcomes but also for designing support system that strengthen resilience and reduce the long-term burden of TB (110),

Gaps in Existing Research: Only a few studies have explored TB's economic burden on patients in Tanzania. One study focused on the costs of TB incurred by patients during diagnosis and treatment but did not cover the costs faced by TB survivors or the relatives of a TB patients, nor did it examine the pre-treatment costs (126). Another study by Mhalu et al.

investigated care-seeking pathways and associated costs, but it lacked a qualitative component that would provide deeper insights into the personal and social impacts of TB (!61). These gaps highlight the need for a comprehensive study that examines the social and economic consequences of TB among patients, their families, and survivors in Tanzania. Therefore, collecting detailed information on the costs incurred by TB patients before and after diagnosis, as well as the impact on their families, was crucial. The data filled existing gaps in research and provided valuable insight for policymakers and healthcare providers. Understanding the financial and social burden of TB helps in designing more effective interventions that alleviate the impact of the disease on the most affected population. While TB remains a major public health issue in Tanzania, most existing studies have focused on biomedical aspects or direct costs of diagnosis and treatment. There is a lack of comprehensive, qualitative research that explores the broader social and economic and psychosocial impacts of TB particularly the burden faced by TB patients, survivors and family members, as well as the coping strategies used to manage the illness and its consequences.

Contribution to knowledge: This study's innovative approach lies in its focus on the intersection of social determinants of TB care. By systematically examining these factors, the research generated new insights into how SDH influenced TB outcomes, an area that has been underexplored in previous studies. The knowledge produced contributed to the academic literature and had practical implications for improving TB control programs in Tanzania and similar settings, ultimately contributing to the global fight against this deadly disease.

2.2.3.1 Research Question

The key research question for this study were these: What social and economic effects does PTB have on individual patients, their households/families, the community (TB survivors), and the healthcare providers in the Mbeya and Songwe regions in Tanzania? What coping strategies do those affected by TB (TB patients and Survivors) employ in response to these challenges?

2.2.3.2 Study Objectives

The main aim of this study is to broaden an understanding of the social and economic impacts of PTB on individual patients, their households, the community (TB survivors), and

healthcare providers in the Mbeya and Songwe regions of Tanzania, and to explore the coping strategies employed by TB patients and survivors in response to these challenges.

1.2.3.3 *Specific Objectives*

1. To describe the impact of direct and indirect financial **costs** incurred by patients, their households, TB survivors, and healthcare providers before and during PTB treatment.
2. To explore the PTB's social and economic **consequences** as experienced by patients, their households, TB survivors, health care providers, and policy/decision-makers.
3. To explore the coping strategies adopted by patients, their families, TB survivors, and healthcare providers in navigating PTB illness and treatment, with particular emphasis on how social support strengthens these approaches.

CHAPTER 3

3.0 METHODOLOGY

This chapter presents the methodological approaches employed to analyse the social and economic impacts of TB in Tanzania.

3.1.1 Study design

The study employed a cross-sectional survey design, integrating quantitative and qualitative techniques for data collection, analysis, and interpretation. The primary approach was qualitative, as this constituted the core of my PhD research data collection, analysis, and reporting, supplemented with the quantitative data drawn from the main TB Sequel study to allow a reasonable triangulation of information based on the analysis performed in light of the view presented by different participants. The qualitative data were utilized to achieve specific objectives two and three, as outlined above. The quantitative component relies on data obtained from a longitudinal multi-country survey on TB Sequelae (https://www.tbSequel.org/), which provided insights into objective number one. The quantitative data collection was conducted in four countries: Tanzania, South Africa, Mozambique, and The Gambia. The data from Tanzania specifically were used to address the first objective of this study (191). The table below summarizes the TB sequel project methodology **(Table 3.1).**

Table 3.1. Summary of the TB Sequel Project

Item	Explanation
Design	Multi-country TB observational cohort study Pulmonary TB patients (including Drug-susceptible (DS) and DR-TB) (HIV positive or negative)
Study sites	South Africa, The Gambia, Tanzania and Mozambique
Sample	1600 pulmonary TB patients (**400** per site) Non-competitively enrolled. Tanzania successfully recruited 261 study participants for TB Sequel Phase 1. Given that more than 20% of the study population exhibited severe lung impairment.
Outcome	Significant impairment of pulmonary function, as assessed by spirometry at least two years after the initiation of treatment.
Data	Study database – paper and/or electronic CRFs
Visits	0, 2, 6, 12, and 24 months (before-treatment, during-treatment and post-TB treatment)

3.1.2 Study Areas

This study was carried out in the Mbeya and Songwe regions. Both of these regions are situated in the southwestern highlands of Tanzania **(Figure 3.1)**. The total population of the Mbeya region is 2,343,754, with a population growth rate of 2.7 per annum (192). The Songwe region, established as an administrative area in 2016 after being separated from Mbeya, is home to a population of 1,344,687. With a strong annual population growth rate of 3.2, Songwe is undergoing notable demographic expansion (192). The two regions have 655 healthcare facilities, including hospitals, health centers (HCs), and dispensaries, with Mbeya having 395 and Songwe having 260. Out of these health facilities, only 292 (45%) offer TB care and treatment, with 160 (41%) in Mbeya and 132 (50%) in Songwe. Furthermore, only 99 (15%) of the reported health facilities are accredited to provide TB diagnosis, with 71 in Mbeya and 28 in Songwe (193). In the selected regions, 24 health facilities providing TB diagnostic and treatment services were randomly selected to refer new patients to the TB Sequel project based at the Mbeya Zonal Referral Hospital (ZRH) in Mbeya city.



Figure 3.1. Location of Mbeya and Songwe regions in Tanzania

Mbeya Region, a Tanzanian administrative entity, is divided into seven districts: Busokelo, Chunya, Kyela, Mbarali, Mbeya City, Mbeya Rural, and Rungwe. Geographically, it borders Tabora to the northwest, Singida to the northeast, and Iringa to the east. It shares its southern and western boundaries with Songwe Region. Additionally, Mbeya shares an international border with Malawi to the south **(Figure 3.2).** Climatically, the Mbeya region has long periods of cold weather in several areas, the leading one being the Rungwe district. The region is relatively much colder than the majority of other regions in the country, except Njombe (194).

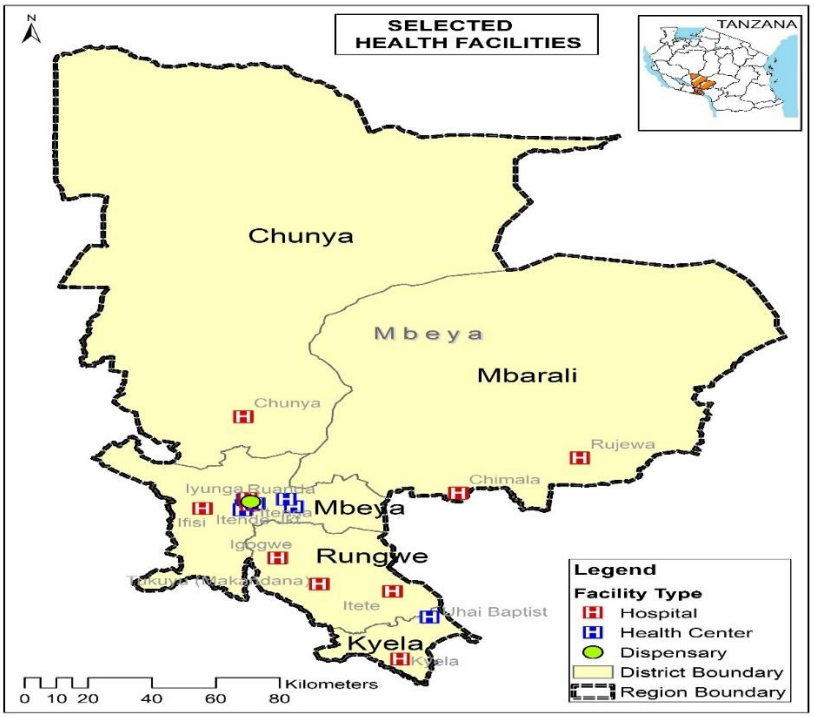

Figure 3.2. Map of Mbeya region showing districts and the selected healthcare facilities (Source: Google Maps 2024 & Tanzania Health Facility registry)**.**

Songwe Region, a Tanzanian administrative entity, is divided into Tunduma town and four districts: Ileje, Mbozi, Momba, and Songwe. Geographically, it borders Zambia and Malawi to the south, Tabora to the northwest, Mbeya to the east, and both Rukwa and Katavi to the west (NBS, 2017) **(Figure 3.3).**

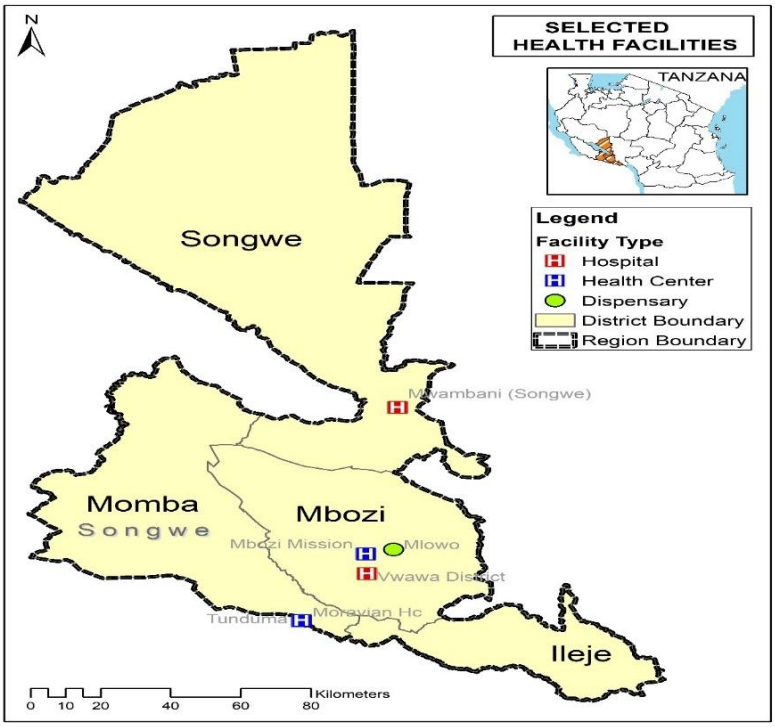

Figure 3.3. Map of Songwe region showing districts and the selected healthcare facilities (Source: Google Maps 2024 & Tanzania Health Facility registry)

Maps

The maps were created using ArcGIS Version 10.8 software. Administrative boundaries were sourced from the National Bureau of Statistics, while geographic coordinates of health facilities were obtained from the Tanzania Health Facility Registry. GIS specialist was responsible for creating the maps.

Study site justification

The research was conducted in the Mbeya and Songwe regions, both of which have high rates of TB and HIV infections. The Mbeya region was specifically chosen for the TB Sequel project due to the presence of a well-equipped laboratory with advanced TB diagnostic facilities, including GeneXpert, sputum testing, and culture. These diagnostic tools are known for their high level of accuracy and are operated at a standard that ensures reliable results. Furthermore, the regions have sociocultural diversity, whereby there is a mix of rural, peri-urban and urban communities as well as diverse ethnic and socio-economic groups. This diversity allows for the investigation of varied coping strategies and context specific socio determinants that shape TB outcome experiences.

3.2 Study Population(s)

This study comprised adults aged 18 years and older who were confirmed TB-positive. For the quantitative data analysis, the population included TB patients enrolled in the TB Sequel study, referred from 24 selected healthcare facilities. A total of 261 TB laboratory-confirmed PTB patients were selected to participate in the TB Sequel study.

The qualitative respondents included patients enrolled in the TB Sequel study, their relatives, and TB survivors (adults previously diagnosed and treated for PTB 24 months or more ago) who participated as a follow-up in the TB Sequel study. Healthcare providers providing TB care and services in the selected HCFs were also interviewed. Decision-makers at the national, regional, and district levels were also interviewed, particularly those responsible for policy, program, and executive affairs relating to TB control. All selected participants provided written informed consent before participating in the study. TB patients and survivors were reimbursed the equivalent of USD 10 to cover out-of-pocket expenses incurred at the hospital, including food and transportation.

3.2.1. Eligibility Criteria for the Selected Study Participants

The eligibility criteria for the selected participants varied depending on the targeted sub-population and the data collection method, as outlined below:

3.2.1.1 Eligibility Criteria for PTB Patients

For PTB patients to be involved in the study, the following criteria were used: -

a) Positive sputum test (either by Gene Xpert MTB/RIF or positive culture result). Culture positivity refers specifically to growth of mycobacterium tuberculosis complex using either the Lowenstein- Jensen solid media or liquid culture method (MGIT- Mycobacterial Growth Indicator Tube system.
b) Enrolled in TB Sequel study
c) Currently on treatment (0-6 months after treatment initiation)
d) 18 years and older
e) Comfortable communicating in Kiswahili language
f) Willing to participate in the TB sequel study and sign an informed consent form.

Exclusion criteria included

a) A patient who had completed treatment
b) A patient below 18 years
c) A patient who interrupted treatment and returned to restart
d) Unable to speak Kiswahili

3.2.1.2 Eligibility Criteria for TB Survivors

a) An adult (≥18 years of age)
b) Enrolled in TB Sequel study.
c) Previously diagnosed with TB and completed treatment (TB survivors) in the last 24 months
d) Confirmed TB negative upon completion of ant-TB treatment, through clinical assessment by healthcare provider supported by follow up sputum smear or GeneXpert MTF/RIF results indicating no evidence of active TB at the end of treatment.
e) Comfortable communicating in Kiswahili languages
f) Willing to participate in a face-to-face interview by agreeing to sign a consent form

Exclusion Criteria for TB Survivors

a) Adults, diagnosed with extra-pulmonary TB.
b) Failure to complete TB treatment and loss to follow-up.

3.2.1.3 Eligibility Criteria for a relative of a person with confirmed TB diagnosis

PTB relatives (households/family representatives) to be involved in the study, the following criteria were considered:

a) Living with PTB patients enrolled in TB Sequel study
b) A person living with/ever having taken care of PTB patients
c) 18 years and above
d) Being head of the household, if a patient is not head of the household
e) Being aware of a patient‘s TB status (patient agreed to share the TB result with him/her)
f) Comfortable communicating in Kiswahili languages
g) Provided informed consent and agreed to participate in the interview.

Exclusion Criteria

a) Not living with PTB patients
b) Age below 18 years
c) Not aware of a patient's TB status

3.2.1.4 Eligibility Criteria for HealthCare Providers(HCPs)

In this document, two terms (healthcare workers and healthcare providers) have been used interchangeably to mean the same thing, both terms refers to individuals who hold a license or recognized certification to practice medical-related services, including those qualified to perform diagnoses, prescribe medication, and manage patients' health conditions.

a) HCPs working in the TB section facilities
b) Working in the current position for at least six months.
c) Comfortable communicating in English and/or Kiswahili languages.
d) Willing to participate interview and agree to sign consent form.

Eligibility Criterial for Policy/Decision-Makers

These are individuals working at the Ministry of Health and the National TB and Leprosy Programme (NTLP) at the national, regional and district level

a) Working in the current position for at least six months.
b) Comfortable communicating in English and/or Kiswahili languages.
c) Willing to participate interview and agree to sign consent form

3.3 Sample Size Estimation

3.3.1 Quantitative Sample Size Estimation

The TB Sequel project was implemented in four countries, with the hypothesis that the prevalence of severe lung impairment 24 months after TB diagnosis would be 15%, based on a conservative estimate from a literature review. A sample size of 1,600 patients (400 per site) was required to estimate the primary endpoint in the total cohort with a precision of approximately 1.75%. Additionally, subgroup prevalence estimates, such as for HIV-positive patients (representing 50% of the total cohort) and diabetic patients (representing 5% of the total cohort), were calculated with a precision of 2.5% and 7.8%, respectively (191). With a

pre-set alpha of 5% (two-sided), the sample size was designed to detect risk factors doubling the prevalence of severe lung impairment with at least 80% power, even for risk factors with a low prevalence of 5% in the total cohort. However, adjustments to the sample were allowed based on the availability and quality of patient endpoint data or if the primary outcome prevalence was lower than the estimated 15% (191).

3.3.2 Qualitative sample size

Two districts were selected randomly from each region, encompassing both urban and rural areas. Mbeya City was chosen from the Mbeya Region, while Chunya and Kyela Districts were excluded. Similarly, Mbarali was selected to represent other rural districts, including Busokelo, Rungwe, and Mbeya Rural. In the Songwe Region, Tunduma town and Mbozi district were chosen to represent urban and rural districts, respectively. Participants with tuberculosis and TB survivors were purposively selected from these districts, and healthcare providers from the 12 clinics were purposively selected. Interviews were conducted until data saturation was reached.

3.4 Sampling approaches

3.4.1 Quantitative Sampling Techniques

The TB Sequel project has enrolled new patients from 24 designated health facilities as part of the ongoing study. Upon referral, these patients undergo confirmatory tests at the TB Sequel clinic, including sputum analysis, culture testing, and X-rays. The recruitment process targeted individuals who tested positive for sputum during their TB diagnosis. A total of 261 respondents, ages 18 to 60 years, were recruited to participate in the TB Sequel project in Tanzania. The recruitment process started from September 2018 to May 2021. Furthermore, all selected patients completed a socio-economic questionnaire after routine clinical visits.

3.4.2 Qualitative Sampling Techniques

The qualitative data collection employed a purposive sampling method to engage specific participants for face-to-face in-depth interviews (IDIs) and Key Informant Interviews (KII). Participants were selected based on a list of PTB patients obtained from the TB Sequel study. The study targeted individuals who were either currently undergoing treatment (0-6 months) or those who had completed PTB treatment for the last 24 months, commonly known as PTB

survivors. Qualitative data collection started from October 2020 to March 2021. This approach aimed to capture the perspectives of both those undergoing treatment and those who had recently completed it (196).

The methodology sought to extract valuable insights from individuals with extensive experience and knowledge about the subject. This approach was designed to offer comprehensive information on the socioeconomic impact of TB. A detailed discussion of the sampling approach, including its strengths and limitations, is presented (169,197).

3.4.2.1 IDIs with PTB Patients and TB Survivors

The study involved participants aged 18 years and older from the Mbeya region (Mbeya City and Mbarali districts) and the Songwe region (Tunduma and Mbozi districts). The number of participants was determined based on the principle of saturation, ensuring data collection continued until no new or significant information emerged from additional interviews.

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3.4.2.2 IDIs with Relatives Living with PTB Patients

Relatives of the TB-positive patients were purposively selected based on their relationship with the TB patients. Interviews targeted the household head, the spouse, or another adult relative, provided the TB patient had disclosed their status to that individual. Patients were requested to share their relative's contact information and a suitable time for the interviewer to arrange the interview. Ultimately, eight relatives consented to participate, most of whom had accompanied the patients for treatment. However, several factors prevented other relatives from participating in the interviews: two patients lived alone, and while their relatives knew of their illness, they were unaware it was TB; three patients were heads of households with children under 18, making these relatives ineligible for interviews; two patients lived with elderly parents who were unable to participate in the interviews; and three patients were uncomfortable with their relatives being interviewed due to non-disclosure of their TB status.

3.4.2.3 KIIs with Healthcare Providers in the Health Facilities

These interviews were conducted with Healthcare Providers working in TB clinics, with participants selected using purposive sampling. This group selected HCPs from 12 facilities offering TB services (care and treatment) in the selected districts. KIIs were conducted with

individuals employed in 12 HCFs. Participants were selected based on their experience, specifically requiring at least six months of work in a tuberculosis clinic. The number of participants was determined by the saturation point.

3.4.2.4 KIIs with Policy/Decision-Makers

The study participants comprised key stakeholders, including representatives from the Ministry of Health (MoH), Regional TB and Leprosy Coordinator (RTLC), and District TB and Leprosy Coordinator (DTLC). The selection relies on participants' professional expertise, roles, and experience in addressing TB. Eight participants were interviewed face-to-face, including two at the national level, two at the regional level, and four at the district level. The following figure **(Figure 3.4)** summarizes the study population and the methodology used.

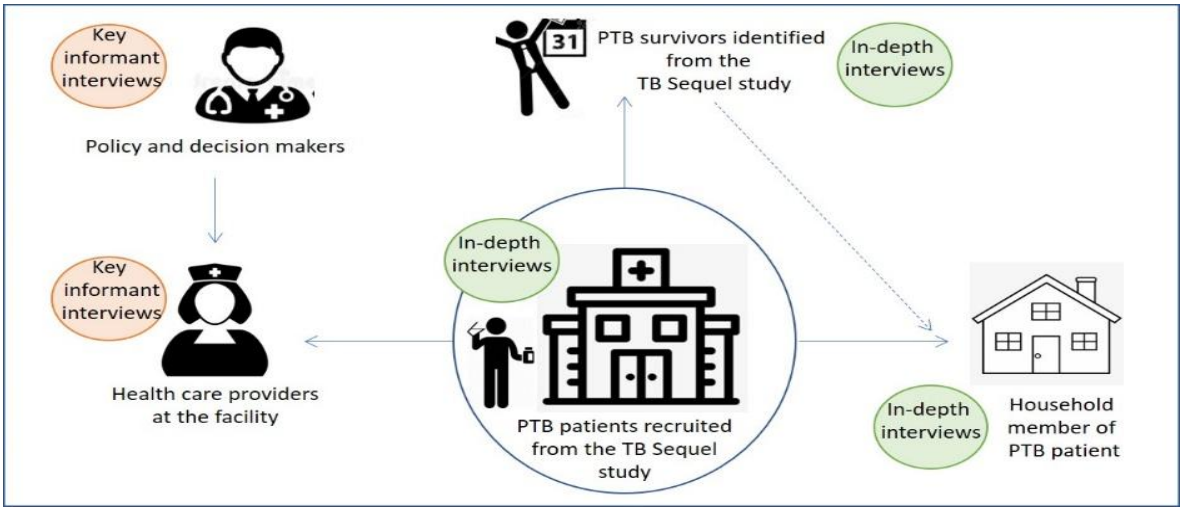

Figure 3.4. Summary of the study populations and methods used.

3.5.1. Training and Orientation of the Tools

Comprehensive training workshops on quantitative social and economic tools were conducted in South Africa, with participation from research teams representing four selected countries. The training was conducted by an expert from the Health Economics and Epidemiology Research Office (HE2RO), a division of the Wits Health Consortium. The training consists of plenary sessions (tuberculosis, rationale for the survey, and Standard Operational Procedures (SOPs). Subsequently, country-specific training sessions were conducted, led by specialists in the respective fields. These sessions involved simulated role plays in which the participating

teams actively engaged. As a result, adjustments were made to the questionnaires to enhance their clarity.

During the qualitative phase, a comprehensive three-day training session was conducted with the participation of a moderator and note-taker. The primary goal of this training was to provide participants with essential skills for collecting qualitative data and to facilitate discussions on important aspects, including consent forms and the preservation of participant dignity.

The training encompassed a thorough review of all tools and ensuring consistency between the English and Kiswahili versions. Subsequently, the tools underwent a pre-test on the final day, and necessary adjustments were made based on the pilot test findings. The researchers then refined the tools to ensure their comprehensibility, tailoring the language to align with the Tanzanian context. In qualitative research, five distinct tools were employed to engage with five different categories of respondents (TB patients, TB survivors, Patients' relatives, Healthcare providers, Policy and decision makers), all serving the same fundamental objectives.

3.5.2. Pre-Survey Workshop

In preparation for data collection in Mbeya and Songwe region, a pre-survey workshop was conducted with the Reginal TB & Leprosy Coordinator (RTLC), District TB & Treatment Coordinators (DTLCs), health facility leaders providing TB care and treatment, and community members (TB survivors). The workshop aimed to introduce the project at regional and district levels. During the seminar, the Local Principal Investigator (PI) outlined the objectives of the TB Sequel project and underscored its significance to the community. Additionally, workshop participants received training on identifying eligible TB patients for referral to the TB Sequel project and were encouraged to facilitate TB diagnosis at nearby facilities, a critical step in enrolling TB patients.

3.6.1. Data Collection Techniques

Between 2018 and 2021, a total of 261 TB patients from 24 different HCFs were enrolled in our research project. The patients were from the 24 selected facilities offering TB care and treatment services after being confirmed TB-positive. All the patients transferred to the TB Sequel project were given the consent form to read, and participants who agreed to join the

project signed the consent form. Following that, the patients underwent additional confirmatory tests to confirm eligibility. Eligible patients were enrolled in the TB Sequel project and had other medical tests. After undergoing all the medical procedures, the selected patients participated in a socio-economic survey. Two social scientists were available to assist in filling out the questionnaires. The questionnaires were filled to all the selected patients in each visit, starting with days zero (baseline), two, six, 12, and 24 months after TB treatment initiation. The baseline data from day 0 was used for the first objective.

For the qualitative research, selection was done by identifying TB patients who have been undergoing treatment for 0-6 months to participate in IDIs. TB survivors are those patients who have completed treatment and have been confirmed to be TB-negative. We selected individuals who are two years and above to come in for follow-up. In addition, face-to-face interviews with healthcare providers and policy decision-makers were conducted. Before starting the interview, all agreed participants signed the informed consent forms.

For our qualitative research, we selected TB patients undergoing treatment for 0-6 months to participate in in-depth interviews. TB survivors, defined as patients who have completed treatment and tested negative for TB, were included in the study. We specifically targeted individuals 24 months after completion of TB treatment. In addition, healthcare professionals and policymakers were also interviewed.

The primary data collector, who is a PhD student, played a leading role in the moderation process. At the same time, a social assistant, trained in aspects of qualitative research and good clinical practice, joined in to participate in activities such as note-taking, observation of non-verbal communication during face-to-face interviews, and assisting the moderator in putting questions in certain ways that may be easier to understand by some of the study respondents. To ensure full participant understanding and maximize the chance for an effective response, the interviews were held in Kiswahili.

The data collection exercise especially qualitative was conducted during the COVID-19 pandemic. To minimize the risk of infection among researchers and study participants, the research team provided protective gear such as face masks and hand sanitizer. The data collection team ensured consistent use of this protective gears by all participants. Physical distancing was maintained throughout the interviews, and alcohol-based hand sanitizer was used regularly. The principal investigator (PhD student) and research assistants closely

monitored adherence to these safety protocols and throughout the data collection period. Furthermore, the COVID-19 pandemic affected data collection processes, including limited access to health facilities, reduced follow-up visits, and disruptions in record-keeping. These factors, combined with shifting healthcare priorities, may have introduced gaps or inconsistencies in the data. Which were acknowledged and discussed in the study's limitations.

Below is a summary of the objectives, data collection technique, and study participants **(Table 3.2**).

Table 3.2. Objectives, paper published, data collection techniques, and source of data.

Objective	**Papers**	**Data collection Tool(s)**	**Participants**
To describe the impact of direct and indirect financial costs incurred by patients, their households, TB survivors, and healthcare providers before and during PTB treatment.	**Paper 1:** Kilima SP, Hirasen K, Mubyazi GM, Moolla A, Ntinginya NE, Sabi I, Mwanyonga S, Evans D. Implications of pre-diagnosis costs incurred by patients and their families for tuberculosis-related health-seeking behaviours in Mbeya and Songwe regions, Tanzania. Status: Submitted PLOS ONE journal	IDI guide (face-to-face at the study site)	18 PTB patients IDI
To explore PTB's social and economic consequences as experienced by patients, their households, TB survivors, health care providers, and policy/decision-makers	**Paper II**: Kilima SP, Mubyazi G, Moolla A, Ntinginya N, Sabi I, Mwanyonga S, Evans D. Understanding the implications of social and financial burdens of pulmonary tuberculosis on patients, survivors and their family caregivers on care seeking and treatment in Tanzania: Feedback from a qualitative study in Mbeya and Songwe regions. Tanzania Journal of Health	IDI guide; KII guide (face-to-face)	18 PTB patients and 12 PTB survivors; 8 Patients' relatives; 12 KII with a healthcare provider

	Research. 2023 Jul 10;24(3):241-54. https://dx.doi.org/10.4314/thrb.v24i3-8		
To explore the coping strategies adopted by patients, their families, TB survivors, and HCPs in navigating PTB illness and treatment, with particular emphasis on how social support strengthens these approaches.	**Paper III** Kilima SP, Mubyazi GM, Moolla A, Ntinginya NE, Sabi I, Mwanyonga SP, Evans D. Perceived access to social support during and after TB treatment in Mbeya and Songwe Regions, Tanzania: Perspectives from TB patients and survivors set against health care providers. Frontiers in Health Services. 2024 Jul 11;4:1273739. https://doi.org/10.3389/frhs.2024.1273739	IDI guide; KII guide (face to face)	PTB patients and PTB survivors; 12 Health care providers

Abbreviations: KII-Key Informant Interview; IDI In-depth Interviews; PTB – Pulmonary Tuberculosis

3.7. Data Analysis

3.7.1 Quantitative Analysis

A data clerk coded the questionnaire responses to produce quantifiable data and then entered them into OpenClinica software. Accuracy was diligently maintained, and errors were rectified by cross-referencing the original data.

A clean dataset was exported for analysis in SAS version 9.4. This study utilized data from the TB Sequel study, which focused on profiling the characteristics of adults starting treatment for drug-susceptible pulmonary TB. The primary objective was to provide a descriptive analysis of the patient characteristics, TB care-seeking behaviours, and associated costs. Therefore, the study aimed to stratify travel time, visit duration, and costs (including direct medical, direct non-medical, indirect, and total costs) in USD per patient based on the

number of providers consulted prior to TB treatment initiation (i.e., one, two, or three or more providers).

The study population, as identified in the patient cost survey, was characterized by descriptive statistics. Medians with interquartile ranges (IQR), frequencies, and simple proportions/percentages were employed as suitable measures. Mean costs incurred by patients and their caregivers, including both direct and indirect costs, were reported with standard deviations (SD). To attain this objective, the data were classified to disclose the averages (means), extreme values, and other measures of central tendency, such as medians and interquartile ranges (IQR). The selection of the measurement type was influenced by the nature of the data, whether categorical or continuous (136).

Measuring patient costs

The TB Sequel project incorporates an assessment of the socioeconomic costs incurred by patients before and after treatment as a key component of its data collection process. For the purposes of this study, the focus was on the costs accrued before the commencement of treatment. The term "pre-treatment costs" pertains to the expenses accrued from symptom onset to treatment initiation, as reported at baseline (Month 0) through a longitudinal survey aligned with WHO TB Patient Cost Handbook guidelines (106,198). Specifically, the aim was to quantify costs incurred between the onset of TB symptoms and diagnosis. These costs were categorized into: 1) direct medical costs (consultations, imaging, laboratory tests, medications, supplements, and hospitalization) and 2) direct non-medical costs (transportation, food, and accommodation).

Indirect and opportunity costs associated with PTB these include productivity losses and economic impacts (106). These costs were primarily measured through income loss, which is calculated based on the total time patients spend seeking care before receiving a diagnosis. This time encompasses travel, waiting, and attending consultations, representing hours of income that are lost. To estimate the total patient time lost due to TB, researchers multiply the average number of visits to providers before a diagnosis by the combined average travel time and the duration of each visit (106). Following the human capital approach, the total indirect patient cost was calculated by multiplying the total time lost due to TB (in hours) by the hourly wage rate (106). For individuals earning cash-based incomes (i.e., those in formal

employment), the hourly wage rate was calculated by dividing the monthly income before TB diagnosis by the total number of working hours in a month. Conversely, for those engaged in informal employment without fixed working hours or wages (e.g., home-based workers, street vendors, etc.), an hourly rate equivalent to the Tanzanian minimum hourly wage in 2021 was adopted ($0.29) (199). Indirect costs associated with accompanying household members and caregivers were calculated as the per-visit expenses incurred by a household member for transportation, food, and accommodation, multiplied by the total number of pre-treatment provider visits that the household member spent accompanying the patient.

Cost inflation and Conversion.

All costs were initially recorded in Tanzanian Shilling (TZS). Expenses incurred before 2021 were adjusted for inflation to 2021 values using the World Bank GDP deflator for 2021. These costs were then converted to United States Dollars (USD) using the 2021 average exchange rate (USD 1 = TZS 2297.76) as referenced by the currency converter. All quantitative analyses were conducted using SAS version 9.4.

3.7.2 Qualitative Analysis

A research assistant performed a verbatim transcription of the IDI sessions. Subsequently, a PhD student reviewed all transcriptions to verify accuracy through audio comparison. The interviews, conducted in the local language (Kiswahili), were simultaneously transcribed and translated. Two experienced research assistants transcribed the audio recorded verbatim. The transcriptions were then translated from Kiswahili to English for analysis. Researchers employed both inductive and deductive approaches to review the transcripts thoroughly and ensure complete familiarity with the data for pattern recognition. Subsequently, the researchers independently coded the transcripts before meeting to discuss the general themes and sub-themes (200). They reviewed and coded the transcripts independently before discussing their generated themes and sub-themes, agreeing upon any overlap. In cases of disagreement regarding the themes, further discussion occurred until a consensus was reached. All the transcripts were uploaded into NVivo 12 software for coding and subsequent data analysis. In the data collected, several **themes** and sub-themes emerged, and some of them were as follows.

a) Healthcare seeking pathways, underlying causes, financial burden prior to PTB diagnosis
b) Diagnosis and Health Care Seeking Journey
c) Factors external to the formal health care system behind a delayed PTB care-seeking
d) Experience before visiting a health facility and the cost associated
e) Social and economic consequences of TB
f) Role of social support in TB management
g) Treatment Experiences
h) Financial Impact of TB on Respondent
i) Post-TB experience (of illness and associated costs
j) Community and Family Responses to TB
k) Social Support Networks
l) Coping with PTB

3.8. Data Management

3.8.1 Qualitative Data Management

All the hard and electronic copies of the data collection tool and informed consent forms were securely stored. Hard copies were stored in a locked cabinet with access restricted to the study team. In contrast, electronic copies saved in the PI's computer were protected by passwords to avoid easy access by people outside the research team.

3.8.2 Quantitative Data Management

The researcher diligently adhered to all established management protocols to guarantee the handling of the collected data, ensuring the production of high-quality results. All quantitative data collected through the patient cost survey were managed locally and entered into OpenClinica, an electronic cloud-based data capture and clinical data management application available at https://www.openclinica.com/. The data underwent thorough scrutiny for range and consistency. Subsequently, the refined data set was transferred to SAS version 9.4 for further refinement and analysis.

3.9. Ethical Considerations

Permission to conduct this study was granted by the National Institute for Medical Research (NIMR) in Tanzania (Certificate Ref. No. NIMR/HQ/R.8a/Vol. IX/3527). Ethical approval was obtained from the Human Research Ethics Committee of the University of the Witwatersrand, South Africa (Approval No. M200570, dated 29 May 2020), as well as from the Mbeya Medical Research and Ethics Review Committee (approved on 16 January 2020). Furthermore, the main project, TB Sequel, also received ethical clearance from NIMR Tanzania (Certificate ref No. NIMR/HQ/R.8a/Vol. IX/2449).

All participants were made aware of the study's objectives and significance. Before enrolment, those who agreed to participate signed an informed consent form to confirm their willingness. Participants were informed that their participation was completely voluntary and that they could withdraw from the study at any time. The study guaranteed confidentiality and anonymity; no participant's information was disclosed outside the research team. A separate consent form was signed for participants participating in the qualitative study. Since the qualitative data collection involved an audio recorder, the participants also signed a consent form to be recorded.

To ensure good research practices, the study involved researchers with sound knowledge and skills of ethical conduct in health research and who were trained in good clinical practices. The research assistants had relevant training backgrounds and some experience in health research data collection. The consent forms and questionnaires were available in English and Kiswahili.

3.10 Anticipated Risks

The study poses no significant risks for participants. The questions pertain to non-sensitive topics and thus are not expected to cause distress.

During the data collection period between 2020 and 2021, adherence to COVID-19 safety protocols was mandatory. This includes the use of masks and other protective equipment by the Principal Investigator, research assistant, and participants during interviews. Additionally,

hand sanitization was compulsory before interviews, and social distancing guidelines recommended by the World Health Organization were strictly followed.

All eligible TB patients referred to TB Sequel have an equal opportunity for selection in the study. The risks associated with participation were minimal as enrolment was consecutive based on eligibility. Additionally, there was no gender disparity, and participants received remuneration for their time and travel costs, thereby mitigating any possible financial strain.

CHAPTER 4

4.1 PAPER 1

Implications of pre-diagnosis costs incurred by patients and their families for tuberculosis-related health-seeking behaviours in Mbeya and Songwe regions, Tanzania

At the time of dissertation submission, Paper I had been submitted to the PLOS ONE journal, and reviewer comments had been received. The manuscript is presented using the sections and layout specified by the journal but has been reformatted to align with the dissertation style requirements of the university.

Reference: Stella Kilima, Kamban Hirasen, Godfrey M. Mubyazi, Aneesa Moolla, Nyanda E. Ntinginya, Issa Sabi, Simeoni Mwanyonga, Denise Evans. Implications of pre-diagnosis costs incurred by patients and their families for tuberculosis-related health-seeking behaviours in Mbeya and Songwe regions, Tanzania. *PLOS ONE journal*

Abstract

Background: Pulmonary tuberculosis (PTB), remain one of the leading causes of death from infectious disease worldwide, its burden is disproportionately affecting low-and middle-income countries (LMICs), including Tanzania. This study aimed to examine the direct and indirect costs incurred by patients and their families prior to PTB diagnosis, and how such costs influence patients' health-seeking behaviours.

Methods: A mixed-method approach was employed, integrating qualitative and quantitative methods for data collection, analysis and interpretation. The study was embedded within a longitudinal observational cohort involving 261 adult patients diagnosed with PTB. Quantitative data were collected using a structured questionnaire adapted from the WHO's generic patient cost survey tool, administered after TB diagnosis was confirmed. To gain a deeper insight, additional data were gathered through, in-depth interviews (IDIs) with purposively selected participants, aimed at identifying both financial and non-financial challenges experienced by patients and their family supporters prior to diagnosis.

Results: Of all the 261 respondents, approximately 59% were men, 48% were married, and 51% were living with HIV, with median age of 35 years. The majority 185 (72.8%) delaying visiting a healthcare facility (HCFs) by more than four weeks following the onset of symptoms. The average total pre-treatment cost per patient was USD 28.80, comprising direct medical, direct non-medical, and indirect costs. These costs varied based on the number and type of healthcare providers consulted. Qualitative findings indicated that participants frequently associated this pre-treatment costs with delays in seeking formal care, often influenced by self-medication, limited awareness of TB symptoms, and long travel distances to formal HCFs.

Conclusion: The study highlights the significant financial and non-financial barriers faced by patients diagnosed with PTB and their families prior to diagnosis. Delays in care-seeking not only worsen health outcomes but also increase the overall economic burden. Addressing these challenges requires a comprehensive, multisectoral approach to improve early diagnosis, reduce patients costs and strengthen TB control efforts in high-burden setting.

Keywords: Pulmonary Tuberculosis, pre-diagnosis costs, health care seeking behaviour, indirect costs, healthcare facilities, Tanzania

Background

Overview of evidence on the economic burden of PTB

Pulmonary TB remains a major global public health concern. According to the World Health Organization (WHO), TB is among the leading causes of death from infectious diseases, with the majority of cases occurring in LMICs, where the burden is disproportionately high (1). Each year, approximately 10 million people develop TB, and more than one million die from the disease (1,2). TB contributes significantly to healthcare utilization, including outpatient visits and hospitalisation, and continues to be a major driver of morbidity and mortality in affected populations.

Economic burden of PTB and pre-diagnosis costs

Beyond its clinical impact, TB imposes considerable economic burden, particularly among socio-economically disadvantaged populations (3,4). Although TB diagnosis and treatment are provided free of charge in many public health systems, patients often incur substantial out-of-pocket expenses, especially during the pre-diagnosis phase of care (5,6). These costs include direct medical expenses (consultation fees, tests, medications), direct non-medical costs (transportation, food, accommodation), and indirect costs (lost income due to time spent seeking care) (7-9). These indirect costs are frequently excluded from traditional costs of illness studies, despite their substantial contribution to the overall financial burden (6,13). These expenditures are often incurred across multiple providers, including pharmacies, private practitioners, and traditional or spiritual healers, before a confirmed TB diagnosis is made in the formal health system.

Evidence consistently shows that pre-diagnosis costs are critical component of the overall economic burden of TB, particularly in high burden settings (10). A systematic review of the economic burden of TB in Africa found that pre-diagnosis costs average expenditure was $36 in Malawi, $109 in Zambia, and $196 in Ethiopia accounting for 11.3%, 10.6%, and 35.0% of pre-diagnosis household income, respectively (11). In The Gambia, a recent study reported

average pre-diagnosis direct costs of $22.93, constituting nearly 47% of the total direct costs incurred throughout the TB care continuum (11). This phase represented the highest income loss, with patients who consulted traditional healers incurring the greatest average expenses of $30.80 and spending up to 50 hours seeking care, substantially more than those who visited private clinics, who reported average costs of $14.84 and only 5 hours of care seeking time (11).

Catastrophic costs and opportunity losses

Pre-treatment expenditures, though often overlooked, can be financially devastating for TB affected households (5,12). These out-of-pocket (OOP) costs can delay diagnosis, reduce access to treatment, and negatively impact treatment adherence and outcomes, ultimately reinforcing the cycle of poverty and poor health. TB-related illness often leads to reduced productivity, absenteeism and diminished earning potential (6,13).

According to the WHO definition, TB related "catastrophic costs" occur when total costs of TB care seeking including direct medical, direct non-medical and indirect costs exceed 20% of household's annual income prior to TB diagnosis (14). These financial hardships reduce the ability of affected families to meet basic needs and may deter care-seeking, particularly when upfront payments are required. Geographic and systematic barriers further exacerbate these issues, especially in rural areas where transportation costs and opportunity losses are substantial (15-18).

TB Services in Tanzania

Tanzania is one of the 30 high TB burden countries globally, yet it has made notable progress in recent years. According to the National TB and Leprosy Programme (NTLP 2023), the national TB incidence rate declined from 306 per 100,000 population in 2015 to 183 per 100,000 in 2023 representing a reduction of 40% (19). TB related mortality also dropped by 68%, from 58,000 deaths in 2023 to 18,400 in 2025 (19). Furthermore, case notification rates increased by 6% annually between 2015 and 2022, peaking at 165 per 100,000 population, but showed a slight decline in 2023, which is 145 per 100,000 population (19). To strengthen TB control efforts, the Tanzanian government, in collaboration with international partners, has expanded TB services through decentralization and integration into lower-level health

facilities (20). However, limited access to diagnostic services remains a challenge (21,22). Only 45% of the 655 health care facilities (HCFs) in the Mbeya and Songwe regions offer TB care, and just 99 facilities (15%) are accredited for TB diagnostics (23). Advanced diagnostic tools such as GeneXpert and drug susceptibility testing (DST) are largely confined to regional hospitals, limiting access in rural settings. Lower-level facilities often rely on clinical diagnosis and sputum smear microscopy, which have limited sensitivity, particularly in individuals living with HIV and extrapulmonary TB. Despite existing sample referral systems (from lower to higher levels facility), logistical delays persist (24). The TB services are offered mainly through public and a few selected private health facilities, in Tanzania, government health facilities serve about 72% of TB patients for diagnosis and treatment (19).

Limited access to accurate diagnostic tools, combined with low public awareness of TB symptoms, contributes to delayed diagnosis and extended care-seeking pathways (25). Patients commonly consult multiple providers before obtaining a confirmed diagnosis, resulting in increased OOP expenses (25). These delays elevate the financial burden, compromise treatment outcomes, and heighten the risk of continued TB transmission (25).In regions like Mbeya and Songwe, this pattern is particularly evident. Patients often seek care at multiple facilities or non-formal providers before receiving an accurate diagnosis. This care-seeking trajectory leads to high pre-treatment costs that many households can ill afford, making them vulnerable to catastrophic financial consequences even before initiating treatment.

Importance of addressing pre-diagnosis costs in Tanzania

Despite their significance, pre-treatment costs are often excluded from cost-of-illness studies, leading to an incomplete picture of TB's economic burden. Recognizing and quantifying these early-stage financial burdens is essential for informing health policies and designing interventions aimed at reducing economic barriers to care. Comprehensive inclusion of pre-treatment costs in research and policy frameworks is critical for achieving universal health coverage, improving treatment outcomes, and breaking the cycle of poverty associated with TB. This study focuses specifically on the economic costs incurred during the pre-diagnosis phase of PTB care, with a focus on patient and household experiences in high-burden settings of Tanzania. By highlighting this under-researched aspect of the TB care continuum, the findings aim to inform equitable and cost-sensitive strategies for TB control.

Material and methods

Study Design

This study, employed a mixed-methods approach, incorporating both qualitative and quantitative components, and was nested within a longitudinal, multi-center observational cohort study known as TB Sequel (26). TB sequel 1 (2016-2022) was a longitudinal cohort study aimed at understanding the long-term clinical, socio-economic and respiratory health outcome among individuals diagnosed with pulmonary TB. This parent study was conducted across four Sub-Saharan Africa (SSA) countries: Mozambique, Tanzania, The Gambia, and South Africa. However, this paper focuses exclusively on data collected from participants enrolled in Tanzania

Setting

The study was conducted in two study regions, Mbeya and Songwe, located in the southwestern highlands of the United Republic of Tanzania (URT), specifically on the mainland. The TB sequel project recruited newly diagnosed TB patients from the 24 randomly selected HCFs across the study regions. The HCFs were selected among those officially accredited to provide both TB diagnosis and treatment services, include 13 hospitals, 10 health centres and one dispensary. These HCFs were selected to refer newly diagnosed TB patients to the TB Sequel project, which is hosted at Mbeya Zonal Referral Hospital (ZRH) in the City of Mbeya. Interviews were conducted in a quiet, private area within MZRH, separate from the TB Sequel clinic. It is important to note that while participants took part in the TB Sequel study, they continued to receive their standard TB treatment at the referring facilities in line with national guidelines and the standard of care. The TB Sequel study activities were designed to run in parallel with routine care, without interfering with clinical management.

Study Population

Convenience sampling was employed, whereby eligible participants presenting at participating HCFs were referred to the study as they become available. Referred patients underwent confirmatory tests at the TB Sequel clinic before enrolment. Recruitme occurred

following a TB diagnosis, with only individuals confirmed as sputum-positive enrolled in the study. The recruitment period spanned approximately two years from September 2017 to March 2020. Participants agreed to take part in the TB Sequel project largely due to the active involvement of the National, Regional, and District Tuberculosis and Leprosy Programs (NTLP, RTLP, DTLP), as well as support from the local community. These stakeholders played a crucial role in raising awareness and educating communities about the purpose and importance of the TB Sequel project.

Participants were benefited from additional diagnostic services provided free of charge, beyond what is typically offered in routine care. These services included spirometry, electrocardiogram (ECG), 6-minute walk test (6MWT), chest X-ray, and urinalysis. Moreover, follow-up visits were conducted for individuals who had completed their TB treatment, offering continued monitoring and care as an aspect that was highly valued by participants. To further reduce participation barriers, transport costs were reimbursed, which helped alleviate financial constraints. These combined efforts significantly contributed to enhancing participant engagement and retention in the project.

The inclusion criteria for participants in the **quantitative** component were: A positive result for Mycobacterium tuberculosis (MTB) from at least one sputum sample, as determined by Xpert MTB/RIF assay in the study clinic/laboratory, or a positive culture result from either the study laboratory or other accredited TB laboratory (26,27); Aged 18 years or older; willing to provide a written informed consent (IC), or witnessed oral consent if illiterate before the collection of the first sample or any other study-related data; willing to undergo HIV testing; consent to provide and allow collection and storage of blood, urine, and sputum samples; Willing to initiate anti-TB treatment following diagnosis. Lastly, residence within the study area and willingness to notify the study team of any address changes during the treatment and follow-up (26). Exclusion criteria included: receipt anti-TB treatment within the past 6 months; inability to produce and provide two sputum samples; severe medical or psychiatric conditions (as determined by the site investigator) that could impair the ability to provide informed consent or comply with study requirements; participation in ongoing investigational trials related to TB or lung diseases and lastly currently imprisoned.

For the **qualitative study** component, participants were drawn from the ongoing TB Sequel project. A purposive sampling strategy was employed to select individuals attending routine clinic visits. Eligible participants were identified and provided with detailed information about the qualitative study. To minimize financial burden, interviews were scheduled to coincide with routine follow-up appointments.

Eligibility was determined based on predefined inclusion and exclusion criteria. To be eligible, participants were required to have a confirmed diagnosis of PTB and be currently receiving treatment or attending a follow up visit. Additional inclusion criteria included being 18 years of age or older, the ability to communicate comfortably in English or Kiswahili, and willingness to participate in a face-to-face interview and provide informed consent. Individuals were excluded if they had completed TB treatment and all follow up visits, were under the age of 18, having significant medical or mental health conditions (as determined by the site investigator) that could affect their ability to provide informed consent or had previously interrupted TB treatment and subsequently restarted therapy.

Data Collection

Quantitative Surveys

Trained researchers conducted structured interviews using a questionnaire adopted from the WHO's general patient cost survey (15). The original English version of the questionnaires was verbally translated into the local language by experienced researchers fluent in both English and local language (Kiswahili). A standardized structured questionnaire was maintained across all participating countries to ensure consistency. Before data collection, the research team, including research assistants, underwent a five-day training to familiarize themselves with the study's objectives, methodology and ethical considerations. This was followed by a pilot test of the questionnaire. Based on the pilot feedback, the questions were revised to enhance clarity, user-friendliness, and contextual relevance, ensuring questions were easily understood by the study participants (28). Data collection was paper-based. Completed questionnaires were collected weekly and submitted to a Data Clerk for double entry into an OpenClinica software. The dataset was subsequently imported into SAS version 9.4 for analysis. Patients' pre-treatment costs were calculated by assessing expenses incurred from the onset of PTB symptoms until the time of diagnosis. The analysis focused on direct

medical costs, direct non-medical costs, and indirect costs. Time expenditure was used as a proxy for opportunity cost, capturing potential income loss due to hours spent without working (8).

In addition, several steps were taken to minimize potential recall bias and its impact. We applied structured recall techniques including time anchoring and sequencing to help participants accurately trace their care-seeking journey from the onset of symptoms to diagnosis, and to recall associated costs and time lost (29). Moreover, data from the TB Sequel cohort show that the median duration between symptom onset and the baseline interview was approximately 8 weeks (IQR: 4–16 weeks). Given this relatively short recall period, we considered the likelihood of recall bias to be minimal and that participants were likely able to report their out-of-pocket expenditures and time costs with reasonable accuracy.

Qualitative Interviews

An IDI guide was developed, pretested, and used to facilitate qualitative data collection. The guide included questions on basic demographic characteristics, such as education level, age, and marital status, as well as the history and duration of TB symptoms before seeking care. It also explored the costs associated with all healthcare providers visited, participants' perception of the availability and quality of health facilities, and related OOP expenses. The original English versions of the qualitative interview guide was fully translated into written Kiswahili, and the translation was independently reviewed for accuracy and consistency by two bilingual researchers fluent in both English and Kiswahili. After completing their clinic visit, individuals exiting the TB clinic were approached by a member of the research team to determine their interest in participating in an in-depth interview (IDI). Those who agreed provided written IC, since participation in the IDI was separate from the main TB Sequel cohort study (30). Separate written consent was obtained for audio recording of the interviews. Qualitative data were gathered using open-ended questions designed to complement and enrich the quantitative findings (27). The interviews were conducted by two trained and experienced social scientists, a moderator, and a note-taker.

This study employed a pre-established interview guide developed for individuals diagnosed with TB. IDIs were conducted until thematic saturation was reached, indicating that no new information was emerging from subsequent interviews (31)

Data Analysis

Quantitative data

Quantitative data were analysed using SAS version 9.4 (SAS Institute, Cary, North Carolina, USA). This analysis aimed to describe participants characteristics, care-seeking behaviours and the costs associated with such behaviours. Therefore, the travel time, visit time (including wait time), and costs (direct medical, direct non-medical, indirect, and total) were stratified by the number of providers the participants reported to have visited before a PTB diagnosis and treatment initiation. Data were categorized to highlight averages, extremes, and key measures of central tendency, such as medians and interquartile ranges (IQR). Cost data are summarized using mean and standard deviation, consistent with standard practices in economic evaluation (32).

Therefore, the nature of the data influenced the selection of appropriate analytical methods, depending on whether the variable were categorical or continuous in nature. The 'pre-treatment costs' in this paper referred to all costs incurred from the onset of TB symptoms until the initiation of TB treatment, as reported at baseline (Month 0 or the start of TB treatment). The analysis involved comparing costs incurred by respondents from different residential settings (urban versus rural), sex (males versus females), and marital status (married or cohabiting versus single individuals).

Using the human capital valuation approach (33), we took the product of total time lost due to TB (in hours) and multiplied it by the value of the hourly wage rate in Tanzanian shillings. For individuals with cash-based income, such as those working in formal employment sectors, we determined an hourly wage rate by dividing the monthly salary/wage received by the individual before a TB diagnosis by the total number of hours worked in one month. Accordingly, the monetary value of the productivity time lost, was estimated by multiplying the calculated hourly wage rate by the total working hours lost during the month. However, for those informally employed, such as domestic workers, street vendors, farmers, and the like whose working hours and monetary earnings were unspecified, we utilised an hourly rate that was equivalent to the minimum hourly wage of $0.29 in Tanzania in the year 2021 (34). The costs reported before 2021 were first inflated to 2021, using the 2021 World Bank GDP

deflator, and then converted to the USD using the average exchange rate (USD 1 = TZS 2297.76, based on currency converter http://www.oanda.com/currency/converter) (34).

Given the non-normal distribution of cost data, non-parametric tests were employed to evaluate differences in pre-treatment costs across groups. The Kruskal-Wallis test (¥) was used for comparisons involving more than two categories, while the Wilcoxon rank-sum test (§) was used for binary comparison. Statistically significant was set at $p<0.05$.

Qualitative data

Audio-recorded in IDIs were transcribed verbatim and translated into English by two experienced research assistants. Transcripts were independently reviewed against field notes for quality assurance and data validation (35). The principal investigator (PI) verified transcript accuracy by cross-checking with the original audio recording. All transcript were imported into NVivo 12 for thematic analysis. A mixed deductive-inductive approach using axial coding was employed. A codebook was developed to ensure consistency in coding. Three trained analysts reviewed the transcripts to familiarize themselves with the content, followed by systematic coding. Themes and sub-themes were identified in line with study objectives. Discrepancies or new themes emerging during coding were resolved through discussions to achieve consensus. Although the broader project identified three main themes and ten sub-themes, this paper focuses on two main themes and six sub-themes (**Table 4.1).** These are discussed in detail in the qualitative results section.

Table 4.1. Identified qualitative themes and sub-themes

Themes	**Sub-themes**
Healthcare seeking	Financial expenditures for pre-treatment care-seeking

pathways, underlying causes, financial burden before PTB diagnosis	Delays in contacting formal HCFs due to limited knowledge of PTB symptoms
	Coping strategies for managing PTB symptoms
	Influence of domestic and social obligations on delayed healthcare-seeking
Factors external to the formal health care system behind a delayed PTB care-seeking	Rural-Urban Differences in TB Care Accessibility
	Perceived Quality of Care related Costs
	Limited knowledge of PTB symptoms
Experience before visiting a health facility and the cost associated	Informal support received before being TB diagnosis
	Referral and companion support received from family members and cost associated
	Feelings about pre-treatment procedures costs

Ethics Approval

The quantitative study protocol was reviewed and approved by the National Institute for Medical Research (NIMR) in Tanzania (Reference: NIMR/HQ/R.8a/Vol. IX/2449). Likewise, the qualitative study protocol was approval by the Health Research Ethics Committee (HREC) of the University of the Witwatersrand, South Africa (M200570, 29 May 2020), the Mbeya Medical Research and Ethics Review Committee (January 2020) and the National Institute for Medical Research in Tanzania (Reference: NIMR/HQ/R.8a/Vol. IX/3527). In this study, all participants consented to participate by signing the informed consent form.

Inclusivity in global research

Additional information regarding the ethical, cultural, and scientific considerations specific to inclusivity in global research is included in the Supporting Information (S1 Checklist)

Results

In the quantitative study, 319 participants were initially recruited. Of these, 49 did not meet the eligibility criteria, 6 tested negative for TB, and 3 declined to proceed with follow-up procedures. Consequently, 261 participants with laboratory-confirmed PTB, representing 81% of those initially recruited, were enrolled in the TB Sequel study. All enrolled participants completed the socio-economic questionnaire after their routine clinical visits.

Background information

Participants were mainly between 25 and 34 years (**Table 4.2**). About two-thirds of participants (62.8%) had primary education and only 37.1% were employed, either formally or informally. Nearly half of the participants (47.9%) were married, and approximately 51% were diagnosed with PTB while also living with HIV. Almost all respondents (98.8%) were initiated on the TB standard-regimen, two months of rifampicin (R), isoniazid (H), pyrazinamide (Z), and ethambutol (E) (RHZE), followed by four months of R and H, particularly for the drug-susceptible TB (36). Four patients were started on a second-line anti-TB regimen because they were diagnosed with multidrug-resistant TB (MDR-TB).

Table 4.2 present the pre-treatment costs and stratified by several key patient characteristics at baseline (Month 0 or the start of TB treatment). Costs were similar across most baseline patient characteristics (p>005). The analysis showed a significant difference in costs by marital status (p=0.01), with married individuals incurring higher pre-treatment costs compared to those who were divorced, separated, or widowed **(Table 4.2).**

Table 4.2. Total pre-treatment patient costs by patient characteristic (n=261)

Characteristic	**Description**	**Quantitative sample (N=261) N (%)**	**Total pre-treatment cost, Median (Q1-Q3)**	**Significance test¶ (Kruskal-Wallis test¥ / Wilcoxon rank-sum§)**
Age (years)	Median (IQR)	35.0 (29.0-43.0)	-	P-value (0.19)¥
	18-24	31 (11.9%)	13 (4.8-32.3)	
	25-34	98 (37.7%)	22.1 (10.7-40.8)	
	35-44	75 (28.9%)	14.8 (7.1-35.5)	
	≥45	56 (21.5%)	15.9 (3.3-34.2)	
Sex	Female	108 (41.4%)	15.3 (8.8-33)	P-value (0.46)§
	Male	153 (58.6%)	21 (7.2-37.4)	
Employment	Yes	93 (37.1%)	19.9 (10.2-38.4)	P-value (0.21)§
	No	158 (62.9%)	18.9 (7.1-34.9)	
Education level	No schooling	29 (11.1%)	20.8 (10.3-32.5)	P-value (0.24)¥
	Primary school	164 (62.8%)	15.9 (7.1-38.2)	
	Secondary/high school	57 (21.8%)	26.4 (12.1-37.4)	
	Vocational training	6 (2.3%)	14.2 (3.7-21.4)	
	University or	5 (1.9%)	7.4 (1.2-24.6)	

	higher			
Relationship status	Single/living with a partner	64 (24.5%)	17.3 (7.5-32.3)	P-value (0.01)¥*
	Married	125 (47.9%)	22.6 (9.7-42.1)	
	Divorced/separated/widowed	*72 (27.6%)*	*10.3 (6.7-25.2)*	
HIV status	Negative	128 (49.0%)	19.3 (9.6-40.2)	P-value (0.29)§
	Positive	133 (51.0%)	18.7 (6.4-34.2)	
Smear microscopy	Negative	13 (5.0%)	42.1 (5-50.7)	P-value (0.60)§
	Positive	246 (95.0%)	19 (8.6-36.3)	
Treatment regimen	2HRZE/4HR	257 (98.9%)	19.1 (7.5-37.2)	P-value (0.81)§
	Other	3 (1.2%)	17.6 (9.3-47.1)	

IQR: inter-quartile range; HIV: human immunodeficiency virus; 2HRZE: 2 months of isoniazid, rifampicin, pyrazinamide, and ethambutol; 4HR: 4 months of isoniazid and rifampicin

Significance test¶ (Kruskal-Wallis test¥ / Wilcoxon rank-sum§)

Respondents' Health Care Seeking Behaviours Pre-Treatment Initiation

Figure 4.1 illustrates the pre-diagnosis health-seeking behaviour or pathways of individuals diagnosed with PTB. From the overall sample (261), a third have not contacted any other service providers before presenting to the referral HCFs (where they were diagnosed). The reminder (67.3) reported contacting one or several care providers before being diagnosed. Among those who reported contacting any provider, 50% indicated that they had contacted a retail pharmacy. Furthermore, it has been demonstrated that over 40% had visited a public hospital as their second or third provider (**Figure 4.1).**

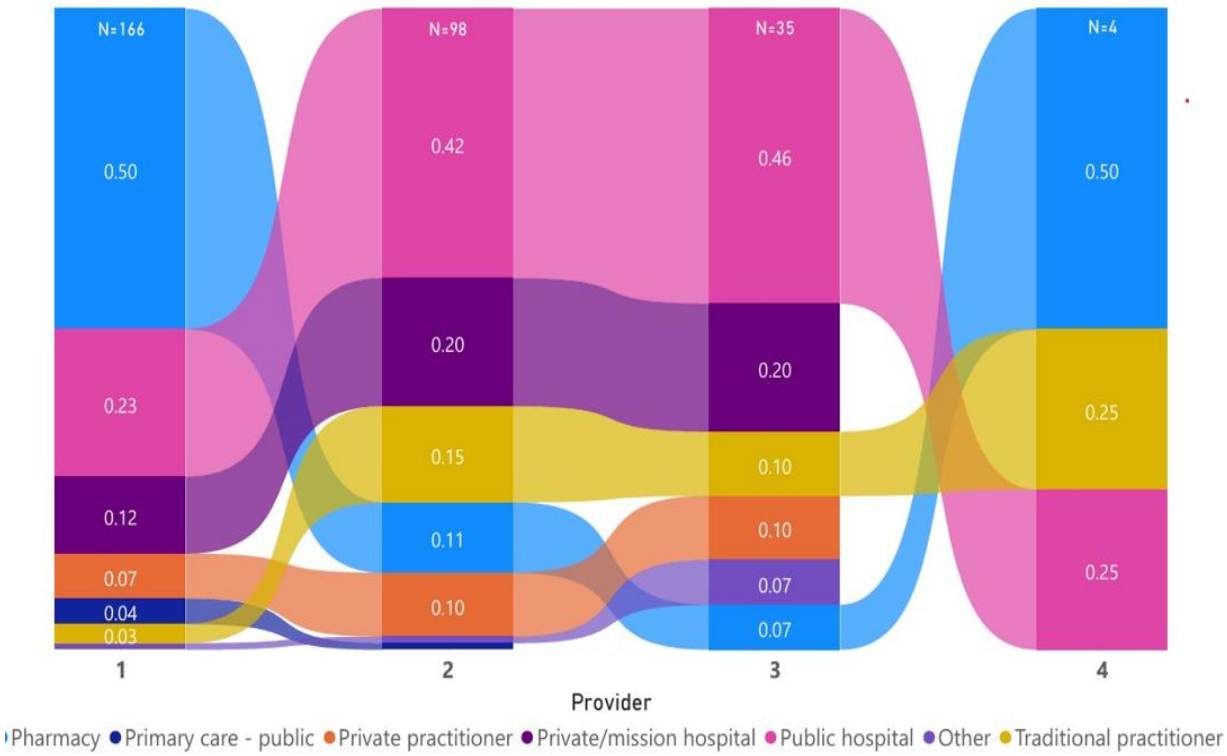

Figure 4.1: Order and frequency of pre-treatment providers seen.

Table 4.3 presents the duration between the onset of symptoms and the initiation of TB treatment. The median time to treatment initiation was 8 weeks, with an interquartile range of 4 to 16 weeks. Furthermore, only a small proportion of patients (1.2%) started treatment between 4 and 16 weeks after symptom onset. Furthermore, only a small proportion of patients (1.2%) started treatment within one week of symptom onset, as the median time from sputum collection to treatment initiation ranges from 2 to 7 days for drug-sensitive TB, even when molecular diagnostics are available. The majority of participants (72.8%) experienced a delay of more than 4 weeks before starting TB treatment. These findings highlight a significant delay in treatment initiation for most study participants, which could contribute to ongoing transmission, worse health outcomes, and increased financial and social burdens **(Table 4.3).** It was noted that visit duration tended to increase with each successive additional provider, suggesting a cumulative pattern of time spent during consultations. Travel time appears to behave additively, as the total distance travelled to the first provider is comparable to that of the third provider, while visit time accumulate across encounters **(Table 4.3)**.

Table 4.3. Pre-treatment health-seeking behaviour and time from symptoms onset to treatment initiation (N=261).

Time from symptoms onset to DS-TB treatment initiation (weeks)	**Median (IQR)**	**8.0 (4.0-16.0)**
	≤ 1	3 (1.2%)
	1-2	12 (4.7%)
	2-4	54 (21.3%)
	≥4	185 (72.8%)
Pre-treatment health-care provider 1		
Travel time to provider (hours)	Median (IQR)	1.5 (0.7-3.0)
Visit time at provider (hours)	Median (IQR)	1.0 (0.5-4.0)
Pre-treatment health-care provider 2		
Travel time to provider (hours)	Median (IQR)	1.5 (1.0-2.8)
Visit time at provider (hours)	Median (IQR)	4.0 (2.0-8.0)
Pre-treatment health-care provider 3		
Travel time to provider (hours)	Median (IQR)	2.0 (1.0-4.0)
Visit time at provider (hours)	Median (IQR)	6.0 (2.5-14.0)

Abbreviations: IQR: inter-quartile range; DS: drug-susceptible; TB: tuberculosis

The costs that were reported for direct medical expenditures encompassed fees for medical consultations, screening through radiography or labs, and medications. These costs increased as the number of providers contacted increased. The average total direct medical costs were USD16.54, with costs for the first, second, and third providers being USD6.82, USD11.58, and USD12.04, respectively. Non-medical and indirect costs also varied with the number of contacted providers. It is important to note the variability in the cost data, which may be influenced by some extreme values **(Table 4.4).**

Table 4.4. The costs for direct medical expenditures per provider.

Cost category	**Description**	**Provider 1 (n=166)**	**Provider 2 (n=98)**	**Provider 3+ (n=35)**	**Total (mean, SD)**
Direct medical costs (mean, SD)	Consultation	0.60 (1.44)	1.72 (4.06)	1.58 (2.06)	2.00 (3.78)
	Radiography/imaging	0.23 (1.33)	0.80 (2.42)	1.27 (2.92)	1.01 (2.66)
	Other procedures	0.10 (0.93)	0.18 (1.07)	0.12 (0.75)	0.22 (1.29)
	Laboratory tests	0.62 (1.78)	0.86 (1.94)	1.01 (3.38)	1.36 (2.76)
	Drugs	5.04 (6.00)	7.38 (12.42)	8.05 (13.98)	11.20 (14.15)
	Other (supplementation)	0.09 (0.46)	0.47 (2.09)	0.01 (0.05)	0.38 (1.72)

	Hospitalization	0.28 (2.34)	0.34 (1.92)	0.00 (0.00)	0.48 (2.84)
	Total direct medical costs	6.82 (8.09)	11.58 (13.68)	12.04 (14.51)	16.45 (16.54)
Direct non-medical costs (mean, SD)	Transportation	0.62 (1.02)	1.76 (2.94)	1.90 (2.47)	2.14 (3.32)
	Food	0.21 (0.50)	0.47 (1.10)	0.81 (0.91)	0.69 (1.24)
	Accommodation	0.00 (0.00)	0.01 (0.07)	0.12 (0.73)	0.03 (0.36)
	Other – non-medical	0.03 (0.37)	0.17 (1.14)	0.09 (0.27)	0.16 (0.98)
	Total direct non-medical costs	0.85 (1.40)	2.39 (3.78)	2.90 (3.45)	2.99 (4.30)
Total direct costs (mean, SD)	Direct medical + direct non-medical costs	7.53 (8.65)	13.60 (15.05)	14.64 (16.59)	19.25 (19.29)
Indirect costs (mean, SD)	Patient travel time to pre-treatment providers	1.01 (1.50)	1.81 (5.45)	1.98 (3.40)	2.56 (5.83)
	Patient visit time at pre-treatment providers	1.74 (3.65)	3.64 (8.58)	6.15 (10.79)	5.36 (11.81)
	Total patient indirect costs (travel + visit time)	2.74 (4.41)	5.45 (12.48)	8.13 (13.38)	7.89 (16.53)
	Family costs – transport	N/A	N/A	N/A	6.56 (14.08)
	Family costs – food	N/A	N/A	N/A	1.79 (3.25)
	Family costs – accommodation	N/A	N/A	N/A	0.51 (2.38)
	Family costs – other	N/A	N/A	N/A	0.34 (1.52)
	Total family costs	N/A	N/A	N/A	8.78 (16.18)
Total indirect costs (mean, SD)	Patient + family costs	N/A	N/A	N/A	10.09 (22.13)
Total pre-treatment costs (mean, SD)	Total direct + total indirect costs	9.95 (10.77)	19.05 (22.95)	22.01 (23.29)	28.80 (35.84)

Abbreviations: IQR: inter-quartile range; DS: drug-susceptible; TB: tuberculosis; SD standard deviation

The average pre-treatment total cost (direct medical + direct non-medical + indirect costs) per patient was USD 28.80 (SD35.84). These costs varied according to the number and type of healthcare providers visited, increasing from USD9.95 (SD10.77) to USD19.05 (SD22.95), and USD22.01 (SD23.29) for one, two, and three or more providers that were visited, respectively **(Table 4.4)**. To put these costs in perspective, the average annual per capita income in Tanzania is approximately USD 1,080 or about USD 90 per month (37.38). Notably, the cost of seeking care from single provider (USD9.95) represents nearly 11% of the average monthly income. For individuals who consulted multiple providers, the cumulative costs could account for a substantial proportion of their monthly earning (32%). This burden is even more severe for those without employment, who made up a large proportion of the study participants, underscoring the significant financial burden associated with healthcare-seeking behaviours in low-income settings. These findings highlight the urgent need for cost-effective healthcare interventions and policies that mitigate the economic impact on vulnerable populations (34).

Healthcare-seeking pathways, underlying causes, financial burden before PTB diagnosis

This theme explores participants' challenging experiences prior to receiving formal PTB diagnosis. Many reported incurring substantial financial costs when seeking treatment, often purchasing various medications and consulting multiple healthcare providers without knowing the underlaying cause of the symptoms. Several individuals described visiting informal and non-specialized providers before eventually accessing formal TB related services. A common cited reason for this pattern was the absence of nearby formal HCFs, which contributed to delays in receiving an accurate diagnosis and appropriate care.

> *I spent a lot of money buying various medications to treat a persistent cough. Although the cough temporarily subsided, it returned after a few weeks. I then tried stronger medication, not knowing it was TB. After seeing my condition remained unchanged for about six months. Eventually, I decided to visit a government hospital for a tuberculosis test, which confirmed a positive diagnosis* (Male, 35 years old, Mbeya region).

Participants expressed regret over the loss of productive time and financial resources incurred while traveling to distant providers. In the absence of the accessible formal care, many

reported relying on self-medication from local drug shops and frequently consulting traditional healer, both of which were described as common practice. Qualitative respondents also highlighted a general lack of awareness regarding PTB symptoms and the costs associated with diagnostic services. Among those were able to recognize the symptoms and understood their potential consequences, limited financial resources particularly for transportation and pre-diagnosis service emerged as primary barriers to timely and continuous PTB care-seeking. The following statements illustrate participants' experiences:

> *It is common practice in our village to begin treatment by obtaining medicine from a local drug shop, especially since we have a well-stocked one nearby. However, some community members prefer first to consult traditional healers. If there's no improvement after using the prescribed medicine, the next step is to visit a hospital.* (Male, 48 years old, Tunduma district, Songwe region).

> "*Accessing services can be challenging. For example, I struggled to find a nearby facility for TB diagnosis and had to travel to Kiwanja-Mpaka Health Center, which caused inconvenience due to transportation and financial costs."* (Female, 38 years old, Mbeya region).

Many participants reported that initially patients relied on self-medication, purchasing over-the-counter remedies such as cough syrup, pain relievers, or antibiotics like amoxicillin. However, when these treatments proved ineffective, participants often experience frustration and a sense of financial loss. This experience heightened their awareness of the seriousness of their condition, ultimately prompting them to seek professional medical care. One participant shared experience of starting with cough syrup, then progressing to antibiotics, before realizing after three months that the illness was more serious than initially thought, leading to a hospital visit for a proper diagnosis

> *"When I first started coughing, I assumed it was just a normal cough, so I bought some cough syrup. However, it didn't help. As the condition worsened and I noticed no improvement, a pharmacist recommended an antibiotic. But by then, the cough had become much more severe, and I began to realize that this was no normal cough. It took about three months before I finally decided to visit the hospital for a more thorough diagnosis* (Female, 44 years old, Mbeya region).

The following pictorial diagram illustrates the patient pathways and the associated factors prior to tuberculosis treatment initiation. The diagram maps the sequential care-seeking steps taken by participants, showing how various factors such as proximity to care, provider type, and delays influence the trajectory. This visual summary helps readers follow the multi-step decision-making process and identifies key determinants affecting care pathways (**Figure 4.2).**

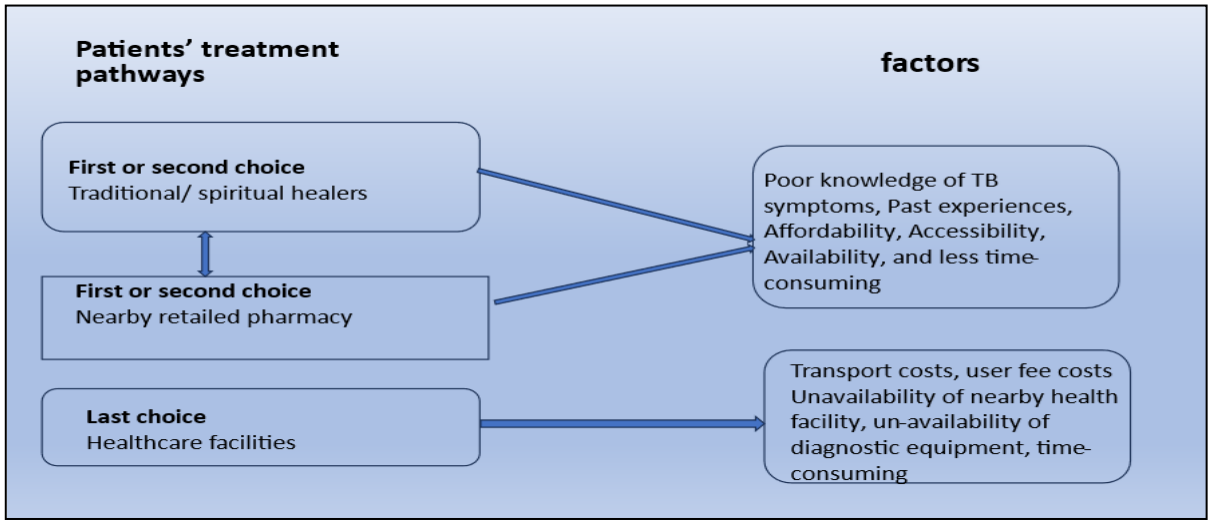

Figure 4.2. Pre-treatment Healthcare Seeking Pathways and Causes

Financial Expenditures for Pre-Treatment Care-Seeking

Participants reported that the onset of symptoms often compelled them to choose among the available care providers based primarily on proximity rather than perceived quality of care. Consequently, consulting traditional healers or practitioners was frequently viewed as the most accessible and immediate option, often complementing modern pharmaceuticals obtained from nearby retail drug outlets. However, the cost of traditional medicines prescribed by these traditional healers was often prohibitively high for less privileged individuals. Several respondents recounted personally paying OOP expenses or knowing someone who had paid money to compensate a traditional healer. For example, one woman confessed to having stayed with a traditional practitioner for approximately sixty days. During this period, her family provided food such as maize, flour, and beans to support her stay. Moreover, seeking care from a traditional healer across national border was also reported as a common practice.

“I stayed with the traditional healer for about two months, during which he treated me with a specific medicine that I drank daily. I spent nearly all my money there because he instructed us, as a family, to bring food to last the entire stay. This placed a significant financial burden on my family and me personally, as I had to take food meant for my household, leaving my children with very little for their own consumption” (Female, 43 years old, Songwe region).

“*I was running from one traditional healer to another. I even went to Malawi, where I was told there is a traditional healer who is good at handling this cough problem. However, I did not get any relief while there, and instead, I ended up losing all my money on transport and procuring medicine. If I knew earlier that I was suffering from TB, how could I have dared to do that*?” (Male, 40 years old, Songwe region)

Delays in contacting formal HCFs due to limited knowledge of PTB symptoms

Delayed attendance at formal health facilities for PTB diagnosis and treatment was frequently reported as a regrettable factor contributing to unexpected high costs. This delay was particularly pronounced among individuals lacking prior knowledge of PTB symptoms. Interestingly, the comments from several respondents conveyed a shared sense of regret experienced by patients and their families, especially when delayed care led to referral to a distant health facility that imposed user fees. Such delays not only exacerbated financial burdens but also hindered timely access to appropriate care.

"*I coughed for more than two months without realizing it was tuberculosis because I was unaware of the symptoms."* (Male, 35 years old, Mbeya City, Mbeya Region).

"*I spent over a year seeking treatment until a friend suggested I go to a government hospital for a diagnosis. That's when I found out I had TB, but by then, I had lost everything. All of this happened because I wasn't aware of the symptoms of TB.*" (Male, 55 years old, Mbeya Region).

"*I didn't know what type of disease I had. I ended up selling everything I owned, including a mattress, a radio, and a plot of land, just to access the treatment I*

sought from various traditional healers, but to no avail." (Male, 55 years old, Mbarali District, Mbeya Region).

Furthermore, the COVID-19 pandemic contributed to delays in TB diagnosis and treatment, as overlapping symptoms between TB and COVID-19 created confusion among patients. These symptoms overlap, combined with widespread fear of quarantine or isolation, caused many individuals to avoid seeking care at HCFs. Although the majority of participants were enrolled prior to the pandemic, a few were enrolled in March 2020 and later participated in the qualitative component of the study. These participants reported that during the COVID 19 outbreak, fear of being misidentified as having COVID-19 discouraged people from visiting HCFs when experiencing TB-related symptoms. This reluctance contributed to delays in diagnosis and treatment as well as continued transmission of TB within a community. The following quote illustrates this:

> *"You know what, People were scared to go to the hospital when they had a cough. Everyone thought it was corona, and they didn't want to be taken for quarantine, so they stayed home and kept spreading the disease*". (Male, 37 years, Songwe Region).

Coping strategies and financial implications for managing PTB symptoms

Several respondents reported resorting to the disposal of personal or family/household valuable assets to raise funds needed to settle service fees charged by HCPs. This coping strategy was particularly common among patients seeking care from private HCFs, where user fee were perceived as excessively high and often unaffordable for the less privileged individuals to afford, resulting in substantial OOP payments. Similarly, some traditional healers were reported to set user-fees beyond the means of underprivileged clients. As a result, these clients and their families frequently resorted to paying in-kind, offering valuable property such as tamed animals, poultry or portions of farm crops believed to hold monetary value equivalent to the required fees. This often necessitated finding immediate buyers for these assets. When buyers were unavailable, patients or their relatives sometimes transferred ownership of such property directly to the service provider through mutual agreement. In these cases, the assets were often sold at significantly reduced prices, causing psychological distress and financial loss for the disposers

Rural-Urban differences in TB care accessibility

Some patients also delayed attending formal HCFs due to living in remote areas with limited or no access to healthcare services. This was particularly common among those in rural settings, where such services are often limited or unavailable. As a result, these patients frequently postponed seeking care at formal HCFs for PTB diagnosis and timely treatment initiation. The following quote illustrates this experience;

> "*I lived in a remote rural area where there was no nearby health facility. Because of the long distance and lack of accessibility healthcare services in our village, it took me almost a whole year of suffering with this illness before I finally decide to go to the facility and was diagnosed with tuberculosis."* (Male, 43 years, Songwe Region).

Perceived Quality of care related costs

Respondents expressed dissatisfaction with certain HCFs they visited, citing an inability to access the expected standard of care. Upon further probing, participants explained that many of these facilities lacked reliable laboratory services necessary for the diagnosis of PTB, such as sputum or chest X-ray imaging. Although some HCFs had designated PTB clinic or units, they were often under resourced lacking either necessary diagnostic equipment or skilled personnel to perform accurate testing. These deficiencies often compelled patients to resort to self-medication, using pharmaceuticals obtained form local retail outlets, traditional herbal remedies, or both. Consequently, the delay in accessing the appropriate and timely care exacerbated the progression of PTB, ultimately worsening patient's health conditions and leading to increase OOP expenditures.

> *"Some facilities say they treat TB, but when you go there, they don't have the lab or staff to test TB, no X-ray. So people end up treating themselves with herbs or buying medicine from shops. This contribute to delays real treatment, makes you sicker, and costs even more in the end"* (Female, 40 years, Songwe Region

Discussion

This study is among the few that employ a mixed methods research design to explore the costs incurred by individual diagnosed with PTB before to the initiation of formal TB

treatment in Tanzania. The findings revealed that TB patients and their families incur substantial monetary and non-monetary burden before receiving a confirmed diagnosis and beginning of treatment. These costs both direct and indirect can become catastrophic over the course of patient's journey (12).

A key contribution of this costs is lack of awareness regarding TB symptoms, which often results in delayed healthcare seeking behaviour. Many patients do not initially recognize the need for formal medical evaluation, opting instead for informal treatment methods without a confirmed diagnosis (39). Participants also reported that many HCFs with diagnostic and trained staff are located far from their communities, necessitating lengthy and expensive travel that adds to the overall financial burden. As a results individual often resort to self-medication or consult informal providers, both of which can lead to delayed diagnosis and higher cumulative costs (40). Time based costs which, despite their economic value, are often unquantified and undocumented, along with in-kind payments made to traditional practitioners or expenses related to self-medication with unregulated drugs, remain a persistent challenge in the context of TB care in LMICs. These challenges potentially contribute to life-threatening or permanent health complications, such as lung damage or disability (41,42). WHO documentation underscores that early detection of TB and the initiation of correct treatment regime are critical to prevent poor clinical outcomes and to reduce transmission (43,44).

The delays in seeking care and the tendency to consult multiple healthcare providers before receiving a formal TB diagnosis as noted from the data obtained under the current study confirm the already identified inefficiencies in the current TB detection and notification system in Tanzania (7). Participants in this study also expressed dissatisfaction with the quality of care at certain HCFs, especially those lacking essential diagnosis tools such as sputum microscopy and chest X-ray imaging (46). This perceived inadequacy not only contributed to diagnosis delays but also prompted some of the patients to pursue alternative forms of treatment, further complicating their clinical condition and increasing their financial burden (46).

The average pre-treatment total cost per TB patient comprises direct medical, direct non-medical, and indirect costs. These costs varied depending on the number and type of

healthcare providers visited (47). As patients sought care from multiple providers, their total expenditures increased, indicating that provider utilization plays a significant role in the overall economic burden of TB care. This emphasizes the need for more efficient healthcare coordination to minimize unnecessary expenses. Regarding household expenditures, the average monthly expenditure in the Mbeya and Songwe regions was USD 135.4 and USD 176 respectively (48).

In this context, where the majority of individuals diagnosed with TB are low-income earners, many of whom earn close to the national minimum wage of USD 90 per month (37). Within this socioeconomic context, the financial burden associated with pre-treatment care poses a significant public health challenges. The average pre-treatment cost identified in this study was USD 28.80, which represents around 32% of a minimum wage earner's monthly income (34). This estimate is based on monthly income figures, as the majority of participants reported delays in seeking care exceeding four weeks. Additionally, most had attained only primary-level education, further compounding their economic vulnerability. Notably, the level of OOP spending observed in this study surpassed the WHO threshold for catastrophic health expenditure, define as healthcare costs surpassing 20% of annual household income or expenditure. These findings underscore the substantial economic hardship faced by individual diagnosed with PTB during pre-treatment period. For those earning near or at minimum wage, pre-treatment costs alone may consume a significant amount of their monthly income before even entering the formal TB care facility. This burden is particularly severe for individuals without formal or informal employment. This may represent a significant barrier to timely diagnosis and treatment, particularly for individuals from economically disadvantaged backgrounds. Such delays can contribute to disease progression, increase morbidity and continue community transmission (34).

In addition, the COVID-19 pandemic introduced multifaceted challenges to health systems worldwide, particularly in the diagnosis and management of chronic infectious diseases such as TB. Our findings reveal that the overlapping clinical features of TB and COVID-19 significantly contributed to delays in seeking medical care and treatment initiation for TB. This is consistent with studies conducted in high-burden TB settings, which have reported diagnostic ambiguity due to shared symptoms such as cough, fever, and respiratory distress, resulting in hesitancy among patients to seek formal healthcare services (49,50). The

intersection of TB and COVID-19 has thus exacerbated pre-existing health disparities. Patients delayed care due to fear of isolation, stigma, and the direct economic costs associated with testing and treatment. These factors not only led to disease progression in individual cases but also likely increased community-level transmission due to the extended infectious period in undiagnosed individuals. Moreover, this delay in treatment initiation further strained already burdened TB control programs, complicating efforts to meet global targets for TB elimination (51).

Improving the quality services in Tanzania is vital for enhancing patient outcomes and reducing unnecessary financial and time related burden. While expanding the availability and geographic reach of health facilities is important, it is not sufficient unless these facilities are also adequately staffed with trained personnel and equipped with essential diagnostic tools and supplies. Strengthening quality assurance mechanisms is therefore critical to ensure adherence to standard clinical practices. In parallel, ongoing training and capacity building for healthcare providers especially in rural and underserved areas can support early detection of TB, reduce diagnostic delays, and improve treatment outcomes (46).

To address these challenges more effectively, national TB programs should adopt a multi-pronged approach. First, increasing public health education and awareness is essential, particularly as not all frontline HCWs are sufficiently informed. This effort should extend to informal drug retailers, who may lack knowledge of early TB's symptoms and contribute to inappropriate self-medication without a confirmed diagnosis (27). Social protection measures such as subsidies for TB diagnosis services (e.g., chest X-rays), transportation allowances, or direct financial assistance could alleviate the economic burden on TB patients, promote earlier diagnosis and improve health outcomes (52). Furthermore, the overlap in respiratory symptoms between TB and COVID-19 created significant barriers to care seeking during pandemic, not simply due to misclassification, but more importantly due to patients' fear of being diagnosed with COVID-19 and subjected to isolation, stigma, and additional burdens. This highlights the need for integrated screening approaches where individuals presenting with respiratory symptoms are tested for both TB and COVID-19, as well as for public health emergency responses that are sensitive to these dynamics. Policy makers, healthcare providers, and the public must be equipped with accurate information and stigma prevention strategies to avoid unintended consequences for TB care during future outbreaks.

Given the prominent role of traditional medicine in many Tanzanian communities (53), integrating traditional healers into the formal healthcare system present a valuable opportunity. Training these practitioners to recognize TB symptoms and establishing referral pathways to formal HCFs could improve access to care and reduce diagnostic delays. In this role, traditional healers can act as community-level health allies, helping to identify suspected TB cases and ensure timely referrals. Raising community awareness about the importance of early diagnosis and treatment may also reduce reliance on self-medication and informal care-seeking practices (27,54). Community-based outreach, targeted educational campaigns, and increased engagement of CHWs are remain promising strategies to address these persistent challenges.

Strengths and limitations

A major strength of this study lies in its use of a mixed-methods research design. The integration of quantitative data, obtained through structured questionnaire, with qualitative insights from open-ended questions allowed for a richer interpretation of the findings. This triangulation enhanced the contextual understanding of the statistical results, enabling us to support key arguments with first hand perspectives from respondents.

The study also provides relevant insights for the national TB program in Tanzania by shedding light on the TB pre-treatment costs-related barriers that hinder timely initiation of treatment among eligible patients in the study regions. These findings align with reports from other parts of the country (55,56). Although TB diagnosis and treatment services are officially provided free of charge under national policy, this study highlights those direct costs particularly those associated with transportation to and from HCFs pose a substantial burden (57). These barriers suggest a need to decentralize TB services and bring them closer to communities in need. Without such measures, many individuals may remain excluded from the benefits of so-called ‘free’ services. The analysis of cost related delays in the TB care pathways provides valuable information for refining TB policy and program implementation both in Tanzania and similar settings (58).

Despite its valuable contributions, this study has some limitations. Although social science techniques were employed to encourage openness and accuracy in responses, recall bias may have influenced the reliability of the data, as participants were asked to reflect on experiences that occurred over extended periods. To mitigate recall bias, structured techniques such as time anchoring and sequencing were applied to help participants accurately reconstruct their care-seeking pathways from symptom onset to diagnosis. Moreover, data from the TB Sequel cohort indicate that the median time between symptom onset and the baseline interview was approximately 8 weeks (IQR: 4–16 weeks), representing a relatively short recall period. This strengthens confidence in the reliability of participants' reports of out-of-pocket expenditures and time-related costs.

Selection bias is another limitation of this study, stemming from the recruitment of participants through the ongoing TB Sequel project. This approach may limit the generalizability of the findings, as it primarily captures the experiences of individuals who are enrolled in and retained within structured research and care programs. Consequently, it may exclude people with TB who were never enrolled, were lost to follow-up, or are not currently engaged in care groups whose experiences and cost burdens may differ substantially. To mitigate this limitation, purposive sampling was employed to ensure diversity within the participant pool, taking into account geographic variation (across districts in both study regions), urban and rural settings, gender, and the inclusion of individuals living with TB/HIV co-infection. Additionally, several steps were taken to minimize the risk of recall bias and its impact on the accuracy of reported costs and timelines.

The qualitative data collection for this study was notably impacted by the COVID-19 pandemic (2020–2021), as lockdowns, travel restrictions, and the strain on healthcare systems hindered timely and comprehensive fieldwork. These disruptions limited access to participants particularly in remote or underserved areas and reduced opportunities for in-

person interviews, which are essential for capturing rich, context-specific insights. In addition, the pandemic led to a nationwide decline in TB case reporting, affecting both the availability and representativeness of potential participants. Many individuals who might have been included in the study were likely undiagnosed or avoided healthcare services due to fears of COVID-19 exposure or quarantine, introducing potential selection bias and limiting the generalizability of the findings. Despite these constraints, the study provides valuable perspectives on the intersection of TB care and public health emergencies, highlighting the importance of flexible and resilient data collection approaches during periods of systemic disruption.

Moreover, the study focused primarily on patients with PTB, and did not capture costs associated with, extra-pulmonary TB nor on HIV-AIDS or other lung and non-lung related diseases normally faced by the patients, including those experiencing comorbidities (75). These comorbidities could contribute to higher healthcare costs, which were not fully captured in our analysis.

Conclusion

This study reaffirms the significant challenges faced by individuals and households in Tanzania, when seeking healthcare for TB related illness prior to formal diagnosis. Both financial burdens such as transportation and opportunity costs, and non-financial burden, persist across formal and informal care seeking pathways. These delays contribute to disease progression, ongoing transmission, and significant long-term financial hardship for the affected families. While the National TB program promote early detection and free TB services under Universal Health Coverage, findings highlight the need for better integration with traditional healthcare practices and targeted pre diagnosis support mechanisms such as waivers or transport subsidies, may enhance access to timely care. Addressing these barriers through a comprehensive, multisectoral approach is critical to improve TB treatment outcome and advancing public health equity at both the individual and community levels.

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Competing interests

The authors have declared that no competing interests exist.

Author contributions

SPK participated in the conceptualization of the manuscript, data collection, coding of qualitative data, and making the first outline of the manuscript. KH participated in the quantitative data management and analysis. GM, AM, and DE closely followed up on this paper and improved the flow and content of the manuscript at all stages. NE & IS reviewed and edited the manuscript. SM assisted in data collection and the coding of qualitative data. All authors contributed to the critical review of the manuscript, providing multiple rounds of feedback to enhance its intellectual content, and gave final approval for submission.

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Data availability

Data contain sensitive patients information and data access is governed by the Human Research Ethics Committee (University of Witwatersrand, Johannesburg, South Africa). All relevant data are included in the paper. The full data are available from the Health Economics and Epidemiology Research Office for researchers who meet the criteria for access to confidential data and have approval from the data owners (For more information, contact information@heroza.org).

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CHAPTER 5

5.1 PAPER II

Understanding the implications of social and financial burdens of pulmonary tuberculosis on patients, survivors and their family caregivers on care seeking and treatment in Tanzania: Feedback from a qualitative study in Mbeya and Songwe regions.

Paper II was published in the Tanzania Journal of Health Research at the time of the dissertation submission. For inclusion in this dissertation, the paper is presented in the sections and layout specified by the journal. However, it has been reformatted to meet the dissertation style requirements set by the university.

Reference: Kilima SP, Mubyazi G, Moolla A, Ntinginya N, Sabi I, Mwanyonga S, Evans D. Understanding the implications of social and financial burdens of pulmonary tuberculosis on patients, survivors and their family caregivers on care seeking and treatment in Tanzania: Feedback from a qualitative study in Mbeya and Songwe regions. Tanzania Journal of Health Research. 2023 Jul 10;24(3):241-54. https://dx.doi.org/10.4314/thrb.v24i3-8

Abstract

Introduction: Tuberculosis (TB) is the most common fatal infectious disease, having devastating public health and socio-economic consequences. Despite the national TB program in Tanzania strategizing and supporting interventions to end TB, TB is still highly prevalent, suggesting a need for studying the reasons behind it and understanding what could be done to improve the situation. This paper presents findings from a qualitative study that explored the role of social and financial consequences faced by TB patients, survivors, and their family caregivers in their attempt to seek TB treatment.

Methodology: A cross-sectional qualitative study was conducted between October 2010 and March 2021, covering 18 patients, 12 survivors, and 8 of their family caregivers who were identified using a purposive sampling technique to participate in face-to-face in-depth interviews. Data were transcribed and back-translated from Kiswahili to English and then interpreted iteratively using a thematic analysis approach after the initial analysis facilitated by the use of NVivo 12 software.

Results: All respondents shared their experiences of having faced difficulties in mobilizing money for expenditure on transport meals and soft drinks, besides the time lost while seeking care at formal health facilities. TB comorbidity with diabetes, hypertension, and other communicable diseases was reported to intensify the time and financial cost burdens. Social costs such as stigma and isolation from socialization, associating TB symptoms with witchcraft were testified as contributing to treatment-seeking delays and resultant health and financial costs.

Conclusion: Structural barriers must be addressed to reduce costs and improve healthcare access, TB sensitization and economic support for vulnerable families are also necessary to enhance TB treatment and care compliance and reduce the burden of disease in the communities

Keywords: tuberculosis, catastrophic costs, poverty, TB patients, TB survivors, Tanzania

Background

Globally, tuberculosis (TB) is a communicable disease that causes ill health. It is one of the leading causes of death from a single infectious organism (1). This situation has persisted for many years. However, continued efforts have been made to significantly reduce its national, regional, and global burden. In 2022, TB accounted for 1.6 million deaths globally, an increase from 1.5 million reported in 2020 (1-3).

TB is widespread, and new cases (incidences) are reported continually in different countries, but with varying rates and the prevalence of the disease both between and within regions and countries(1,2). Everybody, if exposed to TB infection, is at risk, although the chances of infection and the overall burden of the disease are higher among the people facing and living in poverty. Such people are mostly found in low- and middle-income countries (LMICs) (1). Apart from the physical and mental or psychological pains faced by the patients, TB survivors also face extended costs of that nature after undergoing a formal treatment course. This is because such people do experience certain TB Sequelae, for example, facing post-TB lung disease (s) and other physiological disorders that limit them to participate in the day-to-day activities they used to do. For this reason, TB health and economic consequences contribute to lowering the quality of life of the people currently suffering from it, its survivors, and their families at large, and even expose them to certain social costs such as being stigmatized, discriminated such as exclusion/isolation from social gatherings, meanwhile limiting them to earn money to support their personal and family lives (1).

Tanzania ranks among the TB's 30th highest-burdened countries in the world (1). The National TB and Leprosy Control Programme (NTLP) under the Ministry of Health, in collaboration with allied institutions and development partners, has continued to make efforts towards ending the burden of this disease. The focus is to reach all the people and communities with TB services via the application of different service delivery models for early identification and diagnosis of TB patients (1). At least, new cases have dropped, for example, from 253 per 100,000 in 2018 to 222 per 100,000, with a mortality rate of 47 per 100,000 population in 2021(1,2). A need for additional success stories remains identified, with more efforts done toward a significant reduction of the morbidity and mortality impacts of the disease (1). As in other LMICs, achieving equity in access to the services intended to be

delivered is prioritized, whereby the most targeted are the poorest people or households, and these are ones living below the poverty line since they are the most disadvantaged when it comes to facing TB-associated costs (1) . The negative well-being consequences of TB on people and families affected by it remain widely recognized and regretted based on field experiences. The link between such consequences and an individual's and household/family's poverty status is consistently revealed by the empirical evidence (2,3).

Research-based evidence and reports from other systematic evaluations demonstrate that the financial costs faced by patients with TB and their families may not all be immediate, meaning that some of them come to be experienced later. Moreover, the existing national policies on TB recommend TB treatment for free. However, patients find themselves incurring pre-treatment financial costs such as those involving registration, consultation and screening-based diagnoses, drugs being accessed for free (4,5). Even if the service were accessed for free at the point of care, particularly at the TB clinic level, patients, survivors and their family caregiver (relatives) incur costs on travelling when they have to use public or private transport if living far from the TB clinics concerned (6). These costs are sometimes too high to the extent that the poorest families/individuals find them being unaffordable. As a result, some of the patients and the survivors delay to visit the respective clinics. The outcome of this delay is unhealth since one eventually develops a severe or complicated illness case, with extended or spill-over effects such as reducing their personal quality of life while pushing them into the risk of being socially stigmatized and discriminated, apart from their non-participation in economic, especially food production or income generating activities (7)

Evidence on TB's social and economic impacts on individual patients, survivors, and their families in Tanzania exists, but they have remained sparse and scarce, suggesting a need for additional systematic studies for evidence generation to inform or update the existing national health policy and TB program authorities responsible for higher-level decision-making on TB control aspects (8,9). This is why the currently reported study was conducted, although focusing on pulmonary TB and having been done in two regions located in the southern zone of the country. The results from the study were envisioned also to supplement the extant literature on the topic that continues to be developed from studies carried out previously in Tanzania and beyond, with emphasis also on the importance of understanding

opportunities for addressing the prevailing institutional barriers that require intra- and multi-sector approaches (10).

Methodology

Study Design

A cross-sectional study was undertaken between October 2020 and March 2021 with questions whose answers were envisioned to contribute to an updated understanding of the social and financial consequences of TB treatment and care-seeking among the aforementioned groups. The study was nested in the large, multi-country observational cohort study among drug-susceptible adults (>18 years) with pulmonary TB (PTB), called *TB Sequel*. The main cohort employed a longitudinal design, enrolling patients at the start of TB treatment between September 2018 and May 2021 and following them for at least 24 months after treatment initiation (11). Further, this study used some of the baseline (start of TB treatment +/- 14 days) demographic and socioeconomic information for patients at enrolment in the Tanzanian cohort as part of TB Sequel (12).

Study Setting

The study was conducted in Mbeya and Songwe regions, which are both located in the southwestern highland zone of Tanzania Mainland. They were selected because they are among the regions ranking high in TB and HIV prevalence in the country (13,14). The targeted study participants had to be traced while attending the TB clinic hosted at the Mbeya Zonal Referral Hospital, and in particular, those registered in the TB Sequel project (12)

Study Participants and Recruitment Procedures

The study specifically covered the pulmonary TB registered patients aged 18 years or above found with co-morbidity (TB and HIV). The staff working on the latter project assisted the study team in identifying these people. Both the patients and the survivors found with co-morbidities were selected with an assumption that they had experienced social or financial consequences probably more than those who had TB or HIV only. Patients' relatives referred to in this article imply the members of the families or households from which such individuals

were coming and, therefore, possibly were giving them certain non-clinical support during their illness period either at home or while seeking care and treatment. The pulmonary *TB survivors* were defined as those who had suffered from TB in the past (24 months) and had been confirmed negative (through sputum test) before the current study data collection had taken place. Thus, in the respective TB Sequel project, the survivors concerned continued with a follow-up service for at least 24 months after their treatment initiation (11)

Sampling Strategy

Both patients and survivors were recruited purposively because they could provide information regarding their financial and social well-being following their experiences with TB. In total, eighteen patients, eight family members (relatives), and 12 survivors participated in the interviews. The sample for each of these was sufficient to reach saturation in each subpopulation. No new pertinent information was uncovered as the interview process progressed.

Data Collection Procedures

Each identified study participant category used a separate in-depth interview (IDI) guide. The researchers with sociological backgrounds were trained to participate in qualitative data collection methodology. The information sought for TB patients included their current and past financial experiences before initiating a TB treatment course at a formal clinic, whether they had been affected by the stigma and discrimination such as separation/segregation in certain manners or incidents involving their family members and/or the rest of society/community members. TB survivors were asked about their experience before, during, and after TB treatment, addressing the social and financial burden of the disease although they had completed their scheduled treatment course. Relatives of each of the latter two categories were asked about their experience of living with a TB patient and how it affected or influenced their ability and opportunity to participate in money-generating (financial) activities. The data collection guides were pre-tested and refined for clarity. Kiswahili, Tanzania's national language, was used in the interviews. Interviews were conducted in a private venue to ensure confidentiality. The interview was conducted by two sociologists, one being the moderator and another note taker.

Data Analysis

Audio-recorded data were transcribed verbatim by two experienced research assistants. The initial transcriptions, which were in Kiswahili, were translated into English before being analyzed thematically. Next, all the transcripts were uploaded into NVivo 12 software for coding and data analysis. Three researchers carefully read the transcripts to ensure complete familiarity with the data for pattern recognition. They reviewed and coded the transcripts independently before meeting to discuss their generated themes and sub-themes (15). The discussions mainly concerned achieving consensus in areas where codes, themes, or sub-themes seemed to overlap. After several discussions, initial themes were redefined and reworked until a unanimous consensus was reached. In instances where a disagreement occurred regarding the themes and subthemes, further discussions occurred until an agreement was reached. After coding, all the codes belonging to the same theme were grouped to allow data analysis. This approach allowed us to compare the data obtained from the different participants (15,16). Finally, a codebook was developed, and all 38 transcripts were coded.

Trustworthiness and Information

Data from each participant were compared to that of other participants based on context to enhance the trustworthiness of the study's findings.

Ethics Approval and Consent to Participate

Ethical approval for this study was obtained from the Human Research Ethics Committee of the University of Witwatersrand, South Africa (M200570, May 29, 2020), the Mbeya Medical Research and Ethics Review Committee (January 16, 2020), and the National Health Research Ethics Committee of Tanzania (Ref. No. NIMR/HQ/R.8a/Vol. IX/3527). Targeted participants were individually informed of the study's purpose, implementation approaches, assurance of anonymity and confidentiality, whether the investigator deemed it necessary to handle information with care, non-coercive participation, and discontinuation or withdrawal from the study. We also requested participants' consent to allow the investigator to record the interviews using audio tapes.

Results

Characteristics of Study Participants

Table 5.1 summarizes participants' key socio-demographic characteristics. Most participants were male (25–45 years), married, and had primary education. The results presented in the following subheadings reflect the study themes or subthemes per the data analysis to facilitate logical flow and ease of understanding. The subheadings or themes may appear interrelated or overriding because of their apparent mutual non-exclusivity.

Table 5.1 A summary of key socio-demographic characteristics of participants.

	MBEYA			**SONGWE**		
Socio-demographic Characteristics	**Participant Category**					
	TB patients (N=9)	TB Survivors (N=6)	TB Relatives (N=3)	TB Patients (N=9)	TB Survivors (N=6)	TB Relatives (N=5)
Sex						
Male	7	5	1	7	5	2
Female	2	1	2	2	1	3
Age of the participants						
25–45	9	5	1	8	6	2
46–-60	0	1	2	1	0	3
Education level						
No formal education	1	0	0	0	0	1
Primary school	6	6	3	8	6	4
Secondary school	2	0	0	1	0	0
Marital Status						
Married	5	3	2	5	6	3
Single	1	3	1	0	0	1
Divorced	2	0	0	3	0	1

Financial Barriers Related to TB Treatment

Most patients and survivors reported difficulty meeting the financial costs for TB care and treatment. However, the majority could not pay for necessities such as procuring food for their family, paying children's school fees, buying school uniforms, and other essential requirements. All these are due to the fact that people with TB are unable to participate in economic production activities and, therefore, depend on their relatives.

> *"Truly, tuberculosis needs money for effective management. I was having a difficult time during TB treatment, and even now, the situation is not good because I had no option but to sell everything I had. to take care of my family*" (Male TB survivor, 38 years, Mbozi district, Songwe)
>
> *"Financially, I am very low because I do not work. Initially, I was using the money available, but it reached a point when I no longer had any more to spend and had only relatives to depend on.*" (Male TB patient, 38 years, Mbarali district, Mbeya).

Financial hardship contributed to poor or inconsistent treatment-seeking behavior. Most patients from the Songwe region reported this situation, stating that they resorted to self-treatment for an extended period before seeking care at health facilities. Their decision to self-treat was primarily driven by financial constraints, as they lacked sufficient funds to cover the costs of seeking a diagnosis at health facilities.

> "*I did not have enough money to go to the hospital, so I decided to go to the shop and buy a pain killer and amoxicillin; the medicine helped me to* calm *down, although I kept coughing, but I did not go to the hospital until I started losing weight and people were asking me, what is wrong?"* (Male patient, 48 years old, Mbozi district, Songwe).

Furthermore, the delayed health-seeking behavior was also related to social and financial issues. Several delays were caused by individual, community, and structural factors. Societal stigma and discrimination toward TB are also barriers that cause delays in initiating treatment. Most well-structured facilities are located in town. Furthermore, most patients with TB reside

in rural areas, which contributes to poor health-seeking behavior. The following figure summarizes the factors for delayed diagnosis and its consequences (**Figure 5.1**).

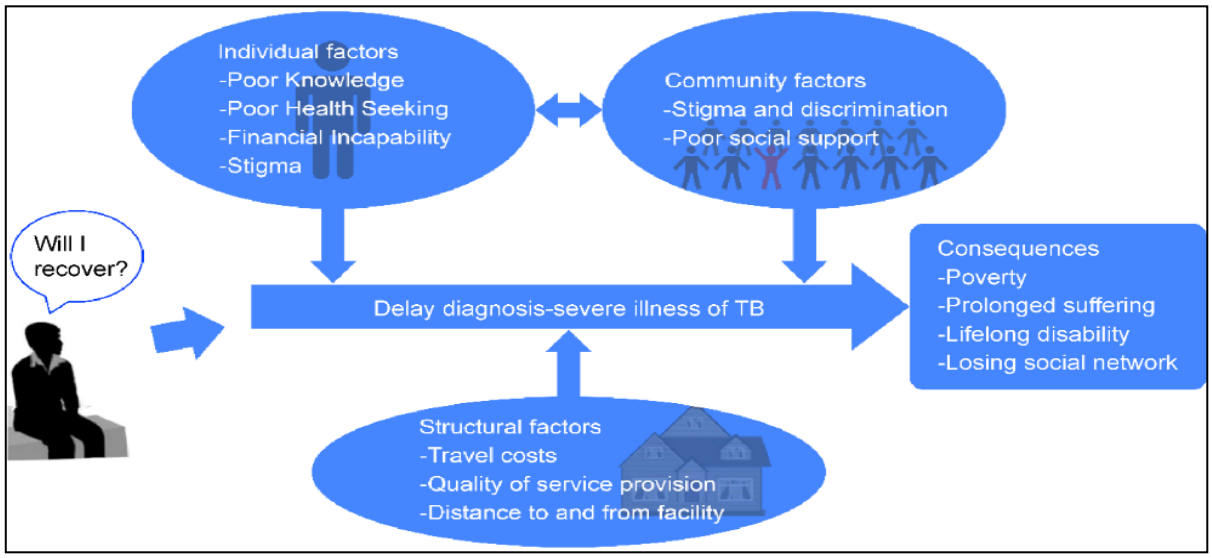

Figure 5.1. The factors contributing to the delay of TB diagnosis and its impact.

Inability to participate in economic production activities

Most patients with TB complained about their inability to participate in economic production activities because of sickness, which made them dependent; some were in debt to their friends, neighbors, and relatives, so they experienced psychological torture. In addition, some patients complained that the coughing was excessive and painful initially. Therefore, they could not participate in any economic production activities. This economic hardship mainly occurred in the first three months. However, for some patients, the situation continued after completing TB treatment. Furthermore, due to late treatment initiation, some indicated they might face many Sequelae even after treatment.

> *"The coughing is too much and very painful. I cannot do anything; I just depend on relatives to help me with food, transport to health facilities, and everything. It is a very difficult and discouraging life just staying and waiting for other people to do everything for you.*" (Male TB patient, 38 years, Mbozi district, Songwe)

> *"I completed taking TB medicine, but still experience problems such as pain in my ribs, and sometimes I have short breath. All this makes me unable to get back to*

my former job in mining, and my life nowadays is not the same as before when I used to make enough money for myself. nowadays, sometimes I need to borrow money from my friends to help meet my daily needs." (TB survivor, Male 32 years, Mbarali district, Mbeya*)*

Additionally, relatives caring for their sick family members reported experiencing the same issue. Some complained about the inability to participate in economic activities.

> *"Because of this sickness, you cannot leave him alone for a long time; therefore, I am not doing anything. My young brothers and sisters always contribute money and provide for us. I will wait until he feels okay; thereafter, I will continue with my business.*" (Patient's relative, 25 years, Mbeya city)

Food insecurity

Due to financial constraints, participants experienced food insecurity contributing to poor health-seeking behavior and poor adherence to TB treatment. Food insecurity was a recurrent theme in the interviews. Many participants reported experiencing distress from themselves or their families facing food shortages. Some participants reported being forced to raise money by any means, including selling their animal or farm products at lower prices to secure funds to use for TB diagnosis or treatment costs. As patients with TB require sufficient nutritious food during treatment, they ultimately face food insecurity. Without food, patients could not adhere to their TB treatment.

> *"TB medicine needs a person to eat well because the medicine makes you feel very hungry; if you have nothing to eat, it is a problem. There were certain times when I had nothing to eat. You cannot imagine; I never dare take this medicine because I am afraid I will get trouble in my stomach."* (Male patient, 55 years, Mbozi district, Songwe)

> "*I delayed going to the hospital for TB diagnosis and treatment because, in the beginning, I was coughing and having a fever at night, but I had no money to go to the hospital. Whatever I got was enough to buy food for my family. It was difficult for me to get enough money to go to the hospital. I usually buy cough syrup and a pain killer, until one day, my friend visited me and found me in a very*

bad situation, and he took me to the hospital with his own money." (Male TB patient, 38 years, Mbarali district, Mbeya)

Transport costs

Most patients with TB are poor and reside in rural areas. However, most health facilities are in urban areas. This discrepancy contributes to poor health-seeking behavior because of transport costs. They reported being dissatisfied with the requirement to remain under care for six months following the initiation of their TB treatment. They were concerned about high transport costs associated with clinic visits because they collected their medicine weekly during their intensive treatment phase. Thus, they experienced frequent visits. In the continuous phase of treatment, patients collected the medicine every two weeks, incurring high transport costs, considering that most of them had lost a source of income since their diagnosis. As a result, most patients could not afford transport and had to wait until they could accumulate sufficient funds and obtain support from other sources. This problem was also reflected in participants' hope for a shorter treatment course reflected below:

"Sometimes, on my clinic day, I did not have money for transport, which affected me. Sometimes, I do not go according to my planned scheduled visit, and the Community Health Worker comes to ask what is wrong; I just told her the truth." (Male TB patient, 48 years, Mbozi district, Songwe)

"I usually spent a total of 5000 shillings going to the facility and returning home. The money is too much for me, so I usually borrow from my relative." (Male, TB patients 37 years, Mbarali, district, Mbeya)

"*My economic situation has continued to deteriorate… The treatment period is very long, six months, it is too much. The government should think of a way to reduce the treatment period as well as the route to the facility. On my side, all this time, I just stayed at home, doing nothing, and all the savings I had are no longer available since I have used them on seeking treatment.*" (Male patient, 39 years, Mbarali district, Mbeya)

TB Illness and care-seeking for non-TB-related illness

TB compromises immunity against other infectious diseases, such as HIV and AIDS. It co-exists with several non-communicable diseases (NCDs), such as diabetes mellitus. These physical conditions were either directly or indirectly reflected in some of the participants' responses in both regions. Hence, patients are prone to acquiring more than one disease. However, in such cases, treating these new diseases, other than TB and HIV, becomes the patients' and their families' responsibility. Some of the common diseases acquired by patients with TB are diabetes and hypertension. Considering the cost required for treating these diseases, patients and survivors indicated that TB intensified the poverty crisis that most of them and their families had been experiencing. All participants demonstrated confusion and a loss of hope when they heard about other patients with TB who had lost their lives after failing to comply with the service requirements due to economic constraints. One tragic situation involved a patient with TB who had to remain at home after being referred for additional medical check-ups or services at advanced healthcare facilities located relatively further away. Three participants—two from the Songwe and one from the Mbeya region—reported episodes of unnecessary deaths that continually occur within their community because of delayed or failed care-seeking for other co-morbidities.

> "*It happens when a TB patient has contracted other diseases, and he has no money for the treatment because only TB services is offered free but no other infectious diseases. This led to death because of the treatment delay due to lack of money*." (Male patient, 38 years, Mbozi district, Songwe)

> *"It is true, I know a friend of mine, we were taking TB medicine together, but he got heart disease. He has a heart, and this caused his death because he did not have enough money for treatment. They said he should go to the big hospital. In that small facility they cannot manage that situation."* (Female patient, 45 years, Momba district, Songwe)

Furthermore, TB has more impact on breadwinners as it creates family dependency.

> *"TB economically affects us, and we find it more difficult to run our families. Personally, I had livestock, but to my surprise, within a month, all the animals*

were gone. I sold them all to meet the disease demands/costs and family needs, and that's really frustrating." (Male patient, 39 years old, Mbozi, Songwe)

Social factors

Loss of network opportunities

TB survivors suffer due to this social determinant after treatment. Some TB survivors claimed to have lost contact with those who initially supported them. This isolation was due to TB making individuals severely weak. They cannot participate in economic activities, and most provide casual labor and depend on their network to acquire job connections. This disease contributed to losing their social network.

"People usually label you as a sick person even if you start to feel better, and this makes them not to include you in any activity, thinking you will not perform. This affected many of us. I used to work as a builder (building houses) with my friends but after sickness they forgot everything about me" (Male TB survivors, 42 years, Momba district, Songwe)

*"You know what, I recovered yes, but I lost all my network, because people think I might not be able to work as before, that is why they avoided working with me. It is very difficult for me to cope with the situation. I decided to go to another place where nobody knows me and join another network." (*Male TB survivor, 38 years, Mbozi district, Songwe)

Association of TB and witchcraft

The delay in help-seeking behavior also has an adverse impact on the patient's financial condition. Some of the patients misinterpreted the TB symptoms, associating it with witchcraft. This problem occurred initially because of poor knowledge of TB symptoms. Testimony was provided regarding the patients or their relatives spending money on a traditional healer. Some sold their animals and farm products to pay the traditional healers' costs. Some patients also confessed to starting treatment late because they used traditional treatment, which was unsuccessful.

*"*TB' *has affected me psychologically. I was asking myself why two people in our family were found with TB. Initially, our relatives believed that sorcerers had bewitched us. They decided to take us to different traditional healers. After seeing no improvement, we went to the hospital and were diagnosed with TB. We started treatment, they came to realize we were not bewitched …"* (Male, 40 years, Mbarali district, Mbeya)

*"I used a lot of my money to pay a traditional healer. I used his treatment for two months, sleeping in his house, and my relatives were bringing food for me to eat in the traditional healer's house, but I did not get any relief rather than losing all my savings." (*Female TB patient, 42 years, Tunduma district, Songwe)

Relatives also had the same opinion on TB symptoms, stating that with some of these symptoms, people thought that they were bewitched. Hence, they sought a traditional healer to rescue them.

"*My brother was sick, and the whole family insisted he should go to a traditional healer for treatment because he was coughing but surprisingly getting weak day by day. We concluded that there were bad people who did that to him. We used a lot of family money to treat him. In the end, we decided to send him to the hospital, although some did not agree with the idea, and you can see he has TB.*" (Patient's relative, 43 years, Mbozi district, Songwe)

Stigma toward TB

A strong relationship exists between TB and HIV in the community. Therefore, the HIV-related stigma has been extended to patients with TB. This factor contributes to the late initiation of treatment because individuals do not admit that they have TB. Therefore, they search for alternative medicine for TB treatment instead of going to the hospital. The stigma also contributes to Loneliness and anxiety in patients with TB. Most participants confirmed that, in their community, individuals associated TB with HIV, and because of the stigma, they were scared of patients with TB.

> *"When I started the medicine, then they stopped coming to see me (*laughter*) since they were scared* [stigma]. *Some had even forbidden their children to play with my children.*" (Male, 32 years, Mbarali district, Mbeya)

> *"When I started the medicine, and taking the results that I had TB, I looked at myself and said, Will I really recover*? *Honestly, I was very disappointed because I could not believe* it [self-stigma]." (Female, 33 years, Mbozi district, Songwe)

Some relatives indicated they had special utensils for patients with TB, which were not shared with other family members to avoid transmission.

> *"There are some families, if they have a patient with TB in their home, they separate the patients' utensils such as cups, spoons, and plates which are not shared by other family members to avoid infection. That is also a stigma.*" (Male TB survivor, 32 years, Mbarali district, Mbeya)

TB survivors also confirmed the existence of stigma toward TB in their communities. They indicated that if they knew an individual had TB in the community, they would avoid the afflicted individual because they feared transmission.

> "*TB is spread by air, and this is the way that increases stigma toward this disease, people are afraid of being infected. Some people set aside the plate, spoon as well as cup for patients which is not supposed to be used by other members. For us who came here, we do not stigmatize patients with TB because they educated us, but others do.*" (Patient's relative, 46 years, Tunduma town, Songwe)

> *"In our community the big problem is stigmatization, you may find three-quarters of the people who hear you have TB are avoiding you." (*Male TB survivor, 32 years, Mbarali district, Mbeya).

Discussion

This study showed that TB affected patients, survivors, and family caregivers financially and socially. TB primarily affects those individuals already impacted by poverty (17). increasing their families' burden. The National TB program provides free diagnosis and treatment at the point of care attracting many individuals to utilize the services. However, other financial burdens exist that the patients must cover before diagnosis, such as registration fees and other preliminary services costs. These expenses are difficult for patients to bear; thus, some decide to use self-treatment, delaying treatment initiation (18-20)

The delay in TB treatment exacerbates disease severity as well as transmission in the community and adds costs for patients, their families, and the community at large (17). Furthermore, food insecurity is associated with poor treatment adherence. Some patients confirmed that they ate once daily, and others were unsure about food availability in their homes. This situation contributes to poor treatment adherence for TB. Food insecurity causes late initiation of TB treatment leading to poor adherence and increasing the risks of treatment failure, drug resistance, and mortality (21-23).

TB affects the patients', survivors', and their families' financial situation. In addition to treatment, associated costs for transport, food, and care are related to other non-TB illnesses such as diabetes. TB management is expensive, and it requires money. Therefore, some patients fail to adhere to the treatment. As a result, the government has provided free TB diagnosis and treatment, but patients must pay for co-morbidities (24).

Some participants complained about the long-term treatment, which lasts six months, with frequent clinic visits (weekly). Some patients live far away from health facilities; hence, they incur transport costs. These expenses have been reported in previous and recent studies in Tanzania, Ethiopia (Asres, Jerene, and other LMICs (25). Such costs become catastrophic to individual patients and their families/relatives, as individuals or households lose opportunities for income generation while needing to pay for household and family basic needs and TB-associated costs (17). Participants further explained the effect of this extensive treatment period on patient adherence to the recommended schedule. Scientists are urged to develop a shorter-duration treatment regimen to improve compliance and minimize the financial burden on TB patients (26-27).

At first glance, specific barriers do not appear to be financial. However, they translate into financial shortfalls, making life more difficult for patients (28). For example, this study's results indicate that when an individual's TB condition intensifies, their ability to work to provide food or income wanes or ends. Thus, they resort to borrowing money from family or friends, a humiliating and degrading experience for most of them. A similar situation occurs when victims or their families are compelled to sell their valuable personal or family assets to finance TB treatments, as revealed by another study in Tanzania (26). Due to their condition, TB patients are unable to participate in income production activities; most depend on their relatives. This dependency sometimes creates psychological torment for TB patients. They struggle with decision-making.

Earlier studies in India and Indonesia have reported a similar finding, where a loss of productivity due to non-participation at work led to increased personal or family debts (29,30). In addition, food insecurity caused by non-adherence to TB treatment has been documented in developing countries (31).Therefore, the patients' hunger (and that of their families) cannot be overlooked if TB treatment is to be effective (32).

The community's association of TB with superstitious powers often denies victims the financial and moral assistance they need and deserve. As a result, patients tend to avoid declaring that they have the disease. Mostly, they use all their money to pay a traditional healer, worsening their situation because they delay initiating necessary medical care, thus prolonging the medical, financial, and psychological consequences. Furthermore, the disease may become more complex. It is common for multidrug-resistant TB to develop, resulting in lifelong body disability or immediate death (33).

Stigma and discrimination against TB and HIV victims were additional psychosocial problems in the study regions. Their persistence contributed to the TB treatment non-adherence noted by the National TB program (34). In this study, participants' quotes confirmed that social- and self-stigma against the disease or those suffering from it led victims to lose self-confidence or self-esteem and hope for a happy life. Those with TB but not HIV were suspected to have the latter. This suspicion is understandable, given their

frequent co-existence (35). and the high prevalence of both these diseases in the study regions.

Study Limitations

This study has some limitations. First, the study sample included only those patients accessing care and excluded LTFU) patients; the LTFU patients' socio-economic consequences may be worse than those remaining in care. However, the LTFU patients in Tanzania are few and difficult to find because they sometimes provide incorrect addresses or change their residence.

Accessing patients' relatives was difficult because patients only needed a family member to accompany them when they were unwell and unable to travel alone. In addition, most patients prefer to go to the clinic alone and not disclose the disease to their family members. However, we acquired sufficient information regarding their socio-economic difficulties from relatives accompanying the patients.

Conclusion

Although national policy and legal frameworks directive the delivery of free TB services to eligible individuals, our findings reveal a disconnect between policy and practice. In reality, TB patients and their families often incur out of pocket costs both financial and social when seeking treatment through formal health systems. These may include transportation, lost income, and strain on social relationships due to stigma. Managing TB and HIV become even more complex in individuals with co-morbidities such as HIV and diabetes, as these conditions increase treatment costs and amplify stigma and discrimination. Such barriers contribute to forced to bear specific financial costs, including certain social costs that touch on patients' or families' social relationships. In addition, we found that controlling TB is complicated when the individual has TB and co-morbidities such as HIV infection and diabetes. Moreover, along with the financial costs they impose on patients and their families, both diseases bring social stigma and discrimination, resulting in delayed and irregular care-seeking behavior by some patients at the recommended clinics. Therefore, the National End-TB strategy's goal is unlikely to be attained by 2035 amid these prevailing social and economic barriers. Thus, enhancing, and sustaining public/community health education on TB, the urgency of timely care-seeking, adherence to medical prescriptions coupled with

sustained poverty reduction interventions, and ensuring universal and affordable financing mechanisms for TB care, such as health insurance and user-fee exemption enforcement, can facilitate bringing services closer to target users.

Declarations

Availability of data and material

Data are available from the corresponding author upon reasonable request.

Competing interests

The authors declare no competing interests

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Authors' contributions

SK conceived the study idea and took the lead in data collection and analysis for her Ph.D. studies. GM, AM, and DE contributed significantly to protocol development, data collection, and analysis. SM participated in data collection in the Mbeya region. NN and IS provided technical guidance during the data collection and analysis processes. All authors contributed substantially to drafting and revising the manuscript critically for intellectual content. All authors approved the manuscript for submission.

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CHAPTER 6

6.1 PAPER III

Perceived access to social support during and after TB treatment in Mbeya and Songwe regions, Tanzania: perspectives from TB patients and survivors set against health care providers.

When this dissertation was submitted, Paper III had been published in the journal Frontiers in Health Services. For this dissertation, the published paper has been presented according to the sections and layout required by the journal. However, it has been reformatted to align with the dissertation style specified by the university.

Reference: Kilima SP, Mubyazi GM, Moolla A, Ntinginya NE, Sabi I, Mwanyonga SP, Evans D. Perceived access to social support during and after TB treatment in Mbeya and Songwe regions, Tanzania: perspectives from TB patients and survivors set against health care providers. Frontiers in Health Services. 2024 Jul 11;4:1273739.

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Abstract

Introduction: Pulmonary tuberculosis (PTB) remains a life-threatening disease in Tanzania, with negative physical, financial, economic and psychosocial consequences to individuals and society. It mainly lowers the quality of life of patients, survivors and their families, especially those in the poorest andsocially deprived categories.

Objectives: To report and discuss a qualitative study that assessed the nature of social support desired and received by PTB patients and survivors. Participants were given a chance to share their experiences and their perceptions on whether the social support they desired had an impact on their treatment-seeking behaviour and treatment adherence.

Methods: Face-to-face interviews were conducted with the three aforementioned groups, purposively selected at a TB clinic between October 2020 and March 2021. The questions covered topics related to the types of social support desired and the sources of support during and after treatment, if any. Interviews were concluded until no new information was obtained. Dataanalysis was facilitated using NVivo 12 software.

Results: Participants pointed out a need for psychosocial, financial, and material support during and after treatment. However, they sometimes miss support from family/household members or the rest of the community. Because of this experience, they lived with difficulties, facing hardships when required to pay out-of-pocket for transport during the care-seeking. Survivors testified experience of a denial of support by even their close relatives who regarded them as no longer needing it after recovering. Patients and survivors also reported experiencing social isolation as they were believed able to transmit PTB infections. Limited psychological support at the contacted TB clinics was another experience reported. TB clinic staff's experiences confirmed almost all the experiences shared by their clients. With limited support, resilience and self-care were identified as key strategies for coping.

Conclusion: Complete recovery from PTB is possible, but reverting to a normal life is difficult without social support. Policies and programs need to increase opportunities for social support for TB patients and survivors. Doing so is likely to improve TB-related treatment, care-seeking practices, and adherence.

KEYWORDS: tuberculosis patients, survivors, emotional, social support, stress

Introduction

Literature Overview

The World Health Organization (WHO) has reported that tuberculosis (TB), a contagious and airborne disease, was found to be the second killer after COVID-19 in 2022, affecting 10.6 million people globally (1). Over 90% of all the recorded TB cases and deaths are recorded each year in low-and-middle- income countries (LMICs), Africa being one of the regions highly affected (2). Pulmonary tuberculosis (PTB), an airborne mycobacterium disease, is found to claim numerous lives across all infected age groups unless there is timely access to appropriate treatment and care (3). In 2019, an estimated 1.4 million people died of TB worldwide (4), the number slightly declined three years later to 1.3 million (5).

PTB commonly affects the lungs and can be fatal if not treated promptly. The standard treatment for TB in Tanzania is a six-month regimen. The first-line regimen is a combination of rifampicin, isoniazid, ethambutol, and pyrazinamide (RHZE) in the first two months (initial phase) and rifampicin and isoniazid in the last four months (continuous phase) (6). During the entire period of treatment, a supporter is assigned to observe the intake of every dose to ensure that patients take the right anti-TB drugs in the correct doses and at the proper intervals (7). This improves treatment adherence and reduces TB infection in close family contacts and the community. It also prevents drug resistance (MDR) to TB. However, the majority of TB patients in LMICs start treatment late, putting respective patients and their family members at risk (8).

Apart from the physical/physiological threats TB poses directly to the patients, it also leads to negative financial and economic consequences to both the patients and their relatives or family members especially those with whom they live in under the same roof. The physiological disorders, coupled with pain and the financial burden of the disease, have far-reaching effects on the overall health and well-being of affected people. The first directly affected are patients and survivors. Besides the direct pain they physically experience during their illness, patients become socially and psychologically affected too (9). If so severe, the pain may drive the sufferer (patient) to think of committing suicide (10).

Survivors also face certain psychosocial consequences after treatment and recovery from the disease. For example, evidence continues to reveal that both the patients and the survivors are sometimes suspected of having TB by the rest of the public/ community members. They encounter certain social stigma and discrimination against their state of health by people perceiving them as contagious (11,12). Such experiences can lead to post-traumatic stress disorder (PTSD), therefore emphasizing the need for receiving or undergoing specific and important interventions to supplement the already conventionally prescribed medicines (9, 13).

Previous studies justify that social support from any reliable and genuine source such as family members (close relatives), friends, colleagues and health care workers (HCWs), for example, TB nurses and physicians, plays a crucial role in increasing a sense of belonging to the respective social group amongst the mentioned ones and to the rest of the community. Their self- esteem or self-confidence remains stable, and their faith or hope in the recipient of such support (13). However, social support in the TB control program within LMICs is found to remain inadequate. There are occasions when both TB patients and survivors miss the support they need from those expected to assist them. The nature of the support needed could be material or non-material. Material support may take the form of either financial or other kinds of resources for direct or indirect consumption (14). Some kind of support may also be given by, or expected from, the healthcare system or the society members around (15). Lack of social support contributes to LTFU among some patients who have initiated treatment (16).

Suggestions continue to be made regarding the need for having in place reliable sources of support for TB patients and survivors (14). Social support networks are highly recommended and have been proven to play an important role (17,18). For example, one study in China found that TB patients with family support significantly adhered to their treatment schedules compared to those without (19). The respective patients in this study were provided with support in the form of regular medication supervision to ensure that the directly observed therapy/treatment (DOT) algorithm was adhered to. This happened concurrently with helping to maintain a healthy relationship between the respective patients and their supervisors, including those in the families and the communities to which they belonged. Another form of

support given includes the individuals concerned finding themselves receiving spiritual advice and emotional encouragement. However, there is a general disappointment experienced by individuals who miss one or more of the mentioned kinds of support—and this makes it difficult for individuals to cope with their lives (19,20).

A strategy to enable TB patients and survivors to cope with persistent health impairments is needed (11). Additionally, systematic studies show that social support serves as a mediator between self-efficacy and various outcomes, including depression, stigma, and financial burdens (17, 21, 22). The amount of support that an individual receives plays a crucial role in determining their health-seeking behaviour, morbidity and mortality outcomes (23-25). These findings imply that health is not only a product of biological determinants. It is also determined and influenced by social and psychological factors (17,26). The authors summarise the support needed by patients and survivors into four categories, namely: (1) informational (including advice and guidance), (2) emotional (including expressions of care, as encouragement) which strengthen or heighten the patient's self-esteem, (3) companionship, which instills a sense of belonging for individuals within their social network or group they can rely on for specific needs and material or tangible support, which includes financial assistance, and transportation to meet one's necessities (27,28). In general, it has been noted that the relationships between social support, experienced stigma, psychological distress, and quality of life (QoL) among TB patients are still insufficiently understood and, therefore, need to be further investigated and discussed (22).

Theoretical framework

The Stress, Social Support, and Buffering Theory developed by Cohen and Wills in 1985 confirms that experience with long-term illness sometimes push patients and their families into regrettable health, financial and economic crises (28,29). According to this theory, a disease faced by one person in the family may have spill-over consequences to the family at large. That is, patients with severe or long-term disease conditions may alter the social reality of the family, particularly if the treatment demand is found to result in conflicts with developmental tasks of a certain life stage. A consistent correlation has been observed between a lack of social support and adverse psychological as well as biological health outcomes. This is often noted mainly when the patients concerned lack (miss) the support they need for them to adhere to the prescribed formal medications, leading to LTFU (28,30).

Furthermore, a lack of support intensifies the patient's stress, and this adversely affects such individuals' emotional and biological outcomes. This underscores the urgency of providing positive social and emotional support since doing so facilitates a quick recovery (31).

In summary, **Figure 2.1 (page 43)** describes literature with research-based evidence demonstrating the importance of social support in a TB control program. **Figure 2.1** is also consistent with Cohen and Will (30), who refer to the Stress, Social Support, and Buffering Theory, whose suggestion is that a lack of positive social relationships leads to negative psychological states, such as anxiety and depression. When interpreting this theory in the context of TB patients or survivors, it emphasizes the necessity of social support for effective disease control programs or interventions. Such kinds of support are aimed at reducing the respective individuals' stressful life conditions and improving their QoL (30,31). Such a school of thought was the essence of the current study undertaken to explore the types of social support received as compared to the one perceived as necessary for TB patients and TB survivors during and after their treatment in Mbeya and Songwe Regions, Tanzania.

Problem Statement and Rationale for the Study

The Global End TB Strategy prioritizes patient-centered care. This means that patients receive respectful and responsive care that considers their individual preferences, needs, and values. All clinical decisions are made with the patient's values in mind. The ultimate goal is to provide high-quality TB diagnosis, treatment, and care to all patients without incurring catastrophic costs (32).

The End TB Strategy specifies further that the patient has to be put at the centre of the heart of service delivery whereby he or she feels to be treated/handled with respect, his or her needs and values considered there is room to listen to the individual's questions, concerns and requests (15), offering meals or breakfast or drinks or any other type of nutrition (33), and supporting the individual with transport facilitation such as fare or fee relief (34). With the social and personal circumstances of that person being observed, not just the immediate requirements of medical equipment (34) should be globally ensured and remain an integral element of the established or planned TB prevention and treatment programs.

However, countries must have strong TB policies and governance systems to realize practicable translation of the proposed interventions into effective implementation. This also needs to leave room for incorporating insights from researchers whose studies have contributed to generating relevant and field- based policy and program-related evidence. The respective researchers' investigations need to explore the potentially innovative or novel approaches capable of significantly reducing the disease burden and, therefore, improving the QoL of eachrespective patient and survivor (35).

Researchers can also advise the authorities concerned on the key areas needing either new or additional prioritization (36). To encourage the public to value the message of early contact with TB clinics for check-ups and diagnosis, the nature of the service provided at these points of care must meet acceptable quality standards (26). This ensures that individuals who eventually decide to visit the clinic are satisfied with the quality of care received. Another consideration is a need to address the problem of the actual or the possible experience of financial hardships when at the time of service seeking. The standard quality of care/service may include, among other conditions, the type of drugs/medicines prescribed and then used to result in certain treatment outcome(s), and this sometimes depends also on the nature of the process involved in delivering the care received/accessed by the client/patient (37).

Part of the process care that is, the procedure concerned relates to the time spent by the client to wait for service at the clinic/ facility, the service providers' attitude including the language such providers use while interacting with their patients, in addition to the physical environment in which the services are being delivered (38, 39).

As identified above, the quality of care-related factors are found in many countries, contributing to the prevailing dilemma or the stigma attached to deciding when and where to seek care (7, 39). It is further noted that, TB-related care does not always stop after the patient completes the prescribed drug course. It is extended to the survivors after treatment (22). Both the conventionally given support, such as the one given within the health care facility settings as well as the one obtained from the family, the community around, and other sources in the society, are important for addressing most of the psychological and the economic challenges individuals who have been traumatised by TB related stress meaning the patients and survivors, are highly needed for the betterment of the lives of such people

(14, 22).

Studies examining at broader determinants of TB, such as poverty, undernutrition, and HIV infection, are essential. They provide valuable insights for policy and program authorities on potential measures for minimizing the chances of having many TB patients categorized as 'LTFU, particularly during the treatment of drug-resistant TB in adults (14,34,40,41). Despite the already established knowledge on the importance of social support, researchers should continue studying and disseminating findings on the role of social support on TB control policies and interventions/programs in Tanzania (42). Furthermore, the WHO supports research to undertake operational research or implementation of science-related studies that focus on TB treatment and care. Studies can focus on practicability (with an emphasis on administration and effectiveness), particularly in TB highly endemic countries. This study recognizes that TB control is a multifaceted issue which requires more interventions. Some interventions can be implemented after considering their designs and context-specificity rather than an overemphasis or over-focusing on biomedical determinants and guideline translation approaches (43).

Materials and Methods

Study Design

This study was qualitative. It used cross-sectional survey by design which was guided by descriptive phenomenology, developed by Edmund Husserl (44). This approach enabled the research team to capture key messages from participants' experiences. The study was nested within a large multi- country, multi-center, observational TB cohort study called "TB Sequel" (45).

Study Setting

The study was conducted in two regions in the southern highlands of Tanzania, namely; Mbeya and Songwe. The regions were selected due to their high prevalence of TB and HIV at the time of the current study. HIV prevalence was estimated at 9.3% for Mbeya and 5.8% for Songwe (46), both exceeding the national average of 5.0% (47). Two districts were identified in each region, one rural and one being urban. In Songwe, the districts were Mbozi and Momba-Tunduma, while in Mbeya, they were Mbeya City and Mbarali, see **Figure**

6.1.



Africa



Tanzania
61,741,120 (2022)
947,303 km2 (365,756 sq mi)



Mbeya
Urban
Approx 2 million (2022)
HIV prevalence 9.3%

Sub-districts
Mbeya City
Mbarali



Songwe
Rural
998,862 (2012)
HIV prevalence 5.8%

Sub-districts
Mbozi
Momba-Tunduma

Figure 6.1. Study Setting.

Study Population(s) and their Recruitment Procedure

The study participants were TB patients, survivors, and healthcare workers (HCWs). Participants were selected purposively, based on their willingness to participate in the interviews on days they visited the TB clinic for the service. **Table 6.1** shows the sizes of the samples for each category of the participants. HCWs included individuals who were service providers for TB patients and TB survivors, for more than six months at the selected TB clinics, within each of the respective regions. All participants were eligible for enrolment in the study after they confirmed their willingness to voluntarily participate by signing the informed consent (IC) form. Measures were taken to ensure that their agreement was given freely without coercion.

Table 6.1. Study population and recruitment criteria.

Target sample size	**TB Patients (18)**	**TB Survivors(12)**	**HCWs (12)**
Eligibility	Adults≥ 18 years confirmed TB positive enrolled in the TB Sequel clinic	Adults≥ 18 years who had completed their TB treatment in the last 24 months. Enrolled in TB sequel cohort coming for their scheduled visits, confirmed TB negative and reside from four selected district	HCWs working in the twelve (12) selected TB clinics. In each clinic one experienced HCW was selected to participate in the KII
Recruitment sites	Being from the selected four districts. Attending TB sequel clinic at Mbeya Zonal Referral Hospital for treatment. Purposively selected.	Being from the selected four districts. Attending TB sequel clinic at Mbeya Zonal Referral Hospital for follow-up. Purposively selected	Purposively selected from the 12 clinics. The clinics selected to refer new TB patients to the TB sequel project.
How identified	Patients attended in the TB clinic from 10/2023-03/2021. The data collection activity conducted during COVID-19 hence contributed to over estimating strass.	Continued attending the TB sequel clinic from 10/2021-03/2021 for further medical follow-up and additional care, including receiving services intended for the management of possible post-treatment, physiological, psychological and other health sequel as recommended	HCWs worked in a TB clinics for not less than six months. In each clinic one experienced HCW was selected to participate in the KII
How invited to participate	Those who agreed to sign an informed consent form. not being critically ill	Those who agreed to sign an informed consent form, having 24 months or more after treatment completion confirmed TB negative	Agree to participate and had experience working in the TB clinic

Data Collection

Before data collection, the interview moderator and note taker attended a three-day training session to familiarize themselves with the study's objectives and methodological approaches. The pretested tools underwent refinement to enhance their user-friendliness, coherence, and increased chances for question understandability and answerability (48). In total, three interview guides were used. Each guide targeted one of the three categories of respondents. Despite different tools/guides, the issues investigated were similar, focusing on collecting data that could meet specific study objectives. The questions focused on self-reported TB experience during or after official treatment at the respective clinic. Patients and the survivors had a chance to comment on the types of support, that they received during and after treatment, the importance of social support to them, and comparing this to what they sought and obtained. HCWs commented on the role of social support for TB patients and survivors as well as their role in supporting patients psychologically throughout treatment.

All interviews were conducted in a separate place at a distant location (about 500 m) from the main TB clinic. The distance was to ensure participants' confidentiality, anonymity, freedom of expression, and confidence. The language used in conducting interviews was Kiswahili, which is the national language spoken fluently in Tanzania. Each interview session lasted between 35 and 45 min. In addition, handwritten notes were taken to supplement audio files (49). The handwritten notes were also validated immediately during the team's daily debriefing session. The audio record and handwritten notes were supplemented by specific annotations for participants' behaviours, such as indicative crying, sorrowful expressions, laughing, nodding, forced coughing, puffing, and denying through head or shoulder shaking (50).

Data Analysis

The interviews were recorded and transcribed verbatim within the same field working days. Two social scientists were involved in transcribing and translating the interviews into English. Translation was done by two individuals independently, who then compared the data. Subsequently, translated transcripts were imported into NVivo 12 software for data analysis and coding. As commonly done when adopting a Grounded Theory (50), the coded data respondents had acquired formal education, although facilitated a thematic analysis. This

approach involved examining both the context in which the data were collected and its contents, aligning with the specific objectives of the study. Three researchers performed a detailed analysis. This involved several steps, including familiarizing the data by reading the transcripts carefully to identify themes and sub-themes. In the process, where there was disagreement in the themes and sub-themes, discussions took place until the coders reached a consensus (51, 52). All reflective notes were taken into consideration during the data analysis process.

Ethics Approval

The permission to conduct this study was received from The Human Research Ethics Committee of the University of Witwatersrand, South Africa (M200570, 29 May 2020), the Mbeya Medical Research and Ethics Review Committee (16 January 2020), and the National Health Research Ethics Committee of Tanzania (Ref. No. NIMR/HQ/R.8a/Vol. IX/3527).

Results

Socio-Demographic Characteristics of the Study Participants

Out of 30 interviewed participants, 24 (80%) were males. Additionally, 28 (93%) of all participants were aged between twenty-five and forty-five years. Similarly, 29/30 (96%) of primary school level. Additionally, 61% (11/18) of TB patients were in the intensive treatment phase (0–3 months) **(Table 6.2).**

Table 6.2. Socio-demographic characteristics of participants TB patients and survivors.

Characteristics	Respondent category	
	Patients (n=18)	Survivors (n=12)
Region		
Mbeya	9	6
Songwe	9	6
Gender		
Male	14	10
Female	4	2
Age		
25–45 years	17	11
46–60	1	1
Education		
Primary	14	12
Secondary	3	0
No education	1	0
Marital status		
Married	10	9
Single	3	3
Divorced	5	0
Treatment status		
Intensive phase (0–3 months)	11	0
Continuous phase (4–6 months)	7	0
Treatment completed (>6 months)	0	12

The 12 HCWs who participated in this study offered services to TB patients and survivors. Most HCWs, 92% (11/12), were females. All HCW participants had served in the TB clinics for at least two years. The dominant staff cadres among the participants were medical attendants and nurses **(Table 6.3).**

Table 6.3. Characteristics of HCWs interviewed in Mbeya and Songwe regions

Particular/**Characteristics**	*N* = 12	Mbeya	Songwe
Gender			
Male	1	1	0
Female	11	5	6
Years of service in TB clinic			
2–5	2	1	1
5–9	5	3	2
10 or above	5	2	3
Occupation			
Medical attendant	9	4	5
Nurses	3	2	1
Medical doctor	0	0	0

Emotional and Psychological Support

Support from HCW

Emotional and psychological support played a crucial role in helping patients and survivors accept their condition and build self-confidence. Without this support, some individuals found it difficult to accept their condition due to feelings of disrespect and lack of trust. Patients often felt guilt and worried about infecting their family and community members, leading them to fear being isolated due to the prevailing stigma against TB. Such a feeling or fear prompted the respective individuals even to isolate themselves by keeping a distance from other people as a way of preventing them from possible infection. Self-stigma can be reduced or removed through emotional support provided by HCWs during service provision and by the patients' families and communities. Such support helps patients feel a sense of belonging and respect, reducing feelings of abandonment and loneliness. The following statements from respondents confirmthis opinion:

> "*You know, if HCW speaks to a patient concerning his condition, the patient will be psychologically stable and able to accept the illness condition faced, and will also reduce stress, and the patient concerned will be able to continue taking medicine comfortably*." (Patient- Mkoani hospital-Mbeya).

Furthermore, most TB patients confessed to not receiving emotional support from the HCWs. The few who received support, asserted that it did not meet their expectations. However, it was interesting to note that many patients acknowledged the demanding schedule of HCWs who often faced heavy workloads. This sometimes made them fail to provide necessary services, including emotional support for psychological rehabilitation, as described below:

> "*Emotional support is very important, especially to us TB patients. However, we cannot blame the healthcare provider. We are many, while they are few. Sometimes, staff does not have enough time to speak to you and give you advice as you expect to hear from a professional*" (TB patients, Mbeya).

Some patients commented on lacking emotional support from the HCWs contrary to their expectations and perceived this as negligence, which contributed to their dissatisfaction:

> "*I am telling you, we need emotional support, especially from the HCW. As you know, we always trust them, but to my surprise, I never experienced such service, rather than being told you have TB and need to swallow the medicine for six months*" (52 yearsmale, TB patient, Mbozi district, Songwe).

Psychological Support from Peers

Some patients highlighted the importance of getting psychological support from fellow patients, a practice that is often observed when waiting for services at the TB clinic/facility. Through sharing experiences, patients encourage each other based on their stories. They teach and remind each other about helpful issues, which improved one another's level of understanding or awareness about the disease, as exemplified below:

> "*I came here very sick and down. I thought I was going to die any time. I met one patient who highly encouraged me by telling me that he was in bad condition when he came here compared to me. After taking medicine for one month, he changed completely and recovered, this encouraged me, and I also believe I will healed*" (TB patient, Mbozi district, Songwe).

> "*In the beginning, I was very down, thanks to my fellow patients, who encouraged me from their own experience and advised me to adhere to the treatment to recover from this disease. Their encouragement helped revive my hope; now I am okay*"

(TB female patient, Mbeya City, Mbeya region).

Although they encountered several psychological difficulties, TB survivors complained that they did not receive psychological support. They believed that after treatment completion, one needs emotional support to enable them to cope. One of the survivors reported:

> "*If you completed TB drugs, other services are seen as if they are not necessary. For instance, emotional support is important because some of us facing difficulties need it along with psychological support. These are not provided to us*" (TB Survivor, Tunduma Songwe).

Psychological Support from Family Members or Other Relatives

There was a general narrative that patients and survivors lacked psychological support from their relatives and other community members. One of the stated reasons for this limitation of support was noted to be due to some of the patients with either TB alone or a TB and HIV comorbidity failing to disclose their personal information about these medical conditions. The reluctance to disclose their status has been identified as a contributing factor to poor adherence to the recommended treatment and care-seeking behaviour. Therefore, identifying those in need of support has proven to be challenging, as evidenced by the following testimony, among others:

> "*I came from a family of thirty children. It is difficult to tell them about my situation because you do not know the heart of everybody. Sometimes, I need support, but hesitate to ask them for it.*" (TB patients, Mbeya City).

Healthcare workers (HCWs) play a critical role in providing emotional support to tuberculosis (TB) patients and their relatives. This support is crucial for patients to adhere to recommended treatment or prescriptions. However, a significant challenge is that most patients only report to the health facility when they are already seriously ill and depressed. This delay in seeking treatment is considered to be due to hopelessness and fear of possible death or permanent disability. HCWs believe that emotional support can help TB patients adhere to the treatment course and prescriptions, and reduce the possibility of death and multi-drug-resistant TB (MDR-TB).

In healthcare facilities, directly observed therapy (DOT) nurses and trained community health workers (CHWs) are responsible for providing emotional support to patients and their families. However, this is not frequently done due to staff shortages or a backlog of duties on certain working days.

> "*In the beginning, you can find a patient is depressed, and we, as HCWs, mostly support them. We can give emotional support to ensure that the patient is in good condition to accept their situation; by adhering to the treatment course as recommended, healing is possible. Although patients may wish a lot from us, it is impossible because of staff shortage at the TB clinic.*" (HCW Songwe).

Information Support and its Implications for Service Utilization

TB patients explained that it was important for their communities to be sufficiently supported with information on TB. This will potentially help alleviate some of the misconceptions about TB and hence contribute to reducing its spread. There would also be a better response and quicker treatment-seeking when one is confirmed to be infected by TB. One patient gave the following narrative:

> "*Maybe I should ask for information support—if education does not pass yet, this disease will bother us a lot; The drug is again free of charge, but without this education, the disease will not reach an end. So, do help us learn about the effects of TB, how a person should live after getting sick, and so on*". (TB patient, Mbozi district, Songwe region.

TB survivors also reported that they needed information support, particularly on how to integrate with others within the community after completion of TB treatment as well as to avoid re-infection. They need to be educated since they return to the same environment and people. However, a few participants reported getting information after asking healthcare workers, for example:

> "*I asked the doctor to tell me how will I stay in the community and avoid another TB infection because I saw my neighbour who completed TB, but now they confirmed him TB positive; I was afraid it might happen to me, then the doctor educated me, I wish everybody who completed drugs should get such kind of education*" (TB Survivor, Tunduma Songwe region).

HCWs, in collaboration with CHWs, emphasised the need for TB education within communities. However, reaching all the villages is difficult due to insufficient budget allocations:

> "*We are giving community education to community members in the villagers; we also have motorbikes for picking samples to send to the Health Facilities. I can say it is not possible to visit all the villages as the budget allocated is not sufficient*" (HCW Tunduma, Songwe)

Additionally, HCWs in TB clinic provided information support primarily to TB patients. For TB survivors, it is rare to receive information support due to the belief they are already informed.

> "*TB survivors, we believe they are aware of TB, as some of them used as champions to educate other people and if they see a person with symptoms, they advise them to come and test*" (HCW- Tunduma, Songwe)

Companion Support from Family Members and other Relatives

Findings suggests that TB patients who were escorted to the health facility on their first day felt comfortable and valued. Those who did not have company while waiting for service on their first day were unhappy, lonely, felt neglected, and helpless. One respondent from the Momba district in the Songwe region testified about the difficult moments that she experienced in the first few days of her testing and diagnosis. She claimed that she was alone while being screened and tested positive for TB. Therefore, she felt lonely, neglected and isolated. In connection with this experience, the HCWs expressed that companion support is crucial, especially in the early days after the initiation of treatment. Patients are usually accompanied and supported by their friends or family members who they trust, and who would remind them to take their medicine daily as well as helped them to maintain their hospital visiting schedule. However, HCWs did not seem to believe in TB survivors' need for companionship or support, except when they had specific difficulties.

Material Support Accessibility Opportunities, Convenience, and Satisfactoriness

Monetary support

TB patients reported needing financial support, mainly for transport costs to visit the healthcare facility. Financial support was primarily sought, expected or received from close relatives, such as a family member. A few patients reported receiving support from their siblings or other family members with whom they share a blood relationship. These were reported in the following participants' narratives:

> "*It's just as I said at the beginning, that I'm dependent, and my brother is helping me by giving me money for transport to and from the facility. He is very supportive to me*" (Patient, Mbozi district, Songwe region).

> "*Some of my relatives are in Dar es Salaam, and when they heard of my sickness, they continued sending me money to assist me in meeting my treatment needs. The money I get some amount is being used for transport to and from the facility*". (Patient, Mbozi district, Songwe).

Another participant who received monetary support from his spouse said,

> "*…my wife is very supportive to my side, is the one making sure I do have money to attend the facility.*" (Patient, Vwawa Songwe region)

However, other patients believed that, although financial support is essential for TB patients, it is difficult to access it from family members or friends:

> "*I always wish my relative to help me with some money, so that they can help me for transport and other need, but it is difficult for people just to give you their money for free*" (Patient, Mbarali, Mbeya region)

> "*Money support is important to TB patients but very difficult to access, and you cannot believe others never came to say sorry even if they see me being seriously sick, thinking that you will ask them for money… I cannot blame them as they*

have a difficult situation financially". (Patient, Mbozi District, Songwe).

TB survivors also reported on the importance of monetary support after treatment completion. They were thankful for the TB Sequel project, which gave them transport allowance whenever they made follow-up visit.

> *"To be honest TB sequel helped us a lot by giving us money for transport. If you show your receipt, they give you double amounts to cover the costs for to and from home. That the only monetary support I ever received" (TB Survivor, Tunduma, Songwe region)*

Excluding the assistance obtained from the TB Sequel project, most patients and survivors reported never receiving financial support from friends or relatives, during or after treatment completion. The concern was that it was not possible to receive money from such sources given the difficult economic situation that most families faced. However, they acknowledged the importance of receiving financial support to access basic dietary and other social needs, although it was difficult to access:

> "*Getting Monetary support is impossible people do not have money for themselves; will they have money to give you? That is why we rely on borrowing*" (TB Survivor, Mbeya DC, Mbeya).

> "*If you are sick, people may feel compassion for your situation and give you some money. But, when you complete medicine, and they see you starting to gain weight, nobody thinks about giving you a single cent again*" (TB Survivor, Mbeya DC, Mbeya).

However, few TB survivors confirmed having received support from their close relatives, as one of the quotes below indicates:

> "*Some of my close friends supported me with a small amount of money for transport to and from the facility, and they know I am not well financially.*" (Survivor, Mbeya DC, Mbeya).

Commenting on the importance of monetary support for TB patients, HCWs reported that they occasionally financially assisted the patients. The assisted patients included those who did not have financial means, or those who had travelled long distances but did not have transport fare to go back home. However, it was impossible for them to help every patient due to lack of funds. In some cases, HCWs were influenced by empathy to support starving patients who also lacked transport fare, as described below:

> "*Yesterday, one patient came here walking from a very far- located village, and she was complaining due to leg pain and having no single cent. I felt sympathetic to her and decided to give her 3,000 shillings for paying a bodaboda (motorbike) driver on her way back home*" (HCW, Songwe).

> "*It became a time you feel compassion and decide to help the patient with some money. Some of the patients are very poor, so due to lack of money to afford to buy food or pay for transport back home, they decide to take a walk*" (HCW_Mbalizi, Mbeya)

Food Support

Most patients reported having received food support from family members when they could not participate in productive economic activities, or engage in crop production. TB patients reported to have had easily accessed food support during the crop harvest season since every family in this period had plenty of food in stock.

> "*I received food support from my family members; they assisted me getting food because I had nothing to eat; hence I need to ask them for assistance*" (TB Patient, Momba-Tunduma, Songwe).

> "*During harvest season, my relative assisted me and my family in getting food; they brought me maize, potatoes, beans, and groundnuts. Until now, I am using the food received from them, and I appreciate their support and pray for them*" (TB Patient, Mbarali-Mbeya)

Findings suggest that an alternative or additional support was received from neighbours. The neighbours brought food or other support in form of gifts, such as cash, that was given to patients or caregivers. Such helpers extend their support out of recognition of their humanity and the burden carried by the caregivers who were staying with the patient for extended period of time, either at home or at the clinic/hospital during severe illness. The following is a statement representing an experience that was expressed by several other participants among the patients:

> "*My neighbours came and brought me food such as a box of maize, and others gave me chicken; if you live well with your neighbours and they know you have a sick person in your house, they bring some gift to support you.*" (Female TB relative, Mbalari Mbeya)

Likewise, TB survivors highlighted the necessity of food support for those facing certain TB Sequelae that deny them a chance to participate in economically productive activities even after the completion of their treatment. If given food support could enable such individuals to return to their normal health conditions, leading to participation in routine or day-to-day productive activities. However, some of the TB survivors interviewed reported that they had never received food support from any sources, since farming and other economic activities continued as usual, which enabled one to have at least food for subsistence use.

> "*Since I started getting well, I never get food support from anyone. I proceeded with my daily activities, and although sometimes I did not have enough food for myself and my family's needs, I had not sought support from anybody. You know what, they will be surprised that I have recovered yet still bothered them*" (TB survivor, Mbarali Mbeya)

HCWs concurred with patients and survivors that food support is essential to seriously ill patients who cannot afford to buy food. However, they also explained that there was a need for patients and their caretakers, family members, as well as their community, to be regularly educated and sensitized on nutritional matters. They included the importance of growing adequate food and keeping reserves in stock, as well as following healthy diets before and after taking the prescribed TB medicines. The reason for this was that patients who take anti-TB pills on an empty stomach complained of side effects, which may contribute to LTFU in

the TB control program. In general, HCWs reported having met or known many patients who were unable to afford or secure food all the time, primarily because they or their families lack enough time to participate in food production or other income-generating activities, as the following statement testifies:

> "*Food support is critical to TB patients. The medicine made patients to eating a lot; for those without food, it is difficult to adhere to the treatment*" (HCW, Mbeya City).

Discussion

Findings suggest that, personal and family support during chronic debilitating illnesses are prerequisites for patients' and disease survivors' well-being (53,54). The findings indicate how those with TB and TB survivors could cope within an unsupported and challenging environment. Patients and survivors tend to expect social support from other people with whom they interact (55). Therefore, there is a need to make social support a part of the policies that are created and established programs, to strengthen efforts towards ending TB (38,53,54).

Findings indicated that there is more to be done with regard to TB treatment than just administering drugs (58). TB patients and survivors need moral support that would make them feel valued while they go through treatment as well as after their illness. This will potentially have a positive effect on their psychological wellness (58,59).

A patient suffering from TB wishes to see and feel that they are cared for during their times of crisis. This can be shown through empathy and cooperation or togetherness. In this study, patients appreciated the moral support from their fellow patients because it kept them feeling alive and able to cope with their current situation (60). The TB patients and survivors also appreciated the support they received from the HCWs. They suggested that support is important in helping the patients cope with the disease and adhere to treatment. HCWs' emotional support should be routinely accessible to all patients because this could make them feel better. It will also improve clinical outcomes and increase the patient's compliance with the prescribed treatment (61). Therefore, service providers and family members or related supporters must ensure that they support the patient with love, empathy, and care (62,63).

Social support is essential in increasing TB treatment uptake and reducing LTFU (28.64).

Supporting an individual patient or a survivor of a given disease does not necessarily imply giving them money or other material resources; even a positive moral attitude in moments of trouble or pain results in significant positive improvement in that person's health and well-being (65). Literature shows that when a patient feels respected when they present their illness to a service provider or caretaker, they may be psychologically motivated (65, 66). Some of the individuals who face post-TB lung disease endure lifelong Sequelae (65). This condition may traumatize them for many years, especially in times that they encounter people who mistreat them (38) The feedback received from both categories of participants confirmed that TB is a burdensome disease not only during the moments of physical health deterioration but also after undergoing treatment and getting cured of the disease (38). Therefore, the current study's findings validate the earlier reported evidence justifying the need for a renewed interest and focus on TB's burden and damaging impact, particularly its long-term sequelae on individual patients, their households, and their communities (67).

The present paper also reveals that those who succeed in completing the required treatment and are eventually clinically cured of the disease may fail to continue contacting the recommended service providers due to financial barriers. For example, survivors may face financial challenges when seeking the recommended healthcare service. They may struggle to afford travel expenses or the cost of foods and drinks while travelling to and from the service provider or while waiting for service at the clinic (16,68,69). Reports from patients and survivors indicate this reality and are consistent with the testimonies in previous studies that were conducted in Tanzania, which maintains the worries that the End-TB Strategy's goal may not be attained (70,71). Such reports also justify the argument made by other viewers that "mitigating the socioeconomic impact of TB is key to the WHO End TB Strategy" (72). Based on all the authors' reports, mainly those cited in the current paper from past studies, it is clear that financial assistance is necessary for TB patients or survivors. The authors point to the need for not generalizing or taking it for granted that the primary TB services, once made available at the designated points of care, are entirely accessed free of user charges as the policy recommends (71,73,74). The respective individuals incur some substantial financial/ monetary costs that are not commonly accounted for by the healthcare system or by most analysts because of the hidden nature of such costs (38,75).

In the health arena, the relationship between social support and illness, on the one hand, and with the mortality outcomes, on the other hand, there are widely documented findings from field studies that were conducted in various countries. Such studies have demonstrated that physical health is not only a well-being outcome or indicator of biological effects of disease such as TB. Social and psychological health also matters in the observed performance of the prescribed medicines or recommended health practice (17,26,38). The evidence from similar studies further reveals that material support is not a sufficient motivation enabler or motivator of a person who is facing a given health problem since there are many examples whereby materially wealthy individuals live in states of unhappiness due to illnesses caused by a disease or injury (76).

Strengths and Limitations of the Study

The present study is based on a comprehensive review of the TB-related literature. It aims to expand the existing knowledge by examining the role of psychological and behavioural factors in influencing individuals' decisions and behaviours related to TB care-seeking. Furthermore, it seeks to address the importance of studying these factors in the prevention and treatment of TB and related infectious diseases, which have significant implications for public health, socio-economic factors, and healthcare systems. The study highlights the crucial role of social support for individuals affected by TB, including those currently battling the disease and those who have recovered but still face financial, moral, or attitudinal challenges that impact their overall well- being and life satisfaction (77,78). The significance of social support extends to all aspects of life, emphasizing its importance in ensuring the holistic well-being of individuals affected by TB.

The study's specific objectives and the methodology employed in attempting to achieve them were guided by or were conceived in light of, the "Theoretical Framework of the Stress, Social Support, and Buffering Theory", developed by Cohen and Wills" (30), with hopefully a meaningful and relevant explanation supporting the illustration presented (Figure 1). The additional chapter has been opened since social-behavioral models need more or further exploration for dealing with or addressing at least some if not all of the context-specific challenges, especially at this stage or moment when the Global End TB Strategy needs increased attention towards its ultimate goal attainment. For example, issues relating to social

stigma and discrimination against the patients and even the survivors of pulmonary TB reported disappointing the respective disease victims signify the presence of social or customary norms, traditions, beliefs, and practices or behaviours that negatively affect the quality of life of such people as they contribute to one remaining unhappy because of having the disease, besides the physical pain they have faced throughout the illness period. Additionally, the currently reported study observes all the necessary ethical guidelines and procedures for seeking informed consent (IC) and then for the data collection activities to take place as recommended and endorsed by the appropriate research ethics review bodies in Tanzania and South Africa. The team involved in the process ensured that, seriously, the urgency of treating the study participants with respect and causing no harm to those who consented to take part or to keep it as minimum as possible (61,62) was taken, and this increased the ownership of the study findings reported and the richness or the validity of the evidence gathered and then presented in the current paper.

The respective harm was expected to be caused by the researcher and therefore to be faced by the respondents when such individuals could find themselves being psychologically affected during the interview session because of the nature of the questions or the topics covered. The apology that was made by the interviewer in advance of starting the interview and even at the end of the interview was found to please the respondents whose minds may have been affected when the question posed concerning certain issues relating to some negative recent or long past events that occurred either during or after TB treatment. The cooperation given by the respondents in question in answering the respective questions and by responding to the interview throughout the planned time without any complain, after they were assured of their anonymity and of the confidentiality of any perceived or seemingly sensitive feedback as given by them was a positive indicator of the value given by such people to the study and the trust they had in both the study and the research team. Nevertheless, several limitations were noted. The use of a purposeful sampling strategy partly cannot overshadow the truth about the researcher's bias apart from the bias originating from the study participants' expressed readiness to be interviewed having dictated who could be interviewed. This implies that, possibly, the individuals who were not interviewed since they did not fall into the sample category could, if given a chance, have presented either a largely or a slightly different experience-based views.

Meanwhile, there was a chance that those who were eventually interviewed could not be open for reporting or commenting on everything the interview had covered and instead they remained with certain reservations or decided to keep some facts undisclosed by hesitating that such facts were not to be known by their interviewers. Some of the respondents might have remained with the belief that the interviewer's interest in hearing about the facts that sounded positive either on their side or the policy and program for which the investigation was being conducted (79). Another obvious shortcoming is specific for the present article/ paper that focuses entirely on the qualitative part of the study, with the quantitative one being presented in a separate paper that has been submitted elsewhere. Triangulating these categories of the findings could obviously have increased the strength of the discussions and the concluding remarks about the study, hence making the evidence-based take-home messages targeting policy-makers, programme officers, and a wider audience to feel more informed and comfortable with what has been reported from the study. Therefore, future research works need to ensure the latter shortcoming is either prevented or minimized, particularly for the studies that aim(ed) at employing a mixed-methods design.

Conclusions and Recommendations

The essential nature of having social support along with the medical services for TB delivered through conventional TB clinics is validated by the findings from a current study in Tanzania. This study highlights that where material kind of support such as those involving a demand for monetary resources is difficult to be provided or access, at least moral support could potentially make a difference, particularly to those needing just to note empathy and encouragement from social members around in order to continue living with hope and to reduce their psychological distress experience encounters or incidents. The respective moral support can be offered by, or expected from the frontline HCWs such as those working in the conventional TB clinics and from other community members such as the relatives of the respective support needers' families, peer groups in the society, as well as the public/community in general. However, this is possible or more practicable if all these potential supporting parties are well-sensitized on the negative health implications of stigmatizing and neglecting or isolating the patients and the disease survivors, as discussed above. Meanwhile, a system-wide approach is recommended for dealing with TB-related challenges and overcoming them (38). The policies and interventions that are currently established need to ensure full engagement of all the key stakeholders, amongst whom are the general public members in the national End-TB Strategy. This can be done through

frequent reminders about the need for health checks in an attempt to detect infectious diseases, including pulmonary TB, seeking care in a timely manner whilst simultaneously encouraging TB survivors to adhere to the recommended lifestyles and to avoid exposure to new mycobacterium infections. Researchers need to cooperate with the existing policy and program for TB to carry out investigations aimed at monitoring and evaluating (M&E) the status of post-TB illness-related psychosocial traumas such as stress along with a continued disease surveillance system (38).

Moreover, the extant lessons learned from a number of countries in Africa and beyond indicating how established or introduced programs whereby mechanisms aimed to enable patients and their families to generate a financial income needed to relieve them from burden of the disease are worthy a recognition. Such countries' governments and their allied local and international development partners have, for example, considered a policy framework allowing the establishment of cash transfers in relation to TB control as part of the mechanisms of social support and as mostly advocated to be one of the key poverty reduction strategies. In spite of the so-far observed or recorded success stories from such kind of resource- based support-related cash transfers, the applicability or feasibility the respective transfers have had on one hand and their acceptability in all socio-economic contexts on the other hand are found to need an additional consideration about among other things, more studies or evaluations being undertaken to confirm their potentials or advantages (54,80).

Thus, in the aim to achieve universal health coverage (UHC), many African countries' governments have through their ministries of Health (MoH) imbibed the advocated idea calling for the establishment safety-net mechanisms to cater for the TB patients and survivors including those that can act as supplements to other strategies available for ensuring translation of the available policy and program opportunities to implement activities with the view to reduce the levels of poverty in their communities (81). Tanzanian is one of the latter countries whose governments allow such an approach, with some demonstrated success stories in areas where they have been tried out through implementation science kind of research projects focusing on how to enable the existing TB program reach a wider targeted beneficiaries especially those seriously needing support for them to access the basic TB-related healthcare services while they are challenged by the income-related poverty states

(71,82).

Furthermore, TB patients and even survivors can live with acceptable levels of resilience through coping if they feel fully receiving empathy and encouragement from service providers, home-based caretakers, and other societal members with whom they live. The encouragement given by the service providers contacted in the TB clinic settings, as well as the moral-based support receivable from their home caregivers and from the rest members of the society/community in which they live puts them in a perspective and a mood of feeling respected and valued. This important psychology-connected element has positive implications for patients or survivors to adhere to the prescribed or recommended medical measures (78). At the same time, it increases the respective support demanders' trust in both the healthcare system, TB-related care seeking, and a hope to live longer, aside from the relief they feel from the painful moments they have been going through.

Finally, the current paper argues that, both the existing literature and the findings obtained from the currently reported study shed more light on the cruciality of psychological and material support for TB patients and survivors since apart from such people being required to accept the condition, their adherence to the recommended measures and their continuity with their lives as usual are very important if the End TB Strategy were to be boldly evaluated and concluded as having been successful at ensuring the health and wellbeing of the TB affected populations.

Ethics Considerations

Ethical considerations were strictly adhered throughout the study, and as mentioned above, these include seeking of Informed Consent (IC) from every individual participant approached with all the rights of respondents protection observed—confidentiality, anonymity, non-maleficence, information that the key study findings will be dissemination for policy and public domain usage, provision for anyone deciding not to participate or to withdraw from participating in the study even after initially consenting, non-ill persuasion through, for example, use of persuasive and yet coercive or inducive means such as payment. The consenting individuals were asked to signed a separate IC form (83,84).

Data Availability Statement

The original contributions presented in the study are included in the article/Supplementary Materials; further inquiries can be directed to the corresponding author.

Ethics Statement

The National Health Research Ethics Committee (NatHREC), Tanzania, approved the human studies. The studies were conducted in accordance with local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author Contributions

SK: Conceptualization, Data curation, Formal Analysis, Investigation, Methodology, Project administration, writing original draft, Writing review & editing. GM: Conceptualization, Formal Analysis, Methodology, Supervision, Writing – original draft, Writing – review & editing. AM: Formal Analysis, Methodology, Writing – review & editing. NN: Conceptualization, Funding acquisition, Writing – review & editing. IS: Conceptualization, Funding acquisition, Writing – review & editing. SM: Formal Analysis, Investigation, Writing – review & editing. DE: Conceptualization, Funding acquisition, Methodology, Supervision, Writing – review & editing.

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Conflict of Interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that couldbe construed as a potential conflict of interest.

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CHAPTER 7

INTEGRATED NARRATIVE

This section is organized into four parts. The first part is the introduction, which provides an overview of the research objectives and explains its significance. The second is synthesizing the findings from the three research papers (Chapters 4–6) to offer a broader understanding of the results. The major findings from each chapter are highlighted and interpreted in the context of the overarching research questions. Third, this section discusses the broader implications of these findings for policy and practice and suggests potential directions for future research. Finally, the contribution of this dissertation to the body of knowledge.

7.1. Introduction

The overarching aim of this dissertation was to broaden an understanding of the social and economic impacts of PTB on individual patients, their households, the community (TB survivors), and healthcare workers in the Mbeya and Songwe regions of Tanzania, and to explore the coping strategies adopted by TB patients and survivors in addressing these challenges. Specifically, the research focused on three major components:

- direct and indirect financial costs,
- the social and financial burden of PTB, and
- coping strategies emphasizing the role of social support.

The detailed discussion section for each objective can be found in a specific section. This chapter synthesizes the research findings, demonstrating how the dissertation achieved its objectives and contributed to the overall aim

7.1.1 Overview and Summary of Key Findings

7.1.1.1 Objective one

To describe the impact of direct and indirect financial costs incurred by patients, their households, TB survivors, and healthcare providers before and during PTB treatment

Before the results presented in Chapter 4, there was limited evidence on the direct and indirect costs of TB in Tanzania. Appendix 1 (Table 1) provides evidence showing that only four papers addressed the costs of TB among patients. However, none of these studies consider the pre-treatment costs for TB patients, nor did they incorporate qualitative methods to gain in-depth insights directly from the patients (161,126,201,202). The results presented in Chapter 4 are unique because they describe TB costs, direct and indirect costs, for patients before treatment initiation (Chapter 4). The pre-treatment costs affect TB patients, who often delay seeking the recommended health care. In Chapter 4, there is an increase in the time between the onset of symptoms and the commencement of TB treatment is observed as patients consult multiple HCPs.

Patients typically start by visiting nearby providers. However, if their symptoms persist, they decide to seek care from more distant providers (not necessarily visiting the formal HCFs), hoping for better results. In doing so, both the time lost and expenses for travel and food associated with visiting these providers increase, resulting in catastrophic financial costs for patients and families (201,202). The findings show that direct and indirect costs increase significantly when patients delay seeking proper diagnosis and treatment from a public health facility. A substantial portion of expenses are incurred during pre-treatment, as patients often spend considerable amounts on alternative services such as traditional practitioners as well as self-medication from the drug store (pharmacy). By the time TB patients choose to visit the HCF, many are already experiencing financial strain. The results in Chapter 4 are noted being distinctive in their focus on the costs patients face by visiting several providers before opting to seek services from a public health facility, which provide TB prevention and care services (53). Moreover, the use of qualitative methods in data collection helps to have an in-depth understanding of why patients decide to seek alternative treatment before going to HCF.

The findings of this dissertation provide critical insights for policymakers and healthcare workers by revealing that, despite the free provision of PTB diagnosis (sputum test) and

treatment services provided in Tanzania, most patients delay utilising services. This delay increases the severity of the disease and infection transmission. In order to effectively reduce patient direct and indirect patient costs both before and during TB treatment and to promote early care seeking for TB, it is recommended that the government provide an enabling environment to enhance community awareness through effective health education on TB symptoms and prevention. TB treatment must go hand in hand with strategies to increase the number of HCFs equipped with basic infrastructure, essential medical supplies, and adequate human resources, including those located in remote and underserved areas. Strengthening such facilities can help bridge the persistent gaps in the quality of care, thereby encouraging community to seek the timely services for early diagnosis and, where necessary, access to appropriate treatment.

7.1.1.2 Objective Two

To explore PTB's social and economic consequences as experienced by patients, their households, TB survivors, health care providers, and policy/decision-makers.

Objective 2 aimed to explore the social and economic impacts of PTB through a multi-perspective lens, incorporating the experiences of patients, their households or family representatives, TB survivors, and HCPs. By embracing a comprehensive approach, it captures the varied experiences and challenges of those directly and indirectly affected by the disease (Chapter 5). In Tanzania, only two studies have investigated the socioeconomic impacts of PTB, yet neither extended their assessment to include insights from relatives, TB survivors or healthcare providers, despite the fact that PTB affects not only the patient but also those around them socially and economically.

From the patient's perspective, the study examined the financial burden endured, including direct costs such as treatment and medication expenses and indirect costs such as lost income due to illness or reduced productivity (because of seeking TB health care or hospitalization). The voices of their families further highlight the ripple effects of TB, where entire households are often thrust into economic instability, struggling to cover both healthcare and daily living expenses.

TB survivors offer insights into the long-term social and financial implications of the disease, providing a unique view of life after treatment (Chapter 5). Many continue to face challenges

in regaining employment or dealing with ongoing health issues, emphasizing that the economic toll of TB does not end at treatment completion. This research adds to the body of knowledge by emphasizing the need for post-treatment follow-up to monitor and address the lasting impacts of the disease on TB survivors. A comprehensive approach to TB treatment should include support systems that reduce the long-term social and economic burden on those who have completed treatment, ensuring their full recovery and reintegration into society (30).

Finally, Chapter 5 reveals how the frontline HCPs shared their perspectives on the strain the disease places on the healthcare system and the barriers they encounter in providing care to economically disadvantaged populations. Their input sheds light on the systemic issues that exacerbate the social and economic consequences of TB, from delayed diagnosis to inadequate access to care in remote areas.

By integrating these viewpoints, this research offers a holistic understanding of PTB's social and economic consequences and identifies gaps in current health policies and practices that could mitigate these challenges. The findings provide a foundation for evidence-based interventions to alleviate the economic burden of TB and enhance the overall well-being of affected populations.

7.1.1.3 Objective Three

To explore the coping strategies adopted by patients, their families, TB survivors, and healthcare providers in navigating PTB illness and treatment, with particular emphasis on how social support strengthens these approaches.

The third objective was designed to explore the coping strategies employed by TB patients, their households or family representatives, TB survivors, and healthcare providers in managing the challenges of TB illness and treatment. This aspect of the research aimed to uncover how individuals and families navigate the social and economic hardships associated with the disease. Appendix 1 (Table iii) provides an overview of the existing literature on coping strategies among TB patients in Tanzania. Only two studies from Tanzania offer limited discussion of coping strategies adopted by TB patients. None of the studies considered social support as a coping strategies (Chapter 6).

Initially, the focus was on understanding the strategies TB patients and survivors used to manage challenges during treatment. However, during data analysis, it was evident that social support significantly helped patients cope with the challenges of PTB. Emotional/psychological, financial/ material, companion, and information support from family members helped alleviate the burden of the illness, particularly when patients were unable to work or contribute financially to their household income (124). In many cases, patients relied on their families to cover transportation costs, food, and other essential needs during treatment.

Beyond the family, community-based social support also emerged as a significant strategy for coping (138). Some patients benefited from support networks within their communities, which helped reduce stigma and provided practical assistance, such as accompaniment to healthcare facilities or the provision of basic necessities during the treatment period.

The interviewed HCPs also indicated to recognize the importance of these support systems and, in many cases, encouraged patients to seek and utilize social support available during their treatment journey (Chapter 5). The findings highlight that TB treatment is not only a medical challenge but also a social one, where both formal and informal support systems are essential to ensure successful recovery (120).

This insight expands the body of knowledge by emphasizing the critical role of social support from healthcare providers as well as family members in TB treatment. It suggests that TB care programs should integrate social support mechanisms into treatment plans, ensuring patients have access to the necessary resources and networks to help them cope with the disease.

7.2 Themes Across the Research Chapters

Each chapter (Chapters 4-6) focused on specific objectives to fulfil the overall aim of the dissertation. The findings from these chapters were discussed in detail. In addressing these objectives, several common themes emerged across the chapters. These themes are identified and described in this section.

The findings in the chapters are interpreted through the lens of the Conceptual Framework illustrated in **Figure 2.1**. The framework highlights the SDH and its influence on PTB care-seeking behaviors. The results underscore the influence of financial, social, and economic factors on TB treatment and outcomes. The alignment with the Conceptual Framework highlights the necessity for comprehensive interventions that address both medical and socioeconomic determinants to improve TB outcomes and support the End-TB Strategy 2030 (182). Furthermore, by viewing PTB through this lens, the framework reveals the complex interactions between individual behaviour, social context, and economic realities that shape both the course of the disease and its broader implications (182,140). These are explained through the following themes.

Costs Associated with Pre-Treatment Care-Seeking

The literature review for this chapter shows that the **costs** associated with TB treatment are relatively well-studied in Tanzania, but the expenses incurred during the pre-treatment phase are often overlooked. The research results in Chapter 4 aim to cover the gap by assessing patients' direct and indirect costs before receiving a TB diagnosis. For TB patients, these early financial strains can exacerbate socioeconomic challenges, delay health-care-seeking behavior, and ultimately worsen health outcomes (203).

Although PTB treatment and diagnosis are officially free in Tanzania, many patients still incur catastrophic OOP expenses and delay seeking care. This contradiction reveals a gap between policy and lived reality, as patients often navigate informal or non-standard pathways (such as traditional healers) before accessing formal care. This reflects a disconnect between availability and accessibility, which is now widely recognized in both global and regional TB research. Similar findings have been reported in other LMICs, including India, Ethiopia and South Africa. costs incurred during the pre-treatment phase often exceed those (204). Likewise, a study from Uganda (21) highlighted that many patients first seek care in the private or informal sector due to perceived quality or accessibility, increasing costs and delaying formal diagnosis. In Ethiopia the absence of nearby diagnosis services forces patients to travel long distances, incurring transport and accommodation costs (205)

This study explores how out-of-pocket expenses, contribute to delayed health-seeking behaviour (203). Many patients, especially those from lower socioeconomic backgrounds, may initially seek alternative treatments, such as traditional healers, self-medication, or

private practitioners, due to cost concerns, cultural beliefs or mistrust of public health services. The research also reveals that the economic burden extends beyond the individual patients, impacting families who provide financial and emotional support or care giving, often at the cost of income loss and disrupted livelihoods. By detailing the pre-treatment cost burden, this dissertation makes a case for more patient-cantered and affordable healthcare policies, especially during the early stages of care-seeking. International evidence also supports such an approach. For instance, studies from Nepal and Bangladesh recommend integrating social protection schemes (e.g transport voucher) into TB care to alleviate financial strain and encourage early diagnosis (206,207).

To address this, the Tanzanian government should consider providing rural health facilities with TB diagnostic services, integrating community based interventions, and implementing public private partnerships (PPPs). Global experiences shows that PPPs can reduce costs and improve access. In India, the Public Private Mix model has improved case detection and treatment completion while reducing delays (208). Similar strategies could be adopted to the Tanzanian context.

While the availability of free medication is meant to reduce treatment barriers, the findings revealed that significant financial strain persists, particularly during the pre-treatment phase an outcome that may appear contradictory to national TB program assumptions. Similarly, despite high awareness of TB symptoms in some communities, stigma and cultural beliefs still led to delays in seeking formal care. This issue also widely reported in countries like Pakistan, Cambodia and Nigeria (86,208).

This study is significant for Tanzania as it contributes to the expanding body of evidence on the economic aspects of TB care, with a particular focus on the often-overlooked pre-treatment phase. It is also aligns with global strategies such as the WHO End TB strategy and Africa Union Health Strategy which emphasize the need to address financial hardship, improve early access, and ensure that no TB patient is left behind due to economic reasons.

Social and Economic Consequences of TB

The previous chapters of this dissertation offered a comprehensive discussion on the effect of costs, consequences, and coping strategies during TB. This is explained in accordance with the conceptual framework explained in Chapter Two. The foundation of this framework lies

in the recognition that PTB is not merely a biological disease but is deeply intertwined with social conditions (20). In reviewing the literature, it became evident that PTB is predominantly viewed from a biological perspective, with limited focus on the social aspects in Tanzania.

The availability of free medication was seen as the primary solution to combat the disease. However, both national and global literature reveal that medical intervention alone is insufficient. Studies from India, Peru, South Africa show that TB patients face substantial socioeconomic challenges including job loss, stigma and out-of-pocket expenses, that affect their treatment and recovery (209,210). These studies reinforce the need for a multisectoral approach as also recommended by the WHO's End TB Strategy, which emphasizes the importance of addressing the social determinants of TB beyond purely biological solutions. Furthermore, the chapters (Chapters 4-6) of this dissertation further explain that poverty, delayed care-seeking, social isolation, stigma, and poor social support provision contribute to the increased risk of TB infection (160,187).

These social determinants are cross-cutting and affect various layers of society. For example, financial constraints weaken referral systems, and the unavailability of TB diagnostics often compels patients to delay seeking care. This pattern is not unique to Tanzania, similar findings were reported in Uganda and Ethiopia, where patients often experience diagnosis delays and incur catastrophic costs despite free treatment policies (21,211). Similarly, cultural beliefs and stigma surrounding TB deter individuals from utilizing formal healthcare services, opting instead for traditional healers or self-medication, which exacerbates the disease's transmission and deepens its social and economic impact (176,191). This has also been observed in studies from India and Nepal, where patients often seek care from traditional healers due to mistrust in public health systems or fear of being stigmatized (212,213). These global parallels highlight how social and cultural factors interact with health system barriers to worsen TB outcomes.

The free diagnosis and treatment policy intend to reduce the economic burden on patients. The research revealed that many individuals still face significant financial and logistical barriers during pre-treatment phase. This contradiction illustrates a clear gap between policy intensions and patients' lived realities experiences, especially for those in rural or low income setting. These realities suggest that the health system's capacity to deliver equitable and timely TB care is not aligned with either policy framework or patients' needs. This challenge

have also been documented in other LMICs, where health system constraints and socioeconomic vulnerabilities reduce access to timely and equitable care (207,214)

The social implications of TB are extensive, impacting not only the individual patient but also their families and the broader community. Families often bear the burden of caregiving, with women disproportionately affected by taking on the additional emotional, physical, and financial burden of caring for a sick relative (105,155). This situation was also observed in studies from South Africa and Uganda (215,216). This can lead to social exclusion and the disruption of family dynamics, as caregivers may be forced to reduce their work hours or abandon employment altogether to provide care. Community stigma, shaped by fear of contagion or moral judgement, further marginalizes affected individuals, this is an issue reported consistently in global literature (86) (115).

Social and Financial Barriers related to TB Treatment (For both Patients and Survivors)

The barriers to effective TB care extend beyond medical treatment, with social and financial factors playing a greater role in shaping patients' experiences (217)). This dissertation is designed to uncover the complex social and financial barriers that TB patients and survivors face, providing a comprehensive understanding of the challenges that continue even after treatment completion (73,218). This dissertation addresses gaps in the existing literature by focusing not only on patients currently undergoing treatment but also on TB survivors who may continue to experience socioeconomic hardships (219). In fact, the global literature has only recently begun to recognize the long term burden on TB survivors, including the risk of chronic health complications, ongoing stigma and barriers to re-employment (168, 218)

This study explores how social barriers such as stigma, social isolation and discrimination affect the daily lives of TB patients and survivors. These experiences impact their social relationships, mental health, and economic stability often leading to job loss or long-term unemployment, which exacerbates financial difficulties. Research from countries like India, South Africa and the Philippines supports this, showing that TB stigma and fear of disclosure can lead to social exclusion, marriage breakdowns, and delayed return to work (212). These patterns show that the social impact of TB is not unique to Tanzania but is part of a wider global phenomenon.

The financial strain of TB includes both direct costs (such as diagnostic tests, medication and transport) and indirect costs (e.g lost wages, productivity and caregiving responsibilities). Families are often forced to absorb these costs, placing pressure on household income and stability. Similar challenges are reported across LMICs. For instance, in Nigeria, Uganda and Nepal, TB was shown to push households into deeper poverty due to the hidden costs of accessing care and the long-term economic consequences of the disease (207). Moreover, survivors often suffer from post TB lung diseases, fatigue, or other health problems that hinder their ability to work, thereby extending the financial impact of TB well beyond the end of treatment (220)

To meet the WHO's End TB strategy, which includes eliminating catastrophic costs and reducing stigma, the government must act to reduce the social and financial barriers that hinder recovery and reintegration. These includes expanding social protection programs, providing transportation subsidies, and integrating stigma reduction campaigns into TB control efforts (221). In India and Brazil, for example, cash transfer programs and community support groups have shown promise in improving treatment adherence and reducing financial strain (210,222).

Importantly, TB survivors should be actively involved in community education and advocacy, using their lived experiences to raise awareness and combat stigma (171,223). Several countries, including Vietnam and Kenya, have begun integrating peer led TB survivor networks into national TB strategies to foster community trust and promote health seeking behaviour (224).

Currently, Tanzania government still needs to introduce post-treatment services for TB patients. The dissertation significantly contributes to the literature on TB by highlighting the interconnected social and financial challenges that affect patients and survivors. It would emphasize the importance of a holistic approach to TB care that goes beyond medical treatment to address the social determinants of health. This study **future research** could build on this work by evaluating the effectiveness of different interventions aimed at mitigating social and financial barriers and assessing their impact on patient outcomes.

The Role of Social Support in TB Management

The results reveal that social support is essential in helping individuals cope with the challenges associated with PTB. Dealing with a PTB diagnosis and the subsequent long-term

treatment can be daunting, with significant physical, emotional, and financial demands. Social support includes the provision of assistance from family, friends, community members, and healthcare providers. It also serves as a coping mechanism that helps patients navigate the complexities of the illness and fosters resilience during the recovery process (225). This study is consistent with studies conducted across various regions. In South Africa, Daftary et al 2012 highlighted how emotional and social support was critical in mitigating the psychological toll of TB, particularly where stigma was high (226). Similarly in India a study by Thomas et al 2021 found that family involvement improved adherence to TB treatment and helped patients manage depression and anxiety (227). Globally, the WHO End TB strategy emphasize the importance of integrated patient centred care, which includes providing social support alongside clinical interventions, recognizing its role in improving treatment outcomes and reducing stigma.

The psychological support of family members plays a crucial role in the well-being and recovery of individuals affected by PTB (32). Emotional and practical assistance provided by loved ones can help patients navigate the challenges associated with the illness, improve adherence to treatment, and foster a more positive outlook during the recovery process. This support serves as a buffer against the psychological distress often experienced by TB patients, who may face social stigma, financial difficulties, and physical suffering (169,221). Evidence from Nepal and the Philippines also underscores the importance of family and community support to reduce social exclusion and enhancing patient engagement with formal healthcare system (228).

Family members contribute to psychological support in various ways, including offering emotional comfort, encouragement, and reassurance. The presence of a supportive family network helps alleviate feelings of isolation, fear, and anxiety that are commonly experienced by TB patients. Relatives who express understanding, empathy, and acceptance can significantly enhance a patient's self-esteem and resilience, making it easier for them to cope with the demands of long-term treatment (229). This emotional support is particularly valuable for overcoming the stigma associated with TB, as patients who feel accepted by their families are less likely to internalize negative societal attitudes toward the disease (39). As seen in studies from Ethiopia (205) and Vietnam (230), such contributions can significantly reduce treatment default rates and improve patient morale. When families understand TB and

actively support patients they help reduce internalized stigma, promote self-worth, and improve treatment outcome (229,39).

However, this research found, the availability and quality of social support varies greatly. family already burdened by poverty or misinformation may be unable or unwilling to provide consistent help. In some cases they may even reinforced stigma, as observed in TB research from Kenya and Pakistan where fear of contagious led to patients being isolated within their own household (214). These findings reinforce the need for community education campaign to combat stigma and empower families with accurate information about TB transmission and care (231,232)

Integrating psychological support from family members into TB care programs can enhance treatment outcomes. Healthcare providers can play a role by involving families in counselling sessions, as has been done successful community TB programs in India and Brazil , where such interventions led to better adherence and reduced stigma (233). Training families as caregivers and advocates strengthens the support system around the patient and reduces the psychological and practical burden of care. Also the findings align with global research that recognizes the multi-dimensional role of social support in both treatment and post-treatment recovery. One important insight from this study is that emotional and informational support were just as crucial if not more than financial assistance. This echoes findings from Indonesia and Cambodia, where community-led peer support groups significantly improved post-treatment well-being and helped reintegrate TB survivors into society (234) (Chapter 5).

All in all, TB treatment does not necessarily bring an end to the struggle. Ongoing isolation and stigma often overshadow the anticipated feelings of happiness and social acceptance (chapter 6). Building resilience in the face of these challenges is complex and multifaceted. Recovery from TB is not a straightforward journey back to health; it is often impeded by social neglect, which continues to affect survivors long after they have been declared medically cured (Chapter 5).

Tanzania, progress has been made through community empowerment approaches, where local ownership of TB care activity promote awareness, reduces stigma and improve early care seeking. When properly implemented, community TB care package have been shown to yield

multiple benefits.; improved diagnosis rate, reduced treatment default, and better collaboration between communities and formal healthcare system. These outcomes are also reflected in regional strategies by African Union and WHO AFRO, which call for community driven responses and social protection as key component of TB control .

Participation in TB care activities also helps to demystify the disease, making it easier for communities to rally around prevention and treatment efforts. When a well-implemented package of community TB care activities is in place, the following outcomes are expected: Improved TB awareness, leading to early detection and diagnosis. Strengthened local capacity to support TB patients throughout their treatment journey, reducing treatment default rates. Enhanced collaboration between communities and health care systems, ensuring that patients are seamlessly referred to and supported by the formal health care infrastructure. Reduced TB transmission due to timely diagnosis and treatment, contributing to overall public health goals.

One unexpected finding was the extent to which social support particularly emotional and informational played a role not only during treatment but also in post-treatment recovery. While the initial research design emphasized financial impacts, the emergence of social support as a recurring and significant theme across all participant groups (patients, survivors, healthcare workers, and families) highlighted the need for a more integrative understanding of coping strategies beyond economics.

Interaction Between Social support, stigma and Financial

In this study, social support is conceptualized as both a buffering and mediating factors in the experience of TB patients. Emotional, information and financial support, whether from family members, HCPs and the broader community can significantly reduce the psychological impact of TB related stigma and help alleviate financial hardship (205). Such support and costs often associated with self-medication or consulting traditional healers.

Importantly, financial burden and stigma are mutually reinforcing. High out-of-pocket expenditures can delay care-seeking, prolong illness, and increase the visibility of TB symptoms, thereby intensifying stigma. In turn, stigma can discourage individuals from accessing formal healthcare services, leading to greater reliance on informal or non-biomedical care, and extending the pre-diagnosis phase (205).

The three elements social support, stigma, and cost are interlinked and influence TB management outcomes either positively or negatively (235). Where strong social support exists, stigma tends to be reduced and patients are more likely to seek care early, resulting in lower overall treatment costs and improved health outcomes. Conversely, in the absence of social support, both stigma and financial burden tend to increase, hindering effective TB control (235).

Therefore, a holistic approach that acknowledges and addresses the interplay between these three factors is critical for improving TB management. Specifically, integrating TB education into community outreach can strengthen social support structures and reduce stigma,

Discrepancies Between Policy Intension and Implementation Realities

The data revealed that patients often expect timely and free diagnosis and financial support throughout their care journey (236). However, these expectation are frequently unmet due to health system constraints such as inadequate diagnostic infrastructure on rural areas and limited access to trained personnel. These mismatches contribute to delays, dissatisfaction and in some cases disengagement from formal care pathways. This discussion highlight how these tensions shape patients behaviour and outcome particularly in the context of socioeconomic vulnerability.

Policies such as the provision of free TB treatment and community-based TB care are well intentioned and aligned with international strategies like the End-TB Strategy. However, findings from the field demonstrate that implementation often falls short such as patients continue to incur high out-of-pocket costs during pre-treatment phases, and social support program are unevenly implemented or poorly integrated. These discrepancies need to be explored to highlight how systematic and operational challenges hinder the effective realization of policy goals, and what this implies for both patients and the broader public health agenda.

Additional Considerations

This section offers a brief reflection on key comments that could not be incorporated into the final published version. These include suggestions to further tighten the thematic structure,

use participant quotes more selectively, and draw out the policy implications more explicitly. While direct revisions were not possible post-publication, we acknowledge these points here and consider them important for informing future research and writing.

Additional Comments Chapter V

Thematic Structure

Familiarization of Coding: all the transcripts were uploaded into NVivo 12 software for coding. Three researchers independently read through the transcripts to achieve a comprehensive understanding of the data. They then each conducted initial coding independently, ensuring they became familiar with the data before identifying patterns or themes.

Theme Development: After individual coding, researchers convened to discuss the generated codes, themes and sub-themes. Discussions primarily focused on achieving consensus in areas where overlap in coding occurred or where themes appear ambiguous. through several rounds of discussion, initial themes were refined, redefined and reworked to ensure clarity and consistency.

Achieve Consensus: In instances of disagreement regarding specific codes or themes, further deliberation took place until an agreement was reached. This iterative process helped to eliminate inconsistencies and improve the robustness of the thematic framework.

Coding and Codebook Development: Once consensus was achieved on the final themes and sub themes, all the codes belonging to the same theme were grouped together for more detailed analysis. A comprehensive codebook was developed to document and standardize the coding process. Finally, all 38 transcripts were systematically coded, ensuring consistency and rigor across the dataset.

The policy implications

Although national policy and legal frameworks directive the delivery of free TB services to eligible individuals, our findings reveal a disconnect between policy and practice. In reality, TB patients and their families often incur out of pocket costs both financial and social when seeking treatment through formal health systems. These may include transportation, lost income, and strain on social relationships due to stigma. Managing TB and HIV become even more complex in individuals with co-morbidities such as HIV and diabetes, as these

conditions increase treatment costs and amplify stigma and discrimination. Such barriers contribute to delayed and inconsistence health care-seeking behavior, undermining progress toward the National End-TB strategy target for 2035. Therefore, to make TB services genuinely accessible, policies must go beyond rhetorical commitments. We recommend the following actionable measures: strengthening enforcement of user-fee exemptions at all levels; expanding universal health insurance coverage to include TB care and co-morbid conditions; investing in sustained community-based health education campaigns to address stigma and promote timely care-seeking; and aligning TB control strategies with broader poverty reduction interventions to address the economic vulnerabilities that hinder access to care. These interventions are essential to close the policy-practice gap and move toward equitable, effective TB control.

Additional comment Chapter VI

The distinction between types of support (emotional, informational, material) is useful but could be more analytically developed.

In our study, this theoretical framewo6rk allowed for a more critical analysis of how each type of support functions not in isolation, but interactively to shape patient and survivor experiences:

Emotional support, such as encouragement, empathy, and companionship from family members, was shown to mitigate the psychological burden of stigma and isolation. This aligns with the theory's assertion that emotional connections can soften the stress of chronic illness and promote psychological resilience.

Informational support: guidance on medication, side effects, and care navigation played a crucial role in empowering patients to remain in treatment. As Cohen and Wills suggest, a lack of clarity and support in decision-making can heighten stress and decrease treatment efficacy.

Material support, such as food packages and transport subsidies, directly impacted treatment continuity and adherence. A participant in a rural setting recounted how they had to underscoring how unmet basic needs intensified physical and emotional stress. This reflects

Cohen and Wills' concept that when practical needs go unmet, the cumulative burden can lead to worsening health outcomes.

According to this theory, social support can buffer the adverse effects of illness-related stress on both psychological and physical health outcomes. It also emphasizes the broader impact of chronic illness not only on the individual but also on the family system particularly when treatment demands intersect with developmental or socio-economic challenges. This framework is especially pertinent in the context of tuberculosis (TB), where stigma, poverty, and extended treatment regimens contribute to a complex web of burdens.

CHAPTER 8: CONCLUSION

This chapter, building on the foundational research findings presented in Chapter Seven, explores the implications of these findings and their relevance to policy. It also examines the study's limitations, identifies potential areas for future research, and highlights its unique contributions to the existing body of knowledge.

8.1 Implications of Research

These findings can be used to evaluate and refine existing policies and programs related to TB care, ensuring they are aligned with the real-world challenges faced by TB patients, TB patients' relatives, TB survivors and healthcare providers. The research underscores the financial impact of TB and highlights the urgent need for supportive financial interventions. This can influence funding decisions and resource allocation to ensure that financial constraints do not hinder access to care and treatment.

Overall, this research stresses the need for a holistic approach to TB care that integrates medical treatment with social determinants of health, addresses barriers to care, and enhances the overall effectiveness of TB control strategies.

8.2 Methodological Implications

Using both qualitative and quantitative, strengthens the validity of the findings through triangulation, enabling cross-verification of results from diverse data sources. Each chapter (4-6) utilized either qualitative, quantitative, or both approaches. this work shows that it is possible to explain costs in a sociological context. This approach provides realistic inputs of data from diverse qualitative sources, such as patients, survivors, relatives of TB patients, and healthcare providers, offering a comprehensive understanding of the needs and experiences of all stakeholders involved in TB care.

8.3 Practical Implications

These practical implications can help policymakers, healthcare providers, and community organizations implement more effective strategies to minimize the burden of TB in the country. The results have the following practical implications for fostering the End TB strategy.

***Improving Health-Seeking Behaviour*:** The study emphasizes the significant social, financial, and structural barriers contributing to delayed health-seeking behaviour among TB patients. Interventions can be designed to address these barriers, such as Strengthening Community-Based TB Care Initiatives by using community leaders, traditional practitioners, religious leaders. These can be engaged through formal training workshop to serve as TB ambassadors, helping to educate the public about TB symptoms, prevention and the importance of early diagnosis. Additionally, TB awareness campaigns can be integrated into existing school health programs, where teachers are trained to deliver age-appropriate education and encourage early health seeking in the households. The study also highlights the potential of involving patients' relatives and TB survivors as peer educators providing lived experience testimonies to reduce stigma and motivate others to seek care. This intervention would improve awareness, encourage early diagnosis and reduce TB burden in the underserved communities.

Social Protection for Vulnerable Households

Recognize TB's effect on household income and well-being, especially in low-income settings. Policy frameworks should consider incorporate TB-affected households, especially those identified during diagnosis and treatment, into social protection schemes, such as the Tanzania Social Action Fund (TASAF) project. This can be operationalized by linking health facilities with TASAF to automatically refer eligible TB patients for support. Specific assistance could include monthly food packages, transport vouchers for clinic visits and conditional cash transfers tied to treatment adherence milestones. Such interventions could help reduce the socio-economic burden of TB, improve treatment completion rates and help prevent long term financial hardship for affected families.

Accessible and Affordable Healthcare Services

The study highlights the need to expand expanding healthcare services in rural and underserved areas to overcome geographic and financial barriers to TB care. This involves deploying mobile health clinics to conduct routine TB screening, diagnosis, and follow ups in remote villages on a regular schedule. In addition, expanding the role of community health workers (CHWs) to include active case finding, treatment supervision and home visits for follow-up would bring essential services closer to patients. These CHW could be trained and supported through partnerships between local health facilities and NGOs. To improve affordability, government or donor-supported transport voucher can be offered to TB patients to attend referral hospitals for advanced care. These combined interventions would enhance early detection, reduce default rates and ultimately lower community transmission TB infection in the community.

Enhancing Social Support Programs:

Findings from this study suggest that social support both material, emotional and information is a critical coping strategy for TB patients and significantly influences treatment adherence and recovery. When Tanzania has taken steps toward ending TB, including adopting a multisectoral accountability framework in March 2023, there remains a gap in formal support systems for patients and their families. To address this the government should introduce structured Programs offering targeted financial, emotional, and information support. For example, TB patients could be linked with peer support group led by TB surviors, providing a platform for emotional encouragement and shared experiences. Healthcare facilities should also integrate psychosocial counselling services, delivered by trained staff, into routine TB care especially during the intensive phase of treatment. To institutionalize these interventions, the MoH should update the national guideline (237) to formally include social support as a core component of TB care and provide implementation guidance of health facilities and local governments. These strategies would improve patients outcomes, reduce treatment default rates, and contribute to the success of the End TB strategy.

Informing Policy Changes for Healthcare Access*:*

The study's insights into healthcare Providers' perceptions and experiences of TB patients and their families. They highlighting the need for more patient-centred and accessible healthcare services, especially in rural and LMICs. Policymakers can act on these findings by

introducing targeted reforms, such as training HCPs in culturally sensitive and patient-friendly communication, which can reduce stigma and improve trust between providers and patients. By investing in public health campaigns and outreach programs, governments can empower communities to recognize TB symptoms and seek timely treatment, thereby reducing the burden of TB in the community (155). The campaigns can also be strengthened by incorporating TB specific messaging into existing public health platform, using radio, community gatherings, and schools to increase awareness of TB symptoms and the importance of early treatment. To support these efforts, health budgets should allocate resources specifically for outreach and community mobilization in underserved regions. These measures would enhance early detection, reduce barriers to care, and improve treatment outcomes contributing meaningfully to the achievement of the End TB strategy.

Research and Data-Driven Approaches

The government should invest in continuous research and data collection system to assess the socio-economic factors impacting TB outcomes in Tanzania. The MoH in collaboration with research institutions and NGOs should conduct regular operational research and community-based assessments to identify emerging barriers to care, such as transportation challenges, food insecurity, or stigma. Data should be disaggregated by region, gender and income level to inform localized interventions for high-risk populations. These evidence-based strategies would help to ensure that policies remain responsive to changing community needs, and that TB interventions are both efficient and equitable, ultimately accelerating progress toward the End TB strategy.

8.4. Recommendations

1. To integrate social and economic support interventions into national TB care policies and programs. This includes developing and implementing targeted interventions, such as conditional cash transfers through TASAF, microfinance opportunities (offer small loans), and health insurance schemes, specifically designed for TB patients and their families. These interventions would serve as a safety net for vulnerable populations, enabling them to manage both the direct and indirect costs related to TB treatment. By addressing the social determinants of health, these interventions can reduce catastrophic costs, improve health equity, and promote sustainable, long-term TB management, thereby playing a vital role in achieving the End-TB Strategy targets by 2030. A scooping review by *Todd et al* highlighted

the importance of cash transfers and microfinance opportunities for TB patients. The value of cash transfers varied from as low as 8 USD in India to as high as 20,000 USD in China. This shows the varied approaches and scales of financial support provided to TB-affected individuals across different countries (238).

2. Incorporate mental health assessments and psychological support into the routine care of TB patients. It is essential to train healthcare providers to provide emotional and psychological support to address fears and anxieties that may hinder treatment adherence. A meta-analysis showed that psycho-emotional (PE) (RR 1.37; CI 1.08–1.73), socio-economic (SE) SE support (RR 1.08; CI 1.03–1.13), and combined PE and SE support (RR 1.17; CI 1.12–1.22) were associated with a significant improvement of successful treatment outcomes (239).

3. Develop and expand programs that provide financial assistance to TB patients, particularly for transportation and nutritional support. This could include partnerships with local government and NGOs to create safety nets for those most in need.

Evidence: In China, the study by Dong shows an increase in TB service uptake. After the introduction of reimbursement of expenses by the program, hospital admission rates increased significantly among patients living in extreme poverty, rising from 48.5% to 70.7%, and among those in moderate poverty, increasing from 45.0% to 68.1% The extreme poverty group also experienced the largest rise in outpatient visits (from 4.6 to 5.7 visits). Patient adherence to medication increased by 15% in the extreme poverty group and by 10% in the moderate poverty group. Overall satisfaction rates were high across all groups. Qualitative feedback from stakeholders indicated that higher reimbursement rates, simplified reimbursement procedures, and allowances played a key role in enhancing patients' utilization of services (240)

4. Implement targeted health education campaigns to increase awareness of TB symptoms, emphasize the importance of early treatment, and highlight the risks associated with self-medication These campaigns should be culturally sensitive and tailored to the needs of different communities, particularly rural areas. These campaigns should focus on educating the public about TB transmission, treatment, and the importance of supporting affected individuals, thereby encouraging patients to disclose their condition and seek timely care.

8.5 Study Limitations

This dissertation faced a number of limitations, many of which are typical for cross-sectional studies. Below, are the key limitations shared across the various papers and their potential implications. Specific limitations for each research paper are discussed in detail within their respective chapters.

Study Design

This study was nested within the larger TB Sequel project, which significantly influenced the choice of sites, age categories, and focus on pulmonary TB (PTB). While this design offers advantages, such as access to a well-established cohort, comprehensive data, and standardized protocols, it also presents limitations that restrict flexibility in adjusting the study's focus to include other forms of TB or broader age groups, which may limit the generalizability of the findings to other TB populations.

Study Area

The data were collected in Mbeya and Songwe regions, chosen for their high rates of TB and HIV infections. However, other regions in Tanzania may differ significantly in terms of socioeconomic conditions, healthcare infrastructure, cultural norms, and geographic accessibility. These variations could affect TB prevalence, care-seeking behaviours, and treatment outcomes in ways not captured by this study. Therefore, the findings may not fully capture the experiences or needs of TB patients in other regions of the country, thereby limiting the applicability of the results to different local contexts.

Sampling bias

This study excluded individuals with extra-pulmonary TB or drug-resistant TB. These subgroups are widely recognized to experience heightened levels of stigma, financial challenges, social difficulties, and psychological distress. Their exclusion introduces a sampling bias that may result in an underestimation of the broader challenges faced by TB population. consequently, the findings may disproportionately reflect the experiences of individuals with pulmonary, drug resistance TB thereby limiting the study's comprehensiveness. This bias may reduce the applicability of the findings to more complex

TB cases, which often necessitate distinct and more intensive interventions. This subgroups, the study may overlook the unique and more severe burdens faced by these patients, thereby limiting the generalizability of the findings. As a result, the study's recommendations may not fully address the needs of those with more complex TB cases, who often require more intensive and tailored support strategies.

The study focused on individuals who have accessed medical care, received a TB diagnosis, and either initiated or completed TB treatment. As a result, it does not account for those who have not sought medical care, did not start treatment, or experienced delays in accessing care. These individuals might face worse financial and social consequences due to delays in seeking treatment, progression of the disease, and associated costs. Consequently, the study may not fully capture the broader spectrum of TB-related challenges and the true extent of the impact on those who are not accessing care.

TB Stigma

The link between TB and HIV, along with the stigma surrounding these illnesses, may cause some individuals to hesitate or refuse participation in this study. To minimize the non-response rate, efforts will be made during the informed consent-seeking process to give an explanation that will encourage the individuals concerned to participate confidently as long as they are assured of the confidential treatment of their information on sensitive matters and the anonymity of their names during and after the data collection processes.

Desirability Bias

There is a possibility of potential social desirability bias, as participants may have provided responses that they perceived as more acceptable or favourable rather than reflecting their true experiences or beliefs. This bias could affect the reliability of self-reported data, particularly concerning sensitive issues like stigma, financial challenges, and adherence to TB treatment. As a result, the findings may overestimate positive behaviours or underreport challenges, potentially affecting the accuracy of the study’s conclusions and the effectiveness of future interventions.

COVID-19 Disruptions

Data collection took place during the COVID-19 pandemic, which disrupted both the research process and routine TB services. In particular the qualitative component of the study faced delay due to lockdown and restricted access to health facilities. Many TB patients were unable to attend scheduled clinic visits, and by the time service resumed a number of TB survivors had been lost to follow-up. To mitigate this the study team carried out community based to follow-up visits to trace these individuals. However, the pandemic also strained healthcare systems, which likely to affected the quality and completeness of health record due to staffing challenges and shifts in healthcare priorities. These disruptions may have introduced gaps and inconsistencies in data which has been acknowledged as limitations in the study. Furthermore, the pandemic may have influenced participants responses, particularly with regard to access to care and psychosocial stressors, potentially skewing some findings.

Limitations in Policy-Level Data

The data collected from policymakers was not included in the results section of this dissertation. Because the responses tended to be high-level, lacking detailed actionable insights into specific community-level challenges and limiting the depth of analysis. Consequently, most of this data was instead utilized to inform practical implications and recommendations. This limitation stemmed from a lack of detailed understanding of grassroots-level issues, which affected the precision of the information provided.

Limited Generalizability

The study's findings are rooted in a specific regional and health system context. Cultural norms, healthcare infrastructure, and socioeconomic factors unique to this setting may limit the generalizability of results to other areas or populations. While efforts were made to capture diverse perspective, the extent to which these findings can be extrapolated to different geographic or demographic context is limited. This constrain highlights the need for further research in varied settings to validate and extend findings.

8.6. Study Strengths

- Using qualitative and quantitative approaches provides a more holistic view of the research problem. Using multiple methods can enhance the reliability of the study. Quantitative data

offer statistical insights and generalizability, while qualitative data provide depth and context, revealing the underlying reasons and motivations behind observed patterns. The study captures nuanced experiences and perceptions that might be missed in quantitative research through detailed qualitative data, including personal testimonies and narratives. This approach provides depth to understanding the emotional and psychological dimensions of TB care

- Healthcare providers' involvement offers valuable insights into the practical challenges and barriers they face in delivering care and the factors that facilitate effective treatment and support. This can help identify gaps in service delivery and areas for improvement. Understanding the perspectives of those directly involved in patient care helps in formulating more practical and effective policy recommendations, ensuring that proposed changes are feasible and address real-world challenges.

- Comprehensive Data Collection using diverse sources: The study includes data from various sources, including TB patients, survivors, healthcare providers (HCWs), and TB patient's relatives. This diversity provides a well-rounded view of the support needs and experiences of all stakeholders involved in TB care.

- Focus on Psychosocial Factors Holistic Approach: The study goes beyond biomedical factors to explore TB care's psychological and emotional aspects. This focus is crucial for a comprehensive understanding of patient needs and outcomes, highlighting the importance of addressing mental health in chronic disease management.

8.7 Policy Implication of the Study Findings

- **Improved Healthcare Accessibility**: The data shows that patients often visit multiple healthcare providers before reaching formal health facilities, leading to increased travel and treatment delays. Policies should focus on expanding TB services in rural and underserved areas to reduce reliance on distant healthcare facilities. Improving local healthcare capacity would reduce the time and costs involved in accessing TB care, especially for vulnerable populations.

- **Early Diagnosis and Awareness Campaigns**: The high percentage (72.8%) of patients who delayed more than four weeks between symptom onset and TB treatment indicates a need for better public awareness about TB symptoms. Health education campaigns should emphasize the importance of early diagnosis and how to access appropriate care to reduce delays caused by poor knowledge about TB symptoms.

- **Financial Support for Patients:** The study reveals that direct medical, non-medical, and indirect costs rise with the number of healthcare providers contacted. The average pre-treatment cost of USD 28.80 can be a significant burden, especially for low-income patients. Policies that subsidize or eliminate pre-diagnosis costs, including transportation and diagnostic services providing more comprehensive care locally, and reducing the need for travel to distant facilities. This could alleviate financial barriers, ensuring timely access to TB treatment.

- **Reducing TB Treatment Duration**: Patients expressed concerns about the prolonged duration of TB treatment and the associated costs of frequent clinic visits. Policies should consider exploring and implementing shorter, evidence-based TB treatment regimens where feasible, to reduce the financial and logistical burden on patients while ensuring treatment efficacy.

8.8 Future Research Directions

This study provides valuable insights into social economic consequences of PTB among TB patients, TB survivors, and relatives, there remain areas that needs further exploration, such as; Investigate long-term social, psychological, and economic impacts on individuals who have completed TB treatment. This research will uncover challenges survivors face in reintegration and inform targeted support strategies. Another area is on Evaluating the effectiveness of ongoing support programs designed to assist TB patients. This includes assessing how these programs impact quality of life and their role in preventing reinfection.

Focus on Specific Vulnerable Groups: The evidence shows that tuberculosis disproportionately affects vulnerable populations compared to the general population (68). This emphasizes the need to improve the integration of these groups through focused efforts in identification, targeted screening, preventive measures, and comprehensive treatment

support. Future studies could target vulnerable populations, such as low-income families, women, or marginalized communities, to better understand the unique barriers they face in accessing healthcare for TB services.

8.9. Conclusion

In conclusion, TB presents a profound health challenge that extends beyond medical concerns, imposing significant financial and social burdens on patients, their families, and the wider community. The associated costs of TB, both pre- and post-diagnosis, contribute to delays in seeking treatment, which can severely undermine the healthcare system's efforts to control the disease. Although free diagnostic and treatment services are available, barriers such as pre-diagnosis costs, limited awareness, and social stigma continue to hinder timely access to care and adherence to treatment regimens.

To effectively combat these challenges, enhancing social support systems encompassing financial and emotional assistance for TB patients, their families, and survivors is crucial. Integrating poverty reduction initiatives into TB care programs can alleviate the economic burden of the disease and support patients throughout their recovery journey. Furthermore, improving community education about TB, ensuring access to affordable healthcare, and enforcing user fee exemptions are vital steps toward increasing early diagnosis and treatment adherence.

Ultimately, a holistic approach that addresses the social, economic, and psychological dimensions of TB care is essential for achieving improved health outcomes. By prioritizing these areas, we can make significant progress toward the goal of eliminating tuberculosis in Tanzania, fostering healthier communities and a stronger healthcare system for all.

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Appendices

Appendix i: Review Summary Tables

Table 1: Direct & Indirect Costs Literature Review Summary for Tanzania studies

Authors	Title	Year published	Data collection time	Location	Gap
Kaspar Wyss, Peter Kilima, Nicolaus Lorenz	**Costs of tuberculosis for households and health care providers in Dar es Salaam, Tanzania. Tropical Medicine & International Health, 6: 60-68.** https://doi.org/10.1046/j.1365-3156.2001.00677.x	2001	1996	Dar es Salaam (Urban)	Use only quantitative, No- pretreatment cost assessed
Wandwalo, E., Robberstad, B. & Morkve, O.	**Cost and cost-effectiveness of community based and health facility based directly observed treatment of tuberculosis in Dar es Salaam, Tanzania.** ***Cost Eff Resour Alloc*** **3, 6 (2005). https://doi.org/10.1186/1478-7547-3-6**	20005	2002	Urban	The study does not explore the direct and indirect in rural area. Also does not consider pre-treatment costs for patients
Kilale AM, Pantoja A, Jani B, Range N, Ngowi BJ, Makasi C, Majaha M, Manga CD, Haule S, Wilfred A, Hilary P, Mahamba V, Nkiligi E, Muhandiki W, Matechi E, Mutayoba B, Nishkiori N, Ershova J.	Economic burden of tuberculosis in Tanzania: a national survey of costs faced by tuberculosis-affected households. BMC Public Health. 2022 Mar 29;22(1):600. doi: 10.1186/s12889-022-12987-3. PMID: 35351063; PMCID:	2022	2019	Urban & Rural	catastrophic costs were identified, but the study does not explore how these financial burdens affect patients' adherence.

	PMC8961947.				-The total costs for pre-treatment was not assessed
Grace Mhalu, Jerry Hella, Francis Mhimbira, Khadija Said, Thomas Mosabi, Yeromin P Mlacha, Christian Schindler, Sébastien Gagneux, Klaus Reither, Kees de Hoogh, Mitchell G Weiss,Elisabeth Zemp,Lukas Fenne	Pathways and associated costs of care in patients with confirmed and presumptive tuberculosis in Tanzania: A cross-sectional study Grace	2019	2016/ Jan 2017	Urban & Rural	Methodology: Lack qualitative component Respondents: TB patients and presumptive

Table 2: Literature review summary on social and economic **consequences** of PTB from the viewpoints of the patients, their households/family representatives, TB survivors, and healthcare providers

Authors	**Title**	**Year published**	**Data collection time**	**Location**	**Gap**
Elizabeth F Msoka, Fred Orina, Erica Samson Sanga, Barbara Miheso, Simeon Mwanyonga, Helen Meme, Kiula Kiula, Alphonce Liyoyo, Ivan Mwebaza, Augustus Aturinde, Moses Joloba, Blandina Mmbaga, Evans Amukoye, Nyanda Elias Ntinginya, Stephen H Gillespie, Wilber Sabiiti	Qualitative assessment of the impact of socioeconomic and cultural barriers on uptake and utilisation of tuberculosis diagnostic and treatment tools in East Africa: a cross-sectional study	2021	2017	East Africa (Urban & Rural)	Did not consider patients' relatives and TB survivors. No clear explanation of how these barriers specifically affect treatment adherence
Kilale AM, Pantoja A, Jani B, Range N, Ngowi BJ, Makasi C, Majaha M, Manga CD, Haule S, Wilfred A, Hilary P, Mahamba V, Nkiligi E, Muhandiki W, Matechi E, Mutayoba B, Nishkiori N, Ershova J.	Economic burden of tuberculosis in Tanzania: a national survey of costs faced by tuberculosis-affected households. BMC Public Health. 2022 Mar 29;22(1):600. doi: 10.1186/s12889-022-12987-3. PMID: 35351063; PMCID: PMC8961947.	2022	2019	Urban & Rural	catastrophic costs are identified, but the study does not explore how these financial burdens affect patients. -Did not consider patients' relatives and TB survivors.

Table 3: Literature review summary on coping strategies employed to **cope** with TB illness and treatment

Authors	**Title**	**Year published**	**Data collection time**	**Location**	**Gap**
Elizabeth F Msoka, Fred Orina, Erica Samson Sanga, Barbara Miheso, Simeon Mwanyonga, Helen Meme, Kiula Kiula, Alphonce Liyoyo, Ivan Mwebaza, Augustus Aturinde, Moses Joloba, Blandina Mmbaga, Evans Amukoye, Nyanda Elias Ntinginya, Stephen H Gillespie, Wilber Sabiiti	Qualitative assessment of the impact of socioeconomic and cultural barriers on uptake and utilisation of tuberculosis diagnostic and treatment tools in East Africa: a cross- sectional study	2021	2017	East Africa (Urban & Rural)	Did not consider patients' relatives and TB survivors. Not considering the social support as one of the coping strategies
en Petrosde de Guex, Domitila Augustino, Paulo Mejan, Rehema Gadiye,, Cornel Massong, Saning'o Lukumay	Blocks and resilience: A qualitative study of the impact of pediatric tuberculosis on Tanzanian households and solutions from caregivers	2023	2020	Semi-urban	Respondents were children and the caregivers. Dealing with socioemotional impact only not other types of social support

Appendix ii: Policy Brief

POLICY BRIEF

Title: Increase TB Treatment utilization by minimizing the direct and indirect costs

Key Messages

In 2021, Tanzania faced significant tuberculosis (TB) burden, reporting 84,791 cases, with an infection rate of 222 per 100,000 people and a mortality rate of 47 per 100,000 (NTLP 2021).

Completing TB treatment requires a lengthy process of six months, involving numerous visits. The direct and indirect costs incurred by patients can hinder their access to care and adherence to treatment, particularly for those residing far from healthcare facilities..

Most TB patients encounter social and financial challenges while seeking treatment. The severity of TB often prevents patients from engaging in productive economic activities. Consequently, they struggle to cover expenses related to transport, food, and other necessities. The high costs of both direct and indirect treatment may lead to poor adherence, increasing the likelihood of treatment failure, drug resistance, and mortality.

Executive Summary

Tuberculosis (TB) remains one of the leading causes of mortality in Tanzania and worldwide, with over ninety percent of cases and deaths occurring in low- and middle-income countries (LMICs) annually. To combat this public health challenge, the Tanzanian government provides free TB treatment, aiming to ensure that all diagnosed individuals receive necessary care. However, TB patients often face significant direct and indirect costs associated with seeking treatment, which can be financially devastating for those living in poverty.

These financial burdens create barriers to adherence, ultimately leading to poor health outcomes and an increased risk of TB transmission within communities. This policy brief outlines strategic policy options designed to enhance TB service delivery by minimizing both direct and indirect costs for patients, thereby improving treatment uptake and contributing to more effective TB control efforts in Tanzania.

Background

The World Health Organization (WHO) has established the End TB Strategy, aiming to eliminate tuberculosis (TB) globally by 2035 (WHO, 2014). This strategy seeks to reduce the number of individuals suffering from TB by 90%, decrease TB-related deaths by 95%, and shield families from catastrophic costs associated with the disease (WHO, 2014). Despite these objectives, research indicates that TB patients often face significant costs when accessing healthcare services (Chandra, 2020). The disease disproportionately impacts households with low socioeconomic status, placing a considerable financial burden on them. Evidence from studies highlights a clear link between TB and poverty, which can lead to delayed care-seeking, increased loss to follow-up, and poorer treatment outcomes (Bates et al., 2004; Ukwaja et al., 2012; Munseri et al., 2019). Although the Tanzanian government provides free TB medication, patients still encounter financial challenges. Due to their illness, many interviewed patients reported being unable to engage in economic activities and relying on support from family, friends, and their communities.

In addition to the medical expenses related to pre-diagnosis, such as registration, consultations, and laboratory tests, TB patients also incur costs for public or private transportation to and from healthcare facilities. Additional expenses include food, drinking water, or other beverages consumed while traveling or waiting for services at the point of care. These costs can become prohibitively high, making it difficult for individuals or families to afford necessary care.

Consequently, some patients may delay seeking formal healthcare, leading to more severe or complicated health conditions that negatively impact their social and economic well-being. This includes lost days or hours that could have been spent engaging in productive activities essential for their livelihoods (Mhalu, 2019; Nidoi et al., 2021). Moreover, many TB patients express dissatisfaction with the requirement to remain under care for six months after starting treatment. Their primary concern revolves around the frequent hospital visits, which come with financial implications. During the intensive treatment phase (the first three months), patients must collect their medication weekly, resulting in a high frequency of visits. In the subsequent continuous phase (months four to six), medication is collected biweekly, leading to significant transportation costs, particularly as many patients have lost their source of income since their diagnosis (Ukwaja et al., 2012).

Studies conducted in Ethiopia have shown that patient non-adherence is more prevalent during the continuous phase (months four to six). In this stage, patients often experience relief and can return to economic activities (Gashu et al., 2019; Adane et al., 2013). Findings indicate that patients in the continuous phase are seven times more likely to be non-adherent than those in the intensive phase. Similar trends have been observed in Brazil, Uganda, and Southern Ethiopia.

Policy Options

To enhance TB treatment outcomes and patient support, the following policy options are recommended:

Inclusion of Registered TB Patients in the Tanzania Social Action Funds (TASAF): Providing TB patients with TASAF support for one year would offer essential financial assistance, helping to alleviate the economic burdens that often hinder treatment adherence and completion.

Utilizing Village Health Workers and Treatment Supporters in Underserved Areas: In regions lacking accessible TB treatment facilities, the Ministry of Health should consider empowering village health workers or treatment supporters to supervise TB patients. Additionally, reducing the frequency of hospital visits by increasing the number of pills dispensed, especially during the continuous treatment phase (months 4–6), would improve adherence, reduce loss to follow-up, and help prevent the development of multidrug-resistant TB (MDR-TB).

- **Implementation Considerations**

Financial Support through Tanzania Social Action Funds (TASAF): TB patients often struggle to meet basic needs and transportation costs for facility visits. The Ministry of Health (MoH) and other TB stakeholders should support financially vulnerable patients by enrolling them in TASAF for at least one year. This assistance would alleviate financial burdens on patients

and their families, improving their ability to adhere to treatment.

Reducing Treatment Visit Frequency in the Continuous Phase: The MoH and TB stakeholders should decrease the number of required facility visits, particularly during the continuous treatment phase (months 4–6). Utilizing Village Health Workers or treatment supporters to monitor adherence locally would reduce the burden on patients, increase adherence, and help prevent multi-drug-resistant TB (MDR-TB).

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Appendix iii: Presentations arising from this study

i. Title: **Financial and Social consequences of TB: What lessons learned from a qualitative study in Mbeya and Songwe regions by** *Kilima, S; Mubyazi,G; Moola, A; Elias, N; Issa, S; Mwanyonga, S; Evans, D*

Conference name: Tanzania Health Summit

Conference date: 11-13 October 2021

Type of presentation: Poster

Place: Dodoma Tanzania

ii. Title: "**I am not working even all my dreams are gone": Qualitative study to explore views regarding socioeconomic consequences associated with TB among TB patients, survivors and their families living in rural Tanzania by** *Kilima, S; Mubyazi,G; Moola, A; Elias, N; Issa, S; Mwanyonga, S; Evans, D*

Conference name: TB Union

Conference date: 9-11 November, 2022

Type of presentation: Poster

Place: online meeting

iii. Title: **Socio-economic impact of TB on patients, their relatives, and those with former TB. Results from a qualitative research study conducted in Mbeya and Songwe regions.**

Date of the Conference: 15-17 March 2023

Conference name: National TB and Leprosy Program (NTLP) research committee and TB Stakeholders

Type of presentation: oral

Place: Dar es Salaam

iv. Title: **Examining the availability and impact of social support during and after TB treatment in the Mbeya and Songwe Regions of Tanzania**

Conference name: Annual Joint Scientific Conference (AJSC)

Date of the Conference: 14-16 May 2024

Type of presentation: oral

Place: Dar es Salaam

Tanzania Health Summit

Appendix iv: In-Depth Interview Guide for Patients with Pulmonary TB

Targeted: ***Patients with PTB***

Study Title: Social and Economic Consequences of Pulmonary Tuberculosis – Perspectives of Patients, their Families, the community and Health Care Providers in Mbeya and Songwe Regions in Tanzania

Basic Preliminary Information of the Interviewee

(a) Date (dd/mm/yyyy)……

(b) Name of interviewer ……

(c) Place of interview:…….

(d)Region.....

(e) District.....

(f) Locality within the district……..

Time of starting interview**……..**

Section A: Personal Particulars

1. Sex: 1. Male 2. Female

1. Age (years) ……

2. Highest level of education of the respondent? ……

3. Marital Status:……..

4. Occupation …….

Section B: The Questions/Study Themes

1. Can you explain to me the whole process on how you came to be diagnosed and found with TB?

Probe for:

● What actions did you take when you started experiencing TB symptoms (the health-seeking practices in chronological order)?

- Whether he or she was referred or just decided to visit the doctor?

● What drove/influenced her/him to seek professional care at a formal health care facility (HCF)?

●What steps were you passed through until you're the actual diagnosis was made and how does one feel about those steps? 2. Can you explain the experiences you have had by living with PTB if you compare the quality of your life before you experienced TB symptoms and after you were diagnosed with PTB?

Probe for :

●

What did you feel the time you were told you have TB and why

● Nature of suffering in terms of pain and frequency of illness episode,

●Frequency of seeking care and treatment services at formal HCFs

●Availability of the care and treatment services at the time of urgent need

●How does the respondent feel now as compared to the situation one year ago – Is there any appreciable improvement or is the condition worsening?

3. What can you say about the TB service availability in this area, coverage, quality and affordability?

Theme-1: DIRECT AND INDIRECT FINANCIAL COSTS INCURRED

4. How does the disease affect your financial status?

5. Since you have been diagnosed with TB what effects have it had on your family?

6. When it comes to the issue of cost of living with PTB, what would you say if asked to give your experiences on the following (***mention them, one after another***).

(a) **Direct costs** such as out-of-pocket expenses incurred for health care seeking, diagnosis and treatment for PTB?

Probe for:

●registration fee at the HCF

● PTB Diagnosis

●Medical/Clinical consultation at the HCF

●Admission (bed) as an inpatient (if any)

Does anyone accompany you to take medication? Why? Who pays for transport, food or accommodation for this person?

(b). **Indirect monetary/financial costs** associated with PTB sufferings?

Probe for:

● transport/travel costs such as fare for public or private transport

●Foods (e.g. lunch or breakfast), bites, and soft drinks (water, etc).

●Accommodation (*for those who travel from far and take a rented room*)

●Amount of income earnings not gained during the illness/sickness period as compared with the situation you experienced before?

(b) Indirect economic (non-financial) costs?

Probe for:

●Loss of working time while ill due PTB? [Productivity time and costs]

-How many hours lost each day while facing illness/seeking care from a service provider?

-What is the estimated number of days of work lost per month?

-Has the disease contributed to change the type or schedule of your occupation? (Please, explain why and how, if yes)

Theme-2: SOCIAL AND ECONOMIC CONSEQUENCES OF PTB

7. Let me have your experiences on the consequences which your suffering from PTB has had to **you personally**, **the people who take care of** (or support) you at household/family level, and **the rest of the community** around (if any)?

Probe for:

●*social consequences* e.g. stigma, discrimination, social isolation,

-From a family member or spouse?

-From community members e.g. in school/college, market place, worship area, public transport, sports fields, HCFs, staff in office?

● *economic consequences:*

budget constraints on basic needs such as food, school fees, medical services other than TB

-Did you ever miss your TB appointment? If yes, what are the reasons (Probe: is it cost and affordability)?

-Refuse other treatment/procedures/lab tests or stop treatment because of the costs/affordability?

-limited chances for employment (job loss), time loss for engaging in income generating and food production activities, socialization, recreation, etc.

-Assets lost during treatment

8. How do people in the community respond when they see a person with TB

Probe for:

●Your relationship with others if at all?

●What did your family perceive the first time you informed them of having TB?

9. Do you find presence of any social support network for people living with PTB like you, and if yes, which ones and how strong are they?

Probe for:

●If there are no networks at all, what impact this seems to have on the burden of PTB on patients?

●If the networks exist, and are strong or weak, what opinion can be made as a suggestion to the TB Program authorities concerned for betterment?

Theme – 3: COPING MECHANISMS ADOPTED DUE TO PTB DISEASE COSTS AND CONSEQUENCES

●Have you received any kind of support during your TB illnesses, if any, from the following sources: (a) service providers (b) family (c) community?

10. What kind of support you have you received during your illness (if any) from (a) services (b) family (c) community– e.g. emotional, information, financial, other economic materials, other?

●What kind of support do you need as a TB patient? [emotional, information, financial and material]

11. Tell me about your treatment experiences in terms of enablers/facilitating factors and/or challenges if any?

12. Given the social, financial, and economic costs and consequences you have discussed, how have you been coping with PTB?

Probe for:

-Social support availability and its impact on their current situation

-Borrowed cash from other parties or a bank or an employer to meet the care and treatment costs?

-Requested for a waiver or exemption from user fee payment?

-Sought help/assistance from a relative, a community member, a religious institution?

-Sold a personal or family asset to raise money for care and treatment?

-Changed type of business/employment occupation?

13. Could you share which types of coping strategies you find most effective? Probe for its accessibility and availability**14.** Please, feel free to ask if you may have anything you would like to share about your life with or without TB or my clarification?

Thanks for your time and kindness. I'm pleased of your active participation and do promise to generate a useful report and feedback from this work.

Appendix v: In-Depth Interview Guide for Relatives

To be asked of: *Family members of TB patients (Relatives).*

<u>Study Title</u>: Social and Economic Consequences of Pulmonary Tuberculosis – Perspectives of Patients, their Families, the community and Health Care Providers, in Mbeya and Songwe Regions in Tanzania

Basic Preliminary Information of the Interviewee/Respondent to be Recorded

(a) Date (dd/mm/yyyy)……

(b) Name of interviewer ……

© Place of interview:

(d)Region.....

(e) District.....

(f) Locality within the district……..

(g) Time of starting interview……..

Section A: Personal Particulars

1. Sex: 1. Male 2. Female
2. Age (years)……
3. Education of the respondent? ……
4. Marital Status:……..
5. Occupation ……
6. Relationship to the patient .....

Section B: The Questions/Study Themes

1. How did you find out that your family member had PTB?

2. The reaction after realizing the relative had PTB?

Probe for

●Can you tell me about [Patient name] before s/he become ill/ diagnosed with TB and afters/he became ill with TB

Probe for

●Patients frequency of seeking care at HCFs?

3. What are the costs to the households of having someone sick with TB?

(a) **Direct costs** such as out-of-pocket expenses incurred by relatives for patients health care seeking, diagnosis and treatment for PTB?

Probe for:

● registration at the HCF

● Diagnosis

●Medical/Clinical Consultation at the HCF

●Admission (bed) as an inpatient (if any)

● Referral to other TB diagnosis/treatment centres (if any)

Ever accompany patient to take medication? Why? Who pays for transport, food or accommodation?

(b). **Indirect monetary/financial costs** associated with PTB?

Probe for:

● transport/travel costs such as fare for public or private transport

●Foods (e.g. lunch or breakfast), bites, and soft drinks (water, etc).

●Accomodation (*for those who travel from far and take a rented room*)

●Amount of income earnings not gained during the time to take care for the patients as compared with the situation you experienced before?

(b) Indirect **economic (non-financial) costs**?

Probe for:

●Loss of working time whiletaking care for PTB?patients [*Productivity time and costs*]

-How many hours lost each day while facing illness/seeking care from a service provider?

-What is the estimated number of days of work lost per month?

-Has the disease contributed to change the type or schedule of your occupation? (*Please, explain why and how, if yes*)

Do you know if the patient ever missed or misses his/her TB appointment visits? If yes, what could be the reasons for these missed appointments? (Probe: is it related to cost and affordability)?

Theme-2: SOCIAL AND ECONOMIC CONSEQUENCES OF PTB

4. Let me have your experiences on the consequences which of PTB has had to **your family a**nd **the rest of the community** around (if any)?

Probe for:

●*social consequences* e.g. stigma, discrimination, social isolation, family ties..

-From a family member or spouse?

-From community members e.g. in school/college, market place, worship area, public transport, sports fields, HCFs, staff in office?

●*financial consequences*, e.g., budget constraints, deferred expenditures on basic needs such as food, school fees, medical services other than TB, forfeiture payment on borrowed money for medical care and treatment, etc.

● time loss for engaging in income generating and food production activities, socialization, recreation, etc.

5. What has the response been by other people in your community or other family when they hear about your relative with TB

6. Do you find any social support networks for people with PTB, and if yes, which ones and how strong are they?

Probe for:

●If there are no networks at all, what impact this seems to have on the burden of PTB on patients?

●If the networks exist, and are strong or weak, what opinion can be made as a suggestion to the TB Program authorities concerned for betterment?

Theme – 3: COPING MECHANISMS ADOPTED DUE TO PTB DISEASE COSTS AND CONSEQUENCES

7. Have you received any kind of support during your relative TB illnesses, if any, from the following sources: (a) service providers, (b) family, (c) community?

●What kind of support have you ever received for having PTB patients (if any) – e.g., emotional, information, financial, or other economic materials, other?

●What kind of support do patients need? [emotional, information, financial and material]

8. How have you been coping with PTB, given the social, financial, and economic costs and consequences you have discussed?

Probe for:

-Social support availability and its impact on their current situation

-Borrowed cash from other parties or a bank or an employer for meeting the care and treatment costs?

-Requested for a waiver or exemption from user fee payment?

-Sought help/assistance from a relative, a community member, a religious institution?

Sold a personal or family asset to raise money for care and treatment?

-Changed type of business/employment occupation?

9. Anything you would like to share about your experiences related to living with people who have TB?

10. **Thanks for your time and kindness. I'm pleased of your active participation and do promise to generate a useful report and feedback from this work.**

Appendix vi: In-Depth Interview Guide for TB survivors

To be asked: ***To people who have ever diagnosed and treated PTB 24 months ago***

<u>Study Title</u>: Social and Economic Consequences of Pulmonary Tuberculosis – Perspectives of Patients, their Families, the community and Health Care Providers in Mbeya and Songwe Regions in Tanzania

Basic Preliminary Information of the Interviewee/Respondent to be Recorded

(a) Date (dd/mm/yyyy)……

(b) Name of interviewer ……

(c) Place of interview:

(d) Region.....

(e) District.....

(f) Locality within the district……..(village)

(g) Time of starting interview……..

Section A: Personal Particulars

1. Sex: 1. Male 2. Female
2. Age (years)……
3. Education of the respondent? ……
4. Marital Status:……
5. Occupation ……
6. Ex TB Patient or Relative .....

THEMATIC QUESTIONS

Theme-1: DIRECT AND INDIRECT FINANCIAL COSTS INCURRED

1. Can I get your opinion on how you find the impact of TB in your life?

<u>Probe</u> for:

●Do people in your community find PTB as a serious disease to draw public health attention? If yes, in what manner and why?

-Do they find it painful physiologically or highly prevalent? How?

-Do they find it costly financially for its management? How?

-Do they find it economically costly in terms of work time lost? How?

2. How did you find out you had PTB? Were you referred?

3. Can you tell me, your reaction after you realize you had TB and why?

4. How does TB affect the person diagnosed, their household/family and the community

5. When it comes to the issue of the cost of supporting patients with PTB what would you say if asked to give your experiences as TB survivor (***mention them, one after another***).

(a) **Direct costs** – types of costs e.g. out-of-pocket expenses and by how much

(b). **Indirect monetary/financial costs** associated with PTB sufferings?

Probe for:

● transport/travel costs such as fare for public or private transport

●Foods (e.g. lunch or breakfast), bites, and soft drinks (water, etc).

●Accommodation (*for those who travel from far and take a rented room*)

●Amount of income earnings not gained during the illness/sickness period as compared with the situation now?

(c) Indirect **economic (non-financial) costs**?

Probe for:

●Loss of working time while suffering from TB [*Productivity time and costs*]

-Has the disease contributed to change the type of your occupation? (*Please, explain why and how, if yes*)

Theme-2: SOCIAL AND ECONOMIC CONSEQUENCES OF PTB

6. Let me have your experiences on the social and economic consequences of PTB

●*social consequences* e.g. stigma, discrimination, social isolation,

-From a family member or spouse?

-From community members, e.g., in school/college, market place, e.g., in school/college, marketplace, worship area, public transport, sports fields, HCFs, staff in the office?

●*financial consequences* e.g. budget constraints, deferred expenditures on basic needs such as food, school fees, medical services other than TB,

●Have you ever missed TB appointments during treatment? If yes, what are the reasons (Probe: its cost and affordability)?

●*economic consequences* e.g. limited chances for employment (job loss), time loss for engaging in income-generating and food production activities, socialization, recreation, etc.

7. Are there any social support networks for people with PTB, and if yes, which ones and how strong are they?

Probe for:

●If there are no networks at all, what impact does this seem to have on the burden of PTB on patients?

●If the networks exist and are strong or weak, what opinion can be made as a suggestion to the TB Program authorities concerned for betterment?

Theme 3: COPING MECHANISMS ADOPTED DUE TO PTB DISEASE COSTS AND CONSEQUENCES

8. Did patients receive any kind of support during TB illnesses, if any, from the following sources: (a) service providers, (b) family, (c) community?

●What kind of support do patients receive (if any) – e.g., emotional, information, financial, other economic materials?

●What kind of support do you think patients need mostly? [emotional, information, financial and material]

9. Can you tell me about post-TB experiences in terms of enablers/facilitating factors and/or challenges, if any?

10. How have you been coping with PTB, given the **social, financial, and economic** costs and consequences you have discussed?

Probe for:

--Social support availability and its impact on their current situation

-Borrowed cash from other parties or a bank or an employer for meeting the family's needs?

-Sought help/assistance from a relative, a community member, a religious institution?

Sold a personal or family asset to raise money for family needs?

-Changed type of business/employment occupation?

11. As a community member, and ever had TB what do you do to prevent TB?

12. 13. Could you share which types of coping strategies you find most effective? Probe for its accessibility and availability

13. Please feel free to ask if you may have anything you would like to share about your experience or my clarification.

Thanks for your time and kindness. I'm pleased of your active participation and do promise to generate a useful report and feedback from this work.

Appendix vii: Key Informant Interview Guide for health care providers

Targeted: Health Care Provider working in the TB section at the facility level

Introduction

Study Title: Social and Economic Consequences of Pulmonary Tuberculosis – Perspectives of Patients, their Families, the community and Health Care Providers, focus being Mbeya and Songwe Regions in Tanzania

Basic Preliminary Information of the Interviewee/Respondent to be Recorded

(a) Date (dd/mm/yyyy)……

(b) Name of interviewer ……

© Place of interview:

(d)Region.....

(e) District.....

(f) Locality within the district……..

g) Gender……..

Time of starting interview……..

Section A: Personal Particulars

1. How long have you been working here?.....
2. Highest education/professional qualification attained …
3. Title / Designation of interviewee ……
4. Number of years working in TB related program/ service_____

Section B: QUESTIONS/STUDY THEMES

1. Considering your role in this facility what can you say if given chance to explain your knowledge and experience with each of the following?

(i) what are the direct costs for PTB from diagnosis to treatment

Probe for:

-How or to what extent do such payments affect patients access to and/or continuous use of TB services at formal health facilities?

(ii) What does the national health policy recommend for formal service providers in relation to PTB services for people in need

(iii) How possible are the recommendations/directives translated into practice?

Probe for:

-user fee- payments, exemptions

-formal and informal social protection systems such as health insurance schemes towards achieving universal health coverage

-availability and quality of human resources and essential supplies, medical equipment and other enabler conditions

2. In your view, is there a link between the quality of the health care services being delivered at this facility and chances for the targeted people to seek, access and utilise the services? [Please clarify]

Probe for:

(i) Availability of TB essential services in relation to its utilization

3. Suppose you were asked due to your present career and with a reflection to your real life experiences to comment on the social, financial, and economic consequences of PTB to the individual patients, their families, TB survivors and health care providers what would you say for each of the groups I have mentioned for you?

Probes:

Social consequences

●Any stigma and discrimination (e.g. social isolation) against the people confirmed to have PTB? If yes, then at which level do such consequences occur? e.g.

-At family/household level? In the Community, In schools/colleges? In marketplaces? In worship areas? In public transport? sports fields? In health care facilities? In offices?

●Any community-level isolation of households with a patient with PTB or the people who support the patients as home caretakers on the belief that they are also infected?

Are TB survivors recognized and used in the community – for peer support or counseling, to teach and educate others?

Financial/ economic consequences

4. What arrangements are there (if any) for enabling patients from the poorest households to access services if they happen to contact private health care providers where public health care providers/facilities are non-existent?

Probe for:

●effectiveness of health insurance or other forms of social protection mechanisms in place (whether these are mentioned or not mentioned)

●if there is intersectoral collaboration in TB service provision between public and private sector providers in terms of sharing health resources and the costs of services whereby patients have to pay or not pay for some services

4. What challenges or barriers are you facing in the facility concerning TB services? (Probe: What makes it difficult to access these TB services offered here?)

5. What experience do you have if at all there are there any ***financial costs*** incurred (i.e., monetary expenditures made) by the front-line health care workers (HCWs) at this facility to support their clients, paying the amount of money needed for care and treatment services in relation to PTB?

Probe for:

● Do HCWs find themselves taking money from their pockets to serve the patients for the services they seem or claim to be unable to afford, and for which types of services and by how much of the money?

● Are the costs borne by the health system/government/health facility owners to support the respective patients and not by the individual HCWs, and if so, for what types of services and by how much of the money?

7. For regions like Mbeya and Songwe, what do you find to be the possible if not actual facilitator and barrier factors to patients access to TB services in rural areas and in urban areas depending on where one resides?

Probe for:

●Any experience or report the interviewee may have from these regions?

●What is special for Mbeya but not Songwe and vice versa or special for these two regions but not for other regions in Tanzania in relation to:

-PTB epidemiology (prevalence, treatment outcomes, etc.)

-PTB service accessibility and costs

-PTB burden on patients, households/families and community economy

8. What kind of support do you think PTB patients should receive from their families and, where necessary, from the society at large for them to cope with the disease situation they are facing?

Probe for:

●If there are any gaps in emotional, financial, or other material kinds of support

●Special support to patients living with other types of diseases and or disabilities

●Gaps so far noted in relation to the support needed by PTB patients from the other groups, including the governmental or non-governmental organizations e.g. - *social protection through*

charity contributions for medical care, job placement, employment protection, transport assistance, health counselling

Please, let me know if you have any questions you would like answer you. Thank you very much for your time and cooperation in this interview.

Appendix viii: Key Informant Interview Guide- National level

National and Regional Level Officers (Policy Makers)

Targeted: *TB Programme Manager, TB Care and Prevention Coordinator, TB/HIV Coordinator and Monitoring and Evaluation Officer**), Regional (**Regional TB and Leprosy Coordinator and District TB and Leprosy Coordinator***)**

Study Title: Social and Economic Consequences of Pulmonary Tuberculosis – Perspectives of Patients, their Families, the Community and Health Care Providers in Mbeya and Songwe Regions in Tanzania

Basic Preliminary Information of the Interviewee/Respondent to be Recorded

(a) Date (dd/mm/yyyy)……

(b) Name of interviewer ……

(c) Place of interview: …….

(d)Region.....

(e) District.....

(f) Locality within the district……..

(g) Time of starting interview……..

(h) Gender ……...

Section A: Personal Particulars of the Respondent

1. How long have you been working here …….
2. Highest education/professional qualification attained ……
3. Title /Designation ……
4. Number of years working in TB related program/ service_____

Section B: The Questions/Study Themes

1. What can you say about the TB service availability in this country?

Probe for:

●The key preventive and key curative services and their costs from the service user‘s perspective

●what are the services available in rural settings as compared to those in urban settings

● The balance between preventive and curative services and implications for the control of TB towards achieving the sustainable development and End TB goals?

●What are the strategies in place to ensure that universal health coverage for TB is achieved, considering issues of access, costs and quality of services needed

2. What observations do you have regarding the presence of user charges or user fee exemptions for patients with PTB in Tanzania?

Probe for:

●The Government policy on TB service accessibility rights of the people with different socio-demographic or economic characteristics

●If there are any direct or indirect payments incurred by patients

or their supporters from family or community level for the services needed, what types of payments are being made and for which types of services?

3. What limitations or challenges the national TB programme as facing in its attempt to translate the existing policies and plans into practice to ensure that the TB services are delivered as required and effectively utilized?

Probe for:

●the degree to which policies and plans are clearly understood by front-line health workers who deal with TB patients problems/issues

●the financing part of the TB services programme including the financing of the set budgets and financing the supply and distribution of key resources to areas where they are needed

●Any genuine or unverifiable public outcry against what they find or feel not to be going well in the health care system in relation to TB services?

4. What arrangements are there (if any) for enabling patients from poorest household access services if they happen to contact private health care providers where public health care providers/facilities are non-existent?

Probe for:

●effectiveness of health insurance or other forms of social protection mechanisms in place (whether these are mentioned or not mentioned)

● if there is intersectoral collaboration in TB service provision between public and private sector providers

5. For regions like Mbeya and Songwe, what do you find to be the possible if not actual facilitator and barrier factors to the access to TB services by patients residing in rural areas and those living in urban areas?

Probe for:

●Any experience or report the interviewee may have from these regions?

●What is special for Mbeya but not Songwe and vice versa or special for these two regions but not for other regions in Tanzania in relation to:

-PTB epidemiology (prevalence, treatment outcomes, etc.)

-PTB service accessibility and costs

-PTB burden on patients, households/families and community economy

6. What kind of support do you think PTB patients should receive from their families and where necessary from the society at large for them to cope with the disease situation they are facing?

Probe on:

●If there are any gaps in emotional, financial, other material kinds of support

●Special support to patients living with other types diseases and or disabilities

●Gaps so far noted in relation to the support needed by PTB patients from the other groups, including the governmental or non-governmental organizations

e.g. - *social protection through charity contributions for medical care, job placement, employment protection, transport assistance, health counselling*

7. What would you recommend if you were requested to comment on the following aspects:

●Possible solution to support patients in order to reduce the socio-economic consequences associated with PTB

● Gaps in research in the area of social and health systems determinants of PTB that need to be filled if the sustainable development and End-TB Strategy goals were to be attained as envisaged?

Please, let me know if you have any question you would like me to answer for you. Thank you very much for your time and cooperation in this interview.

Appendix ix: Quantitative Data Collection Tools

Enrolment (DAY 0)

Prediagnostic & Diagnostic Costs
What symptoms did you experience that led you to seek treatment for your current illness? How long ago did you first experience these symptoms? 1. Cough yes ☐ no ☐ _____ weeks 2. Night sweats yes ☐ no ☐ _____ weeks 3. Coughing up blood yes ☐ no ☐ _____ weeks 4. Weight loss yes ☐ no ☐ _____ weeks 5. Other (specify) _____ ☐ _____ weeks
Did you seek treatment or advice for your symptoms in any health facility (including the private sector, drug shop, or traditional practitioner) before being diagnosed with TB at the public health facility? Yes ☐ No ☐ *(Skip to Q8)*

b) How many weeks ago did you visit the first provider? _____ weeks	
How many times did you visit this practitioner?	_____ times
Travel time (on average - return for each visit)?	_____ hours _____ minutes
Time spent (on average for each visit)?	_____ hours _____ minutes

Local currency	☐ ZAR ☐ GMD ☐ TZS ☐ MZN ☐ Other (specify) _____
In total how much did you spend on each of the following for visits to this particular provider? Consultation fee Radiography or other imaging Other procedures Lab test Medication Other (e.g. supplements) Hospitalization (day charges for time in hospital) **TOTAL medical costs** Transport (return for each visit) Food during the visit/hospital stay Accommodation Other non-medical payments **TOTAL non-medical costs** **TOTAL medical and non-medical costs** Reason for no medical or non-medical costs	_____ ZAR/GMD/TZS/MZN _____ZAR/GMD/TZS/MZN _ ____ZAR/GMD/TZS/MZN _____ZAR/GMD/TZS/MZN _____ ZAR/GMD/TZS/MZN _____ ZAR/GMD/TZS/MZN **_____ ZAR/GMD/TZS/MZN** _____ ZAR/GMD/TZS/MZN _____ ZAR/GMD/TZS/MZN _____ ZAR/GMD/TZS/MZN _____ ZAR/GMD/TZS/MZN **_____ ZAR/GMD/TZS/MZN** _____ **ZAR/GMD/TZS/MZN** No additional costs incurred ☐ Don't know ☐ Refuse to answer ☐
If hospitalized, number of days hospitalized	_____days

Provider 2:

Provider type (*Circle one option)*	1.Pharmacy, drug or grocery store 2.Traditional practitioner 3.Primary care, public 4.Private practitioner 5.Public hospital 6.Private/mission hospital

	7.Other (specify) _____	**c) Complete the following for each provider listed above:**
How many times did you visit this practitioner?	_____ times	

Provider 1:

Provider type (*Circle one option)*	Pharmacy, drug or grocery store Traditional practitioner Primary care, public Private practitioner Public hospital Private/mission hospital Other (specify) _____
Travel time (on average - return for each visit)?	_____ hours _____ minutes
Time spent (on average for each visit)?	_____ hours _____ minutes
In total how much did you spend on each of the following for visits to this particular provider? Consultation fee Radiography or other imaging Other procedures Lab tests Medication Other (e.g. supplements) Hospitalization (day charges for time in hospital) **TOTAL medical costs** Transport (return for each visit) Food during the visit/hospital stay Accommodation Other non-medical payments **TOTAL non-medical costs** **TOTAL medical and non-medical costs** Reason for no medical or non-medical costs	_____ ZAR/GMD/TZS/MZN _____ZAR/GMD/TZS/MZN _____ ZAR/GMD/TZS/MZN _____ ZAR/GMD/TZS/MZN _____ ZAR/GMD/TZS/MZN _____ ZAR/GMD/TZS/MZN _____ ZAR/GMD/TZS/MZN **_____ ZAR/GMD/TZS/MZN** _____ ZAR/GMD/TZS/MZN _____ ZAR/GMD/TZS/MZN _____ ZAR/GMD/TZS/MZN _____ ZAR/GMD/TZS/MZN **_____ ZAR/GMD/TZS/MZN** **_____ ZAR/GMD/TZS/MZN** No additional costs incurred ☐ Don't know ☐ Refuse to answer ☐
If hospitalized, number of days hospitalized	_____days
Provider 3:	1. Pharmacy, drug or grocery store Traditional practitioner

Provider type (*Circle one option)*	Primary care, public Private practitioner Public hospital Private/mission hospital Other (specify) _____
How many times did you visit this practitioner?	____ times
Travel time (on average - return for each visit)?	_____ hours _____ minutes
Time spent (on average for each visit)?	_____ hours _____ minutes
In total how much did you spend on each of the following for visits to this particular provider? Consultation fee Radiography or other imaging Other procedures Lab tests Medication Other (e.g. supplements) Hospitalization (day charges for time in hospital)	 _____ ZAR/GMD/TZS/MZN _____ ZAR/GMD/TZS/MZN _____ ZAR/GMD/TZS/MZN _____ZAR/GMD/TZS/MZNZAR/GMD/TZS/MZN ZAR/GMD/TZS/MZN
TOTAL medical costs Transport (return for each visit) Food during the visit/hospital stay Accommodation Other non-medical payments **TOTAL non-medical costs** **TOTAL medical and non-medical costs** Reason for no medical or non-medical costs	___ ZAR/GMD/TZS/MZN _____ ZAR/GMD/TZS/MZN _____ ZAR/GMD/TZS/MZN _____ ZAR/GMD/TZS/MZN _____ **ZAR/GMD/TZS/MZN** _____ **ZAR/GMD/TZS/MZN** ☐ No additional costs incurred Don't know ☐ Refuse to answer ☐
If hospitalized, number of days hospitalized	_____days
Provider 4:	1. Pharmacy, drug or grocery store
Provider type (*Circle one option)*	Traditional practitioner Primary care, public Private practitioner Public hospital Private/mission hospital Other (specify) _____

How many times did you visit this practitioner?	_____ times
Travel time (on average - return for each visit)?	_____ hours _____ minutes
Time spent (on average for each visit)?	_____ hours _____ minutes
In total how much did you spend on each of the following for visits to this particular provider? Consultation fee Radiography or other imaging Other procedures Lab tests Medication Other (e.g. supplements) Hospitalization (day charges for time in hospital) **TOTAL medical costs** Transport (return for each visit) Food during the visit/hospital stay Accommodation Other non-medical payments **TOTAL non-medical costs** **TOTAL medical and non-medical costs** Reason for no medical or non-medical costs	___ ZAR/GMD/TZS/MZN ___ZAR/GMD/TZS/MZN ZAR/GMD/TZS/MZN ___ZAR/GMD/TZS/MZN ___ZAR/GMD/TZS/MZN ___ZAR/GMD/TZS/MZN ___ ZAR/GMD/TZS/MZN **___ZAR/GMD/TZS/MZN**— _ZAR/GMD/TZS/MZN ____ZAR/GMD/TZS/MZN ____ZAR/GMD/TZS/MZN ___ ZAR/GMD/TZS/MZN **___ZAR/GMD/TZS/MZN** **___ZAR/GMD/TZS/MZN** No additional costs incurred Don't know ☐ Refuse to answer ☐
If hospitalized, the number of days hospitalized	days

Coping Costs	
8. From the time you first realized you were sick until now, did you or your household use any savings (cash or bank deposits) to cover costs due to TB illness?	1. Yes 2. No *(Skip to Q9)*
b) If YES, how much did you need:	_____ ZAR/GMD/TZS/MZN Don't know ☐ Refuse to answer ☐

9. Did you borrow any money to cover costs due to the TB illness?	1. Yes 2. No *(Skip to Q12)*
If YES: How much did you borrow? From whom did you borrow? *Choose most appropriate*	_____ZAR/GMD/TZS/MZN Don't know ☐ Refuse to answer ☐ 1.Family 2. Neighbor/friend 3. Private bank 4. Cooperative 5. Other (specify): _____
10. Are you expected the pay the loan(s) back?	1. Yes 2. No *(Skip to Q12)*
11. What is the repayment on the loan? a) Have you started repayment b) How much interest do you pay per	_____ZAR/GMD/TZS/MZN ☐ once off ☐ per month Don't know ☐ Refuse to answer ☐ 1. Yes 2. No *(Skip to Q12)* _____ % ☐ per week ☐ per month
12. Have you sold any of your property to finance the cost of the TB illness?	1. Yes 2. No *(Skip to Q13)*
b) **If YES: What did you sell?** *Multiple options may apply*	1. Land 2. Livestock 3. Transport/vehicle 4. Household item 5. Farm produce 6. Gold/jewelry 7. Other (specify): __
c) How much money did you receive from the sale of all items of your property?	_____ZAR/GMD/TZS/MZN Don't know ☐ Refuse to answer ☐

13. On a scale of 1 to 5, in which 1 is no impact and 5 is very serious impact, to what extent has the TB diagnosis affected the household financially?	1= no impact 2= little impact 3= moderate impact 4= serious impact 5= very serious impact

Socioeconomic Indicators	
14. What is your electricity supply?	1. Own connection 2. Shared connection 3. None
15. What is your source of drinking water?	1. Rainwater 2. Lake/pond/dam/river 3. Public well 4. Private well/bore hole 5. Piped – in the home 6. Piped – tap in own yard/garden 7. Piped - public tap/kiosk (free) 8. Piped - public tap/kiosk (paid for) 9. Bottled water 10. Other (specify)
16. What type of toilet facility is available?	1.No facility/bush/field 2.Shared pit toilet/latrine 3.Own pit toilet/latrine 4.Flush toilet 5.Bucket toilet 6.Chemical toilet 7.Other (specify) __
17. Current place of residence?	1.House 2. Flat/apartment 3.Cottage or back room (behind another house) 4.Shack 5.Domestic quarters or room in employer's home 6.Student residence 7.Other congregate housing (e.g., workers' quarters, hostel) 8.Other (specify) __
18.Do you rent the house of residence you live in, or own it?	1.Rented 2. Owned, debt outstanding 3.Owned, free of debt 4.Occupied, no rent

19. Do you own *(Choose all that apply)*	Radio Television Mobile phone Landline phone Washing machine Refrigerator or combined fridge freezer Bed with mattress

	Sofa set Table and chairs Bicycle Horse/donkey Motorcycle/scooter Car/truck Livestock (farm animals) Computer or laptop Land Swimming pool DVD player/ Blu ray player Pay TV (M-Net/DSTV/Top TV) Air conditioner Vacuum cleaner/floor polisher Dish washer Tumble dryer Deep freezer Electric or gas stove Microwave oven Built in kitchen sink Home security service Home theatre system Geyser, providing hot running water Solar hot water geyser Solar electrical panel
20. How many rooms are there where you currently stay? COUNT ALL SEPARATE ROOMS – E.G. KITCHEN, BEDROOMS, ETC. EXCLUDE BATHROOMS AND HALLS, PASSAGES.	_____
21. How many people regularly sleep in your house? (including yourself)	_____

22. How many adults and children including yourself have stayed at your place at least 15 out of the last 30 days? **a) Adults (>21 years old)** **b) Children under 10 years old** **c) Young people 10-21 years old**	_____
23. How many children do you have?	_____ children None £ Refuse to answer £
24. Apart from your children, do you have other dependents?	1. Yes 2. No *(Skip to Q25)* 3. Refuse to answer
If yes, how many dependents are you financially taking care of? **a)Children** **b)Adults (≥ 18 years)**	
25. Do any of the following happen where you currently stay? **a) Children or teenagers share bedroom with parents?** **b) Children or teenagers sleep in the room not meant to be used as a bedroom?** **c) Teenagers of opposite sex share same bedroom?** **d) A teenager shares a bedroom with an adult of opposite sex?**	1. Yes 2. No 1. Yes 2. No 1. Yes 2. No 1. Yes 2. No
26. How do you pay for healthcare? *Multiple options may apply*	Don't pay, it's for free Out-of-pocket Private health insurance (e.g. medical aid etc.) Employer pays Reimbursement scheme Medical allowance Family/community fund Donor Other (specify) _____
27. How much did your household spend (e.g. out-of-pocket expenses) on healthcare on average per month BEFORE the TB illness?	_____ ZAR/GMD/TZS/MZN per month Don't know ☐ Refuse to answer ☐

Socioeconomic Information *Individual situation and income*

28.Who is the primary income earner in the household? *Choose most appropriate*	. Patient . Wife/mother . Husband/father . Extended family . Son/daughter . Other (specify _____) . Don't know . Refuse to answer

29. Are you currently employed?	Yes, self-employed Yes, formally employed Yes, informally employed No, unemployed (*Skip to Q35)* No, on sick leave No, student at school or university (*Skip to Q35)* No, retired (*Skip to Q35)* Combination (specify Other (specify _____) Refuse to answer
30. Type of employment	Full-time day Part-time day Full-time night Part-time night Other (specify_____)

31. How are you usually paid?	1. Cash 2. In kind 3. Cash and in kind 4. Not paid 5. Bank transferred salary 6. Other (specify_____)
33. **What is your main occupation? (**interview prompt – e.g. primary school teacher, office cleaner, vegetable farmer etc.)	
33.Which of these best describes your occupation? *[according to the Standard Occupational Classification System]	1. Management 2. Business and financial operations 3. Computer and mathematical

	4. Architecture and engineering 5. Life, physical and social science 6. Community and social services 7. Legal 8. Education, training, and library 9. Arts, design, entertainment, sports, and media 10. Healthcare practitioner and technical 11. Healthcare support 12. Protective services 13. Food preparation and serving 14. Building and grounds cleaning and maintenance 15. Personal care and service 16. Sales and related occupations 17. Office and administrative support 18. Farming, fishing and forestry 19. Construction and extraction 20. Installation, maintenance and repair 21. Production 22. Transportation and material moving 23. Military specific 24. None of the above
34.Thinking back to when you first experienced symptoms that led you to seek treatment, how regularly did you work?	1. Throughout the year 2. Seasonal/part of the year 3. Day labor 4. Other (specify _____)
35. When was the last time you were working?	_____(mmm/yyyy) Not applicable, currently working ☐ *(Skip to Q37)*
36. Is the reason for not working now related to your TB illness?	1. Yes 2. No
37. Do you currently earn less than you used to 6 months ago? **If yes, could you estimate how much less?** **Is the change related to the TB illness?**	1. Yes 2. No _____ ZAR/GMD/TZS/MZN per month 1. Yes 2. No

38. Since you first experienced symptoms related to TB, did you have to change jobs because of your symptoms related to TB?	1. Yes 2. No
39. How many hours did you work on average per day BEFORE you became ill with TB?	_____ hours per day
40.How many hours do you work on average NOW per day?	_____ hours per day
41. Do you currently work less hours than you used to 6 months ago? **If yes, could you estimate how much less?** **Is the change related to the TB illness?**	1. Yes 2. No _____ hours per day 1. Yes 2. No
42. How much do you estimate YOUR income (i.e. after-tax; average you receive from labour related activities) per month <u>before</u> your TB illness (e.g. 6 months ago)?	_____ ZAR/GMD/TZS/MZN Don't know ☐ See prompt below Refuse to answer ☐ See prompt below
PROMPT FOR INTERVEWERS: If the participant cannot give the exact amount refer to the list of ranges in the Interviewer aid. Ask the participant "Thinking of your income per month before your TB illness (e.g. 6 months ago), which range best describes your income?"	
If "Don't know" or "Refuse to answer" then use the following prompt codes and record the applicable code (e.g. 8).	
43. How much do you estimate the average income (i.e. after-tax; average you receive from labour related activities) of your <u>HOUSEHOLD</u> was per month <u>before</u> your TB illness (e.g. 6 months ago)?	_____ ZAR/GMD/TZS/MZN Don't know ☐ See prompt below Refuse to answer ☐ See prompt below
PROMPT FOR INTERVEWERS: If the participant cannot give the exact amount refer to the list of ranges in the Interviewer aid. Ask the participant "Thinking of your HOUSEHOLD income per month before your TB illness (e.g. 6 months ago), which range best describes your income?"	
b) If "Don't know" or "Refuse to answer" then use the following prompt codes and record the applicable code (e.g. 8).	
44. How much do you estimate your average income (after-tax) per month is <u>NOW</u>?	_____ ZAR/GMD/TZS/MZN Don't know ☐ See prompt below Refuse to answer ☐ See prompt below

PROMPT FOR INTERVEWERS: If the participant cannot give the exact amount refer to the list of ranges in the Interviewer aid. Ask the participant, "Thinking of your income NOW per month, which range best describes your income?"	
b) If "Don't know" or "Refuse to answer" then use the following prompt codes and record the applicable code (e.g. 8).	
45. How much do you estimate the average income (after-tax) of your household is NOW?	_____ ZAR/GMD/TZS/MZN Don't know ☐ See prompt below Refuse to answer ☐ See prompt below
PROMPT FOR INTERVEWERS: If the participant cannot give the exact amount refer to the list of ranges in the Interviewer aid. Ask the participant "Thinking of your HOUSEHOLD income NOW per month, which range best describes your income?"	
b) If "Don't know" or "Refuse to answer" then use the following prompt codes and record the applicable code (e.g. 8).	
46. Did you receive any social welfare payment before your TB illness (e.g. 6 months ago)? **If yes, what type?** **If yes, what estimated amount per month**	1. Yes 2. No (*Skip to Q47)* . Paid sick leave . Disability grant . Cash transfer for poor families . Other cash transfer _____ ZAR/GMD/TZS/MZN per month
47. Do you currently receive any social welfare? **If yes, what type?** **If yes, what estimated amount per month**	1. Yes 2. No (*Skip to Q48)* . Paid sick leave . Disability grant . Cash transfer for poor families . Other cash transfer _____ ZAR/GMD/TZS/MZN per month
48. Thinking back to before your TB illness (e.g. 6 months ago), did you receive vouchers or goods in kind? **If yes, what estimated amount per month** **From whom do you receive the voucher or goods?** *(Interviewer – use the following codes – Multiple options may apply)* Government (e.g. health facility) NGO Employer Donation (e.g. neighbour, school, church)	1. Yes 2. No (*Skip to Q49)* Travel voucher: ____ ZAR/GMD/TZS/MZN per month; From _____ Food voucher or assistance: _____ ZAR/GMD/TZS/MZN per month; From _____ Public assistance (e.g. neighbour, school, church): _____ ZAR/GMD/TZS/MZN per month; From _____ Other: _____ ZAR/GMD/TZS/MZN per month; From _____

Reimbursement for participating in this study Other, specify _____	
49. Besides yourself, does anyone else of your household receive treatment for TB? **b) If Yes: How many?**	1. Yes 2. No (*Skip to Q50)* _____

ES, then who is doing the work for you? *(multiple options may apply)*	. Daughter/Son . Spouse . Friend . Service . Other (specify _____)
Do you pay this person to help you? **If YES, how much do you pay per month?**	1. Yes 2. No (*Skip to Q51)* _____ ZAR/GMD/TZS/MZN per month
51. Does someone stay home <u>specifically</u> to take care of you? **If YES: for how long?** **Did they quit their income-earning job to stay home and care for you?**	1. Yes 2. No *(Skip to Q52)* _____ weeks 1. Yes 2. No
52. Do all of your children of school age attend school regularly?	1. Yes *(Skip to Q53)* 2. No

50. Since you first experienced symptoms related to TB, is someone doing the work in your house that you used to do?	1. Yes 2. No (*Skip to Q51)*

b) If NO: Why not? *(multiple options may apply)*	. Needs to help around the house . No money for school fees . Also sick . Has to work to earn income . Other (specify): _____
53. Do any of your children of or below school age work to finance costs due to the TB illness? 1. Yes 2. No	
54. Does someone specifically take care of your underage children (e.g. < 10 years old) for you? **When did this happen?** **How much do you pay per month?**	1. Yes 2. No *(Skip to Q55)* . Before you became ill with TB . After you became ill with TB . Don't know _____ ZAR/GMD/TZS/MZN per month I don't pay anything ☐ Don't know ☐ Refuse to answer ☐
55. Has the TB illness affected your social or private life in any way? *(multiple options may apply)* **b) If yes, how?**	1. Yes 2. No (*Skip to Q56)* Divorce Loss of job Can do less (e.g. work) than used to Dropped out of school Separated from spouse/partner Disruption of sexual life Sick child Food insecurity Other (specify _____)

Household food security	
56. In the past four weeks, did you ur household would not have enough	= No *(Skip to Q58)* = Yes

57. How often did this happen?	= Rarely (once or twice in the past four weeks) = Sometimes (three to ten times in the past four weeks) = Often (more than ten times in the past four weeks)
58. In the past four weeks, were you or any household member not able to eat the kinds of foods you <u>preferred</u> because of a lack of resources?	= No *(Skip to Q60)* = Yes
59. How often did this happen?	= Rarely (once or twice in the past four weeks) = Sometimes (three to ten times in the past four weeks) = Often (more than ten times in the past four weeks)
0. In the past four weeks, did you or any household member have to eat a <u>limited</u> variety of foods due to a lack of resources?	= No *(Skip to Q62)* = Yes
61. How often did this happen?	= Rarely (once or twice in the past four weeks) = Sometimes (three to ten times in the past four weeks) = Often (more than ten times in the past four weeks)
62. In the past four weeks, did you or any household member have to eat some foods that you really did not want to eat because of a lack of resources to obtain other types of food?	= No *(Skip to Q64)* = Yes
63. How often did this happen?	= Rarely (once or twice in the past four weeks) = Sometimes (three to ten times in the past four weeks) = Often (more than ten times in the past four weeks)
64. In the past four weeks, did you or any household member have to eat a smaller meal than you felt you needed because there was not enough food?	= No *(Skip to Q66)* = Yes
65. How often did this happen?	= Rarely (once or twice in the past four weeks) = Sometimes (three to ten times in the past four weeks) = Often (more than ten times in the past four weeks)
66. In the past four weeks, did you or any other household member have to eat fewer meals in a day because there was not enough food?	= No *(Skip to Q68)* = Yes
67. How often did this happen? 1 = Rarely (once or twice in the past four weeks) = Sometimes (three to ten times in the past four weeks) = Often (more than ten times in the past four weeks)	
68. In the past four weeks, was there ever no food to eat of any kind in your household because of lack of resources to get food?	= No *(Skip to Q70)* = Yes

69. How often did this happen?	= Rarely (once or twice in the past four weeks) = Sometimes (three to ten times in the past four weeks) = Often (more than ten times in the past four weeks)
70. In the past four weeks, did you or any household member go to sleep at night hungry because there was not enough food?	= No *(Skip to Q72)* = Yes
71. How often did this happen?	= Rarely (once or twice in the past four weeks) = Sometimes (three to ten times in the past four weeks) = Often (more than ten times in the past four weeks)
72. In the past four weeks, did you or any household member go a whole day and night without eating anything because there was not enough food?	= No *(Skip to end)* = Yes
73. How often did this happen?	= Rarely (once or twice in the past four weeks) = Sometimes (three to ten times in the past four weeks) = Often (more than ten times in the past four weeks)

Additional comments

Appendix x: Qualitative Code Book

Sn	Themes	Su-themes	Description
1	Pre-treatment care-seeking pathways, caused and associated costs	Actions Taken When Symptoms Started	When participants explain the initial steps taken after noticing PTB symptoms e.g. Self-medication, seeking traditional remedies, visiting a pharmacy, and consulting family members
		Financial expenditures for pre-treatment care -seeking	When participants explain the financial burden incurred by him/herself and their families before receiving a PTB diagnosis, including expenses for transportation, self-medication, and other out-of-pocket costs which contributed to delayed health care seeking
		The cost associated with delayed healthcare seeking due to domestic commitments	When Patients explain about the challenges faced before seeking care at a health facility,
		The cost incurred by late contacting formal health facilities due to limited knowledge of PTB symptoms	When participants speak about starting TB treatment late and this is caused by living far from the HCF, poor knowledge on TB symptoms (traditional beliefs and stigma) perceived poor quality of care
2	Diagnosis and Health-Seeking Journey	The decision to Seek Professional Care	When participants explain about factors influencing the decision to seek care at a formal HCF (e.g., severity of symptoms, advice from others).
		Diagnostic process experience	When participants explain the steps experienced during diagnosis and their emotional impact.
		Availability of care and treatment services	Explanation of Perceived availability of TB services when urgently needed.
		Perception of TB Services	When participants explain their Perception of the quality of services provided and give examples of good quality, lack of professionalism, and insufficient care.
3	Factors external to the formal health care system behind a delayed PTB	Rural-Urban differences in TB care accessibility	When participants explain about long distances to the nearest hospital/TB clinic; Rural-Urban differences in TB care accessibility
		Limited knowledge	Explain things that show lack of awareness about TB

	care-seeking	of PTB symptoms	symptoms
		Perceived Quality of care related costs	When participants explain the quality-of-care costs, this made him/her not to go early to HCF
		Gender issue	When participants especially women, go to the facility late because their husbands did not allow them to do so, either did not give permission or money
4	Experience before visiting a health facility and the cost associated	Health-Seeking Behaviour Before Visiting a Health Facility	When participants explain about action taken before seeking professional care; reasons for postponing a visit to HCF.
		Costs patients incur before visiting a Health Facility	Participants explain about money spent on self-medication or traditional treatments, transport e.tc
		Support provided to patients before being diagnosed with TB sickness	Explain the assistance patients received during the pre-diagnosis journey e.g. food and transport
		Referral processes and the support provided by family members, along with the related costs.	If the participants share their experiences regarding a referral to the facility
		cost associated.	
5	Social and economic consequences of TB	Feelings about pre-treatment procedures costs	When participants explain the social and economic consequences of TB, which include stigma and discrimination.
		Inability to participate in economic production activities	When participants explain their inability to participate in economic activities.
		TB illness and care seeking for non-TB illness	When participants complaints about the care seeking for non-TB illnesses (TB Survivors)
		Association of TB and Witchcraft	When participants speak about reliance on witch doctors for TB symptoms treatment and this facilitates a delay in HCF treatment

		Food insecurity	When participants explain their inability to get food
		Loss of network	When participants explain about losing the former network because of PTB
6	Role of social support in TB management	Emotional/psychological support	When participants declare receiving psychological support from family/peers/health care workers or community. Or mentioned psychological social support as an important measure s/he would like to receive
		Material or financial support	When participants declare receiving money as a support for transport, food e.t.c during sickness. Or mentioned monetary support as one of the needed supports.
		Information support	When participants declare receiving information about TB symptoms or treatment at home or HCF. Also if s/he mentioned information support as one of the needed support.
		Companion support	When participants declare receiving companion support from family members or other relatives. Or mentioned companion support as one of the needed support.
7	Treatment Experiences	Facilitating Factors	Participants express positivity about accessing TB care
		Supportive healthcare staff	When explaining about the encouragement and help received from medical personnel.
8	Financial Impact of TB on Respondent	Loss of income	Description of how TB affects the respondent's financial status.
		The financial impact on family	Participants explain about increased family expenses which reduce family income
		Cost of living with PTB	Increase out-of-pocket health expenses (direct costs i.e transport, registration fees, X-ray e.t.c)
		Productivity loss	When participants explain about Hours lost daily due to illness or care-seeking activities (Indirect Economic costs i.e time for travel and waiting time and the relative time while escorting the patient to the hospital)
		Costs for TB	When a participant speaks about the cost s/he incurred before or after diagnosis

9	Post-TB experience (of illness and associated costs		When a participant (survivors) speaks of their experience of TB after treatment
		Consequences of PTB	Experiences of stigma or discrimination from family, community, or institutions.
		Social isolation	Feelings of /or experiences with exclusion or loneliness due to TB.
		Economic Consequences	Struggles to meet basic needs like food, school fees, and non-TB medical services, e.g., I had to stop my child's education to pay for my medicine."
		Missed TB appointments	Missing scheduled appointments due to financial or logistical reasons, e.g "I couldn't afford transport, so I missed my clinic visit.
10	Community and Family Responses to TB	Community perception	How the community reacts to people with TB e.g "Some people think TB is a curse and avoid the sick people."
		family Responses	How the family responded upon learning about the diagnosis e.g "At first, when I told them, they were scared, but later they supported me."
11	Social Support Networks	Existence of networks	When participants explain about the availability of social support systems for PTB patients. e.g "We do have a community support group, for PTB survivors"
		Strength of network	When explaining the effectiveness of the support networks
		Lack of network and its impact	When participant speaks about the consequences of no networks in the community
12	Coping with PTB	Coping strategies	When participants speak about different coping strategies used, e.g., selling assets, taking loans, etc.
		Effective Coping Strategies	When participants explain about effectiveness of Social support networks

Appendix xi: English Consent Forms

Informed Consent Form –English version

Targeted: Pulmonary TB Patients & TB survivors

Date of survey: - -/- -/- - - - (dd/mm/yyyy)

Code number: …….

Name of interviewer: …….

Greetings, My name is _____ I am a PhD student from Witwatersrand, South Africa, I am here with my assistant, his /her name is _____, We are researching **on "Social and Economic Consequences of Pulmonary Tuberculosis – Perspectives of Patients, their families, the community and Health Care Providers in Mbeya and Songwe Regions, Tanzania"** We are happy to invite you to take part in this face to face interview,**.**

Purpose of the study

The main purpose of this study is to determine social and economic consequences of PTB and the ability of patients, their families**,** the community, and the healthcare providers to cope with the disease and to produce recommendations on how most of the key socio-economic and systemic challenges faced in achieving the PTB epidemic control can be mitigated. The research results will be disseminated through a dissertation report and publication.

Study procedure

The participants in this study were purposively selected from TB Sequel list. This is a TB Sequel sub-study that focuses on social- economic impact of TB. In this study we selected people from four districts which represent urban (Mbeya city and Tunduma) and rural (Mbarali and Mbozi). You were among the selected to participate in this study.

What will be required from you

In this interview, we require you to read this informed consent form clearly, if there is any clarification needed do not hesitate to ask me. the interview will take 30 – 45 minutes of your time, I believe you will have enough time to respond to my questions. There will be no re imbursement for your time used in this study

Anonymity and confidentiality

Your identity and participation in this study will be anonymous. I assure you that, all the information you provide will be kept securely and your name or organization will not be included in reporting the findings. The data will be available to the research team only.

Benefits and voluntary participation

There are no direct benefits to participating in this study, but your answers will be very valuable and will only be utilized for the study. Please note that your participation is entirely voluntary and you have a right to withdraw from the study at any time during the interview or discussion. Your decision to withdraw will not affect you in any way. However, it would be much better if you persevered with full participation so that you can be part of giving your views, experiences and advice to the authorities involved in the fight to eradicate tuberculosis in the country.

Participant's position in giving consent

I would like to know if you have any questions concerning this study?

Participant

1= Yes

2= No

I confirm that I have understood the information provided to me about this study. And I had an opportunity to ask question about the study.

Participants signature: …….Date - - /- - /- - - -

Interviewer signature: ……. Date - - /- - / - - - -

Study contacts

If you have any questions or would like further information regarding this study please contact

Ms. Stella Kilima

NIMR Headquarters

P O Box 9653

Dar es Salaam

Landline +255 022 2121400

Email stellakilima@yahoo.com

This study has been approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg ("Committee"). A principal function of this Committee is to safeguard the rights and dignity of all human subjects who agree to

participate in a research project and the integrity of the research. If you have any concerns over the way the study is being conducted, please contact the Chairperson of this Committee who is Professor Clement Penny**, who may be contacted on telephone number** 011717 2700/1234, or by e-mail on clement.penny@wits.ac.za. The telephone numbers for the Committee secretariat are 0117172700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za

This study has also been approved by the National Health Research Ethics Committee (NatHREC) of the National Institute for Medical Research, Tanzania. The main function of this Committee is to safeguard the rights and dignity of all human subjects who agree to participate in research projects and the integrity of the research. If you have any concerns or need further information regarding the way this study is being conducted, please contact the secretariat of this Committee on telephone number +255758587885, or +255222121400. Email: nimrethics@gmail.com.

INFORMED CONSENT FORM – ENGLISH – VERSION

Targeted: RELATIVES

Date of survey: - -/- -/- - - - (dd/mm/yyyy)

Code number: …….

Name of interviewer: …….

Greetings, My name is _____, I am a PhD student from Witwatersrand, South Africa, I am here with my assistant, his /her name is _____, We are researching on **"Social and Economic Consequences of Pulmonary Tuberculosis – Perspectives of Patients, their Families, the Community and Health Care Providers who care for TB patients in Mbeya and Songwe Regions, Tanzania"** We are happy to invite you to take part in this telephonic interview. I will inform you verbally about this study, this interview will take 30 to 45 minutes, if you agree to participate, I will put you in a loudspeaker so that we are able to take notes and record our conversation**.**

I would like to make sure I am speaking to the right person, What is your name ……..; Do you know Mr/Mrs (patient name)…….how are you related……..

okay we can proceed.

Purpose of the study

The main purpose of this study is to determine the social and economic consequences of PTB and the ability of patients, families/households, community members and the healthcare system to cope with the disease. We would also aim to produce recommendations on ways that can be used to mitigate at least most of the key socio-economic and systemic challenges faced in achieving the PTB epidemic control. The research results will be disseminated through a dissertation report and publication.

Anonymity and confidentiality

Your identity and participation in this study will be anonymous. I assure you that, all the information you provide will be kept securely and your name or your organization will not be included in reporting the findings. The data will be available to the research team only.

Benefits and voluntary participation

There are no direct benefits for participating in this study, but your answers will be valuable and will only be utilized for the study. Please note that your participation is entirely voluntary and you have a right to withdraw from the study at any time during the interview or

discussion. Your decision to withdraw will not affect you in any way. However, it would be much better if you persevered with full participation so that you can be part of giving your views, experiences and advice to the authorities involved in the fight to eradicate tuberculosis in the country.

Participant's position in giving consent

I would like to know if you have any questions concerning this study?

Participant

1= Yes

2= No

Participants, confirm to understood the information provided to him/her about this study and he/she was allowed to ask questions about the study. Generally, the participant agrees to participate in the telephonic interview.

Participants Agree to participate in the interview (1) Yes (2) No Date - - /- - /- - - -

Interviewer signature: ……. Date - - /- - / - - - -

Study contacts

If you have any questions or require further information regarding this study you may contact

Ms. Stella Kilima

NIMR Headquarters

P O Box 9653

Dar es Salaam

Landline +255 022 2121400

Email stellakilima@yahoo.com

This study has been approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg ("Committee"). A principal function of this Committee is to safeguard the rights and dignity of all human subjects who agree to participate in a research project and the integrity of the research. If you have any concerns over the way the study is being conducted, please contact the Chairperson of this Committee who is Professor Clement Penny**,** who may be contacted on telephone number 011717 2700/1234, or by e-mail on clement.penny@wits.ac.za. The telephone numbers for the Committee secretariat are 0117172700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za Email. Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za

This study has also been approved by the National Health Research Ethics Committee (NatHREC) of the National Institute for Medical Research, Tanzania. The main function of this Committee is to safeguard the rights and dignity of all human subjects who agree to participate in research projects and the integrity of the research. If you have any concerns or need further information regarding the way this study is being conducted, please contact the secretariat of this Committee on telephone number +255758587885, or +255222121400. Email: nimrethics@gmail.com.

Informed Consent Form – English version

Targeted – HEALTH CARE PROVIDERS

Date of survey: - -/- -/- - - - (dd/mm/yyyy)

Code number: …….

Name of interviewer: …….

Greetings, My name is _____ I am a PhD student from Witwatersrand, South Africa, and my assistants' name is _____, we are researching the **"Social and Economic Consequences of Pulmonary Tuberculosis -Perspectives of Patients, their Families, the community and Health Care Providers in Mbeya and Songwe Regions, Tanzania.** We are happy to invite you to take part in this *face to face* interview.

Purpose of the study

The main purpose of this study is to determine the social and economic consequences of PTB and the ability of patients, their families, the community and the healthcare providers to cope with the disease. It will also produce recommendations on ways that can be used to mitigate at least most of the key socio-economic and systemic challenges faced in achieving the PTB epidemic control.

As a health care provider, the researcher expects to get more information from you on the costs and consequences of TB diseases, how the costs affect patients and health care providers. The research results will be disseminated through a dissertation report and publication.

Study procedure

The participants in this study were purposively selected, according to their role in the TB program. You were among the selected to participate in this study. You will read thes form and if there is any clarification needed, I will be happy to clarify to you. If you agree to participate you will sign this forms and take one copy and I will remain with a copy. The interview will take approximately 30-45 minutes and we will record the conversation by using voice recorder.

Anonymity and confidentiality

Your identity and participation in this study will be anonymous. I assure you that, all the information you provide will be kept secret and the names of individuals or organizations will not be included in reporting the findings. The data will be available to the research team only.

Benefits and voluntary participation

There are no direct benefits to participating in this study but your answers will be valuable and will only be utilized for the study. I will appreciate if you have time to participate in this study. Please note that your participation is entirely voluntary and you have a right to withdraw from the study at any time during the interview or discussion. Your decision to withdraw will not affect you in any way. However, it would be much better if you persevered with full participation so that you can be part of giving your views, experiences and advice to the authorities involved in the fight to eradicate tuberculosis in the country.

Compensation for time

There will be no compensation for participating in this research study but your responses will help to inform policy and decision-makers on how to improve the TB services provided in our country and minimize social and financial consequences that caused with this disease.

Risks of being involved in the study

In this study there is no major risk involved, however, due to this error of COVID-19, I hope you would not mind using protective gear to protect ourselves (Note: if s/he already has face masks, this statement won't be read to him/her)

Participant's position in giving consent

Before signing the consent form, I would like to know if you have any questions concerning this study?

Participant

1= Yes

2= No

I confirm that I have understood the information provided to me about this study and that I had an opportunity to ask questions about the study.

Participants signature: …… Date - - /- - /- - - -

Interviewer signature: ……. Date - - /- - / - - - -

Study contacts

If you have any questions or further information regarding this study please contact

Ms. Stella Kilima

NIMR Headquarters

P O Box 9653

Dar es Salaam

Landline +255 022 2121400

Email stellakilima@yahoo.com

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This study has also been approved by the National Health Research Ethics Committee (NatHREC) of the National Institute for Medical Research, Tanzania. The main function of this Committee is to safeguard the rights and dignity of all human subjects who agree to participate in research projects and the integrity of the research. If you have any concerns or need further information regarding the way this study is being conducted, please contact the secretariat of this Committee on telephone number +255758587885, or +255222121400. Email: nimrethics@gmail.com.

Informed Consent Form – English version

Targeted –POLICY AND DECISION MAKERS

Date of survey: - -/- -/- - - - (dd/mm/yyyy)

Code number: …….

Name of interviewer: …….

Greetings, My name is _____ I am a PhD student from Witwatersrand, South Africa, and my assistants' name is _____, I am researching the **"Social and Economic Consequences of Pulmonary Tuberculosis -Perspectives of Patients, their Families, the community and Health Care Providers in Mbeya and Songwe Regions, Tanzania.** We are happy to invite you to take part in electronic *face to face* interview. I will appreciate to receive the signed form back through my email stellakilima@yahoo.com.

Purpose of the study

The main purpose of this study is to determine the social and economic consequences of PTB and the ability of patients, their families, the community and the healthcare providers to cope with the disease. It will also produce recommendations on ways that can be used to mitigate at least most of the key socio-economic and systemic challenges faced in achieving the PTB epidemic control.

As a health care provider/ policy-decision maker, the researcher expects to get more information from you on the costs and consequences of TB diseases, how the costs affect patients and health care providers. The research results will be disseminated through a dissertation report and publication.

Study procedure

The participants in this study were purposively selected, according to their role in the TB program. You were among the selected to participate in this study. You will read theis form and if there is any clarification needed, I will be happy to clarify to you, through my phone number or my email. If you agree to participate you will be asked to sign this form and send me a copy. The interview will take approximately 30-45 minutes and we will record the conversation by using voice recorder.

Anonymity and confidentiality

Your identity and participation in this study will be anonymous. I assure you that, all the information you provide will be kept secret and the names of individuals or organizations will not be included in reporting the findings. The data will be available to the research team only.

Benefits and voluntary participation

There are no direct benefits to participating in this study but your answers will be valuable and will only be utilized for the study. I will appreciate if you have time to participate in this study. Please note that your participation is entirely voluntary and you have a right to withdraw from the study at any time during the interview or discussion. Your decision to withdraw will not affect you in any way. However, it would be much better if you persevered with full participation so that you can be part of giving your views, experiences and advice to the authorities involved in the fight to eradicate tuberculosis in the country.

Compensation for time

There will be no compensation for participating in this research study but your responses will help to inform policy and decision-makers (*not read this to policy makers)* on how to improve the TB services provided in our country and minimize social and financial consequences that caused with this disease.

Risks of being involved in the study

In this study there is no major risk involved, however, due to this error of COVID-19, I hope you would not mind using protective gear to protect ourselves (Note: if s/he already has face masks, this statement won't be read to him/her)

Participant's position in giving consent

Before signing the consent form, I would like to know if you have any questions concerning this study?

Participant

1= Yes

2= No

I confirm that I have understood the information provided to me about this study and that I had an opportunity to ask questions about the study.

Participants signature: …… Date - - /- - /- - - -

Interviewer signature: …… Date - - /- - / - - - -

Study contacts

If you have any questions or further information regarding this study please contact

Ms. Stella Kilima

NIMR Headquarters

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This study has also been approved by the National Health Research Ethics Committee (NatHREC) of the National Institute for Medical Research, Tanzania. The main function of this Committee is to safeguard the rights and dignity of all human subjects who agree to participate in research projects and the integrity of the research. If you have any concerns or need further information regarding the way this study is being conducted, please contact the secretariat of this Committee on telephone number +255758587885, or +255222121400. Email: nimrethics@gmail.com.

Consent form for audio-recording

In this study, we will use a voice recorder to record the conversation. This will help to avoid missing out on important point when you are speaking, because the person who is writing could not take everything due to the speed of the conversation. This audio recorder will be properly stored and used by the research team only.

Before signing the consent form, I would like to know if you have any questions concerning this issue?

I / We consent to audiotapes being used in this session

Dated…….Signed……..

…….

Be assured the information captured in this audio tape will be confidential and no other person will access this, except the research team.

Dated…….Signed…….

Appendix xii: Ethical clearances

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

Office of the Deputy Vice-Chancellor (Research & Post Graduate Affairs)

TO: Ms S Kilima
School of Public Health
Medical School
University

E-mail: stellakilima@yahoo.com

CC: Supervisor: Drs D Evans and G Mubyazi <devans@heroza.org>
and <HREC-Medical.ResearchOffice@wits.ac.za>

FROM: Iain Burns
Human Research Ethics Committee (Medical)
Tel: 011 717 1252

E-mail: Iain.Burns@wits.ac.za

DATE: 2020/09/07

REF: *R14/49*

PROTOCOL NO: **M200570** *(This is your ethics application study reference number. Please quote this reference number in all correspondence relating to this study)*

PROJECT TITLE: *Social and economic conquences of pulmonary tuberculosis; perspectives of patients, their families, the community and healthcare providers who care for TB patients in Mbeya and Songwe Regions, Tanzania*

Please find attached the Clearance Certificate for the above project. I hope it goes well and that an article in a recognized publication comes out of it. This will reflect well on your professional standing and contribute to the Government funding of the University.

MSWorks2003\Iain0007\Clearacan.wps

UNIVERSITY OF THE
WITWATERSRAND
JOHANNESBURG

R14/49 Ms S Kilima

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M200570

NAME: (Principal Investigator)	Ms S Kilima
DEPARTMENT:	School of Public Health Medical School University
PROJECT TITLE:	Social and economic conquences of pulmonary tuberculosis; perspectives of patients, their families, the community and healthcare providers who care for TB patients in Mbeya and Songwe Regions, Tanzania
DATE CONSIDERED:	2020/05/29
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Drs D Evans and G Mubyazi
APPROVED BY:	Dr CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	2020/09/07

This clearance certificate is valid for 5 years from the date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary on the 3rd Floor, Phillip Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.
I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to submit details to the Committee. **I agree to submit a yearly progress report**. When a funder requires annual re-certification, the application date will be one year after the date when the study was initially reviewed. In this case, the study was initially reviewed in **May** and will therefore reports and re-certification will be due early in the month of **May** each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature Date

THE UNITED REPUBLIC OF TANZANIA

National Institute for Medical Research
3 Barack Obama Drive
P.O. Box 9653
11101 Dar es Salaam
Tel: 255 22 2121400
Fax: 255 22 2121360
E-mail: nimrethics@gmail.com

Permanent Secretary (Health)
Ministry of Health, Community
Development, Gender, Elderly & Children
Government City Mtumba, Health Road
P.O. Box 743
40478 Dodoma

NIMR/HQ/R.8a/Vol. IX/3527

08th October 2020

Stella Peter Kilima
Research Scientist
National Institute for Medical Research
P O Box 9653
Dar es Salaam

RE: ETHICAL CLEARANCE CERTIFICATE FOR CONDUCTING MEDICAL RESEARCH IN TANZANIA

This is to certify that the research entitled: Social and economic consequences of pulmonary tuberculosis–perspectives of patients, their families, the community and health care providers in Mbeya and Songwe regions, Tanzania (Kilima SP. et al), has been granted ethical clearance to be conducted in Tanzania.

The Principal Investigator of the study must ensure that the following conditions are fulfilled:

1. Progress report is submitted to the Ministry of Health, Community Development, Gender, Elderly & Children and the National Institute for Medical Research, Regional and District Medical Officers after every six months.
2. Permission to publish the results is obtained from National Institute for Medical Research.
3. Copies of final publications are made available to the Ministry of Health, Community Development, Gender, Elderly & Children and the National Institute for Medical Research.
4. Any researcher, who contravenes or fails to comply with these conditions, shall be guilty of an offence and shall be liable on conviction to a fine as per NIMR Act No. 23 of 1979, PART III Section 10(2).
5. Sites: Mbeya and Songwe regions.

Approval is valid for one year: 08th October 2020 to 07th October 2021.

Name: Prof. Yunus Daud Mgaya

Signature
CHAIRPERSON
MEDICAL RESEARCH
COORDINATING COMMITTEE

Name: Prof. Abel Nkono Makubi

Signature
CHIEF MEDICAL OFFICER
MINISTRY OF HEALTH, COMMUNITY DEVELOPMENT, GENDER, ELDERLY & CHILDREN

CC: Director, Health Services-TAMISEMI, Dodoma
RMO of Mbeya and Songwe regions.
DMO/DED of respective districts.

THE UNITED REPUBLIC OF TANZANIA

National Institute for Medical Research
3 Barack Obama Drive
P.O. Box 9653
11101 Dar es Salaam
Tel: 255 22 2121400
Fax: 255 22 2121360
E-mail: headquarters@nimr.or.tz

Ministry of Health, Community
Development, Gender, Elderly & Children
6 Samora Machel Avenue
P.O. Box 9083
11478 Dar es Salaam
Tel: 255 22 2120262-7
Fax: 255 22 2110986

NIMR/HQ/R.8a/Vol. IX/2449

10th April 2017

Dr. Nyanda Elias Ntinginya
Mbeya Medical Research Centre
P.O. Box 2410
Mbeya

CLEARANCE CERTIFICATE FOR CONDUCTING MEDICAL RESEARCH IN TANZANIA

This is to certify that the research entitled: TB sequel: pathogenesis and risk factors of long-term sequelae of pulmonary TB defining individual outcomes and public health impact (Ntinginya E. N. *et al)* has been granted ethical clearance to be conducted in Tanzania.

The principal investigator of the study must ensure that the following conditions are fulfilled:

1. A progress report is submitted to the Ministry of Health, Community Development, Gender, Elderly & Children, the National Institute for Medical Research, Regional and District Medical Officers after every six months.
2. Permission to publish the results is obtained from the National Institute for Medical Research.
3. Copies of final publications are made available to the Ministry of Health, Community Development, Gender, Elderly & Children and the National Institute for Medical Research.
4. Any researcher, who contravenes or fails to comply with these conditions, shall be guilty of an offence and shall be liable on conviction to a fine as per NIMR Act No. 23 of 1979, PART III Section 10(2).
5. Site: Mbeya region.

Approval is for one year: 10th April 2017 to 9th April 2018.

Name: Prof. Yunus Daud Mgaya

Signature
CHAIRPERSON
MEDICAL RESEARCH
COORDINATING COMMITTEE

Name: Prof. Muhammad Bakari Kambi

Signature
CHIEF MEDICAL OFFICER
MINISTRY OF HEALTH, COMMUNITY DEVELOPMENT, GENDER, ELDERLY & CHILDREN

CC: RMO of Mbeya
DMOs/DEDs of selected districts.

THE UNITED REPUBLIC OF TANZANIA

National Institute for Medical Research
3 Barack Obama Drive
P.O. Box 9653
11101 Dar es Salaam
Tel: 255 22 2121400
Fax: 255 22 2121360
E-mail: ethics@nimr.or.tz

Ministry of Health, Community Development, Gender, Elderly & Children
University of Dodoma, Faculty of Arts and Social Sciences
Building No. 11
P.O. Box 743
40478 Dodoma

NIMR/HQ/R.8c/Vol. II /980

09th April 2018

Dr. Nyanda Elias Ntinginya
Mbeya Medical Research Center
P.O. Box 2410
Mbeya

RE: APPROVAL FOR EXTENSION OF ETHICAL CLEARANCE

This letter is to confirm that your application for extension on the already approved protocol: TB sequel: Pathogenesis and risk factors of long-term sequelae of pulmonary TB defining individual outcomes and public health impact (Ntinginya E.N. *et al.*) has been approved.

The extension approval is based on the progress report dated 26th March 2018 on the project with Ref. NIMR/HQ/R.8a/Vol. IX2449, dated 10th April 2017. Extension approval is valid until 09th April 2019.

The Principal Investigator must ensure that conditions of approval remain as per ethical clearance letter. The PI should ensure that progress and final reports are submitted in a timely manner.

Name: Prof. Yunus Daud Mgaya

Signature
CHAIRPERSON
MEDICAL RESEARCH
COORDINATING COMMITTEE

Name: Prof. Muhammad Bakari Kambi

Signature
CHIEF MEDICAL OFFICER
MINISTRY OF HEALTH, COMMUNITY DEVELOPMENT, GENDER, ELDERLY & CHILDREN

THE UNITED REPUBLIC OF TANZANIA

National Institute for Medical Research
3 Barack Obama Drive
P.O. Box 965
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Tel: 255 22 2121400
Fax: 255 22 2121360
E-mail: nimrethics@gmail.com

Ministry of Health, Community
Development, Gender, Elderly & Children
University of Dodoma, College of
Business Studies and Law
Building No 11
P.O. Box 743
40478 Dodoma

NIMR/HQ/R.8c/Vol. I/706

17th June 2019

Dr. Nyanda Elias Ntinginya
NIMR-Mbeya Medical Research Centre
P.O. Box 2410
Mbeya

RE: ETHICAL APPROVAL FOR PROTOCOL AMENDMENT

This letter is to confirm that your application for amendment of a protocol on the study entitled: TB sequel: pathogenesis and risk factors of long-term sequelae of pulmonary TB defining individual outcomes and public health impact (Ntinginya N. E. et al), version 3.0 dated 29th August 2018 with Ref. NIMR/HQ/R.8a/Vol. IX/2449, dated 10th April 2017, has been granted ethical clearance to be conducted in Tanzania.

The approval is for the following amendments:

1. The protocol version has changed from version 2.0 dated 10th March 2017 to version 3.0 dated 29th August 2018
2. Xpert ultra assay will be performed to the patients at screening visit
3. Patients with previously confirmed positive HIV status and/or patients on ART will not necessarily need to be tested again for HIV infection
4. Window periods have been made, month 2: increase from +/- 1 week to +/- 10days, month 4: increase from +/- 2 weeks, month 6: increase from +/- 1 week to +/- 2 weeks, month 6: increase from +/- 2 weeks to +/- 3 weeks, month 9: increase from +/- 2 weeks to +/- 3 weeks, month 12: increase from +/- 2 weeks to +/- 4 weeks, month 18: increase from +/- 4 weeks to +/- 6 weeks and month 24: increase from +/- 4 weeks to +/- 6 weeks
5. The baseline visit will not occur later than 7 days after TB treatment start
6. Day 14 visit should be adjusted accordingly to the TB treatment start date
7. Exhaled CO levels will be measured at the same time points with administered risk factors questionnaire at the study clinic and with capturing GPS coordinates at home
8. General laboratory procedure, ferritin is added to the collection of the laboratory values
9. TB specific laboratory procedures and sub-studies assessments: the section of serum prevalence study has been added to the protocol
10. Additional questions added to the socio-economic questionnaire: a TB-related stigima scale is included in the socio-economic sub-study

Approval is valid until 09th April 2020.

Name: Prof. Yunus Daud Mgaya

Signature
CHAIRPERSON
MEDICAL RESEARCH
COORDINATING COMMITTEE

Name: Prof. Muhammad Bakari Kambi

Signature
CHIEF MEDICAL OFFICER
MINISTRY OF HEALTH, COMMUNITY
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NIMR/HQ/R.8c/Vol. I /1448

25th March 2020

Dr. Nyanda Elias Ntinginya
Mbeya Medical Research Centre
P.O. Box 2410
Mbeya

RE: APPROVAL FOR EXTENSION OF ETHICAL CLEARANCE

This letter is to confirm that your application for extension on the already approved proposal: Pathogenesis and risk factors of long-term sequelae of pulmonary TB defining individual outcomes and public health impact (Nyanda E N et al) has been approved.

The extension approval is based on the progress report dated 18th March, 2020 on the project, Ref. NIMR/HQ/R.8a/Vol. IX/2449, dated 10th April, 2019. Extension approval is valid until 09th April, 2021.

The Principal Investigator must ensure that other conditions of approval remain as per ethical clearance letter. The PI should ensure that progress and final reports are submitted in a timely manner.

Name: Prof. Yunus Daud Mgaya

Signature
CHAIRPERSON
MEDICAL RESEARCH
COORDINATING COMMITTEE

Name: Prof. Muhammad Bakari Kambi

Signature
CHIEF MEDICAL OFFICER
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NIMR/HQ/R.8c/Vol. I /1724

08th April, 2021

Dr. Nyanda Elias Ntiniginya
Mbeya Medical Research Centre
P O Box 2410
Mbeya

RE: APPROVAL FOR EXTENSION OF ETHICAL CLEARANCE

This letter is to confirm that your application for extension on the already approved proposal: **Pathogenesis and risk factors of long-term sequelae of pulmonary TB defining individual outcomes and public health impact (Nyanda E.N. et al.)**, has been approved.

The extension approval is based on the progress report dated 19th March, 2021 on the project, Ref. NIMR/HQ/R.8a/Vol. IX/2449 dated 10th April, 2017. Extension approval is valid until 09th April, 2022.

The Principal Investigator must ensure that other conditions of approval remain as per ethical clearance letter. The PI should ensure that progress and final reports are submitted in a timely manner.

Name: Prof. Yunus Daud Mgaya

Signature
CHAIRPERSON
MEDICAL RESEARCH
COORDINATING COMMITTEE

Name: Dr. Aifello Wedson Sichalwe

Signature
CHIEF MEDICAL OFFICER
MINISTRY OF HEALTH, COMMUNITY
DEVELOPMENT, GENDER, ELDERLY
& CHILDREN

Appendix xiii: Originality report

As per the University of Witwatersrand requirements, this dissertation (excluding journal articles) has been submitted to Turnitin. Proof of submission to Turnitin, a copy of the report cover page, and approval from the supervisors are included.

Appendix xii: Co-author declaration for published papers

As per the University of Witwatersrand, requirements for dissertations that include published work, a declaration from each co-author is included.

The co-authors for the publications include (in alphabetical order):

Denise Evans

Godfrey Mubyazi

Aneesa Moola

Issa Sabi

Nyanda Ntinginya

Simeon Mwanyonga

Declaration: Student's contribution to article(s) and agreement of co-author(s)

I, **Stella Peter Kilima**, student number **1944888**, declare that this Dissertation/Dissertation/Research Report is my own work and that I contributed adequately towards research findings published in the article(s) stated below which are included in my Dissertation/Dissertation/Research Report.

Signature of Student ….**Date**……21/10/2024…….

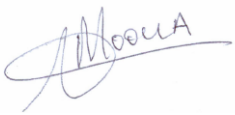
Name of Primary Supervisor……Prof. Denise Evans……

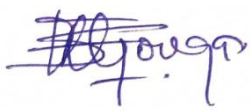
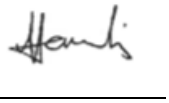
Signature of Primary Supervisor …………**Date**……28/10/2024……

Agreement by co-authors: By signing this declaration, the co-authors listed below agree to the use of the article(s) by the student as part of his/her Dissertation/Dissertation/Research Report. In cases where the student is not the 1st author of a published article, the primary supervisor must explain (under comments) why the student is entitled to use the paper for his/her degree purposes.

Article 1: Title: Understanding the implications of social and financial burdens of pulmonary tuberculosis on patients, survivors and their family caregivers on care seeking and treatment in Tanzania: Feedback from a qualitative study in Mbeya and Songwe regions.

Journal name (Tanzania Journal of Health Research), 2023, volume 24 (3) and page numbers 241-254:

Authors	Name	Signature	Date
1st author	Stella P. Kilima		21.10.2024
2nd author	Godfrey M. Mubyazi		28.10.2024
3rd author	Aneesa Moolla		28.10.2024
4th author	Nyanda E. Ntinginya		29.10.2024
5th author	Issa Sabi		29.10.2024

6th author	Simeon P. Mwanyonga		28/10/2024
7th author	Denise Evans		28/10/2024

Comments by primary supervisor:

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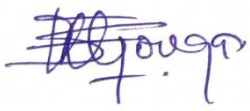
Article 2: Title: Perceived access to social supportduring and after TB treatment in Mbeya and Songwe regions, Tanzania: perspectives from TB patients and Survivors Set against health care providers

Journal name Frontiers in Health Services, years (2024), volume (4) and page numbers (1-15):

Authors	Name	Signature	Date
1st author	Stella P. Kilima		21.10.2024
2nd author	Godfrey M. Mubyazi		28.10.2024
3rd author	Aneesa Moolla		28.10.2024
4th author	Nyanda E. Ntinginya		29.10.2024
5th author	Issa Sabi		29.10.2024
6th author	Simeon P. Mwanyonga		28.10.2024
7th	Denise Evans		28/10/2024

Comments by primary supervisor:

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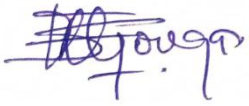
Article 3:

Kilima SP, Hirasen K, Mubyazi GM, Moolla A, Ntinginya NE, Sabi I, Mwanyonga S, Evans D. Implications of pre-diagnosis costs incurred by patients and their families for tuberculosis-related health-seeking behaviours in Mbeya and Songwe regions, Tanzania. Submitted to *PLoS One* journal, and reviewer comments had been received

Journal name, year, volume and page numbers:

Authors	Name	Signature	Date
1st author	Stella P. Kilima		21.10.2024
2nd author	Godfrey M. Mubyazi		28.10.2024
3rd author	Aneesa Moolla		28.10.2024
4th author	Nyanda E. Ntinginya		29.10.2024
5th author	Issa Sabi		29.10.2024
6th author	Simeon P. Mwanyonga		28.10.2024
7th	Denise Evans		28/10/2024

Comments by primary supervisor:

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